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# TRAINING MODULE

## FOR

# HEALTH & ALLIED PROFESSIONALS

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## In–service Training and Sensitization of Key Functionaries of Central & State Governments, Local Bodies and Other Service Providers

**Rehabilitation Council of India**

Department of Empowerment for Persons with Disabilities (Divyangjan)
Ministry of Social Justice and Empowerment
Government of India


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# 1. Introduction

According to the World Health Organisation's (WHO's) global report on disability, people with disabilities account for 15% of the global population, with 80% living in low and middle-income countries. People with and without disabilities have the same general health needs. Yet people with disabilities are vastly under-served when it comes to accessing quality health care.

The right of people with disabilities to enjoy the highest attainable standard of health without discrimination is clearly stated in **Article 25 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)**, the landmark disability treaty ratified by 175 countries by the end of 2017.

At the United Nations General Assembly in 2015, the adoption of the **Sustainable Development Goals** (SDGs) included disability in the post Millennium Development Goals definition, which set the ambitious goal of leaving **"no one behind"**. In particular, **Goal-3** seeks to ensure healthy lives and promote well-being for all at all ages.

Despite these commitments, the WHO estimates that 50% of people with disabilities cannot afford health care. In addition, people with disabilities are 2 to 4 times more likely to be denied health care, to be treated badly in the healthcare system, and to find health care provider's skills and facilities inadequate to meet their health needs. The information available on barriers and facilitators to health care for people with disabilities remain limited with little data disaggregated by gender, age and disability.

# 2. Objectives

This module is relevant to everyone who has an interest or duty to protect and promote the human rights of persons with disabilities; and is especially relevant for decision makers in the context of health, health professionals, health care providers, allied health professionals and civil society organizations working on enhancing the access of persons with disabilities to health services. The **objectives** of the content in this module is to:

- Explain the linkages between health and disability in general.
- Review provisions of the legal instruments pertaining to health services.
- Review specific areas of concern in relation to access to health services.
- Set out measures for overcoming barriers to the inclusion of persons with disabilities in health services.

# 3. Overview

**The WHO defines health as "a complete state of physical, mental and social well-being; and not merely the absence of disease or infirmity."** Good health is a pre-requisite for the enjoyment of enjoyment of and participation in many fundamental aspects of life, including education, work and society.

Health is also determined by social, economic and environmental factors. People with disabilities who experience disproportionately high rate of poverty often face conditions that negatively impact their health, including lack of access to education, sanitary living conditions, clean water and food security, among others. At an individual level, factors such as age, gender, hereditary factors and lifestyle choices are important. Promotion of health services for the prevention of secondary health conditions and to improve general wellbeing are important for quality life and health status of persons with disabilities.

*Divyangjan* have the same health needs as every other member of the population, including immunization, screening, sexual and reproductive health, and all other aspects of regular healthcare. They may have additional or more complex health needs, because of impairment and the consequences of impairment. Persons with disabilities face significant barriers to access healthcare services, which get further aggravated for those in rural areas.

**Some of these barriers include:**

- Physical inaccessible medical clinics and hospitals;
- Lack of accessible transport to help seek medical services;
- Lack of information, communication and accommodation in healthcare settings;
- Untrained personnel and inadequate staffing;
- Negative attitudes of healthcare providers;
- Harmful practices, especially in reference of mental-health disabilities;
- Denial of treatment on grounds of disability, etc.

The range of services available to all the citizens, must also be accessible to persons with all types of disability. Care must also be taken to ensure addressing the health needs of those with invisible disabilities. While governments cannot offer guarantee against illness or disease, however, they can take measures to advance human health, whether in the social, physical, legal or economic environments.

# 4. Legal and Institutional Framework

**WHO** enshrines the highest attainable standards of health as a fundamental right of every human being, which includes access to timely, acceptable and affordable healthcare of appropriate quality.

**Right to Health**

- Includes access to vital public health programmes, basic health services as well as to rehabilitation services, including residential care, community-based care and support services.
- Services must be "person-centred" and must consider the range of support services required (eg. assistive aids/ devices, nursing, respite, personal assistance, etc.)

**The UNCRPD** reinforces and strengthens the protection for *divyangjan* in relation to health and rehabilitation. It recognizes that *divyangjan* have the right to the highest attainable standard of health and that State parties must recognize that right without discrimination on the basis of disability and to provide health services as close as possible to people's own communities, including in rural areas (**Article 25**). It further guarantees the right of *divyangjan* to access rehabilitation services of all kinds (**Article 26**). Also, the Convention recognizes the rights of *divyangjan* to access, within their communities, a range of at-home, residential & other support services (**Article 19**). To prohibit all forms of discrimination, the UNCRPD also requires that reasonable accommodation must be provided.

India is also a party to **Incheon Strategy to 'Make the Right Real'** framed in October, 2012. **Goal 4** of this strategy aims to strengthen social protection, including increase access to all health services including rehabilitation for persons with disabilities.

**The concerned Ministries for health-related issues for *divyangjan* are:**

- **Ministry of Health and Family Welfare**
- **Ministry of Women and Child Development**
- **Ministry of Social Justice and Empowerment**

## Ministry of Health and Family Welfare (MHFW)

MHFW is responsible and instrumental for implementation of various programmes on a national scale in the areas of Health and Family Welfare, prevention and control of major communicable diseases and promotion of traditional & indigenous systems of medicine.

**This is executed through its departments, namely:**

- Department of Health & Family Welfare
- Department of AYUSH (Ayurveda, Yoga & Naturopathy, Unani, Siddha and Homeopathy)
- Department of Health Research

**The primary role of MHFW with regard to *divyangjan* is in the area of prevention.** Under the National Rural Health Mission, the Ministry conducts the National Leprosy Eradication Programme (NLEP); the **National Programme for Control of Blindness**; National Iodine Deficiency Disorders Control Programme; and the **National Programme for the Prevention and Control of Deafness**. The **National Mental Health Programme**, which is a part of the National Health Programme addresses the issues of persons with mental health disabilities.

## Ministry of Women and Child Development (MWCD)

The vision of MWCD is, "ensuring overall survival, development and participation of women and child in the country." For the holistic development of the child, the Ministry has been implementing the world's largest outreach programme of **Integrated Child Development Services (ICDS)** providing a package of services including supplementary nutrition, immunization, health checkup and referral services, and pre-school non-formal education. The major policy initiatives undertaken by the Ministry in the recent past include universalization of ICDS and *Kishori Shakti Yojana*, launching a nutrition programme for adolescent girls, establishment of protection of Child Rights and enactment of Protection of Women from Domestic Violence Act.

**The activities of the Ministry are undertaken through six bureaus under its aegis:**

- National Institute of Public Cooperation and Child Development (NIPCCD)
- National Commission for Women (NCW)
- National Commission for Protection of Child Rights (NCPCR)
- Central Adoption Resource Agency (CARA)
- Central Social Welfare Board (CSWB)
- Rashtriya Mahila Kosh (RMK)

## Ministry of Social Justice and Empowerment (MSJE)

MSJE ensures the welfare, social justice and empowerment of the disadvantaged and marginalized sections of the population, including SC/ST groups, Minorities, Backward Classes and **Persons with Disabilities**. There are two departments under the Ministry vide notification dated 12.05.2012, namely:


(i) **The Department of Social Justice and Empowerment**, and
(ii) **The Department of Empowerment of Persons with Disabilities** *(previously known as the Department of Disability Affairs)*.

To give a focused attention to policy issues and meaningful thrust to the activities aimed at the welfare and empowerment of persons with disabilities, the Department of Empowerment of Persons with Disabilities was carved out of the Ministry. The infrastructure network that implements the schemes and programmes related to the health and rehabilitation of *divyangjan* consists of:

| Statutory Bodies | National Institutes |
|---|---|
| • Chief Commissioner for Persons with Disabilities;<br>• Rehabilitation Council of India;<br>• National Trust for the Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities<br><br>CPSUs<br><br>• National Handicapped Finance & Development Corporation (NHFDC)<br>• Artificial Limbs Manufacturing Corporation of India **(ALIMCO)** | • Pt. Deendayal National Institute for Empowerment of Persons with Physical Disabilities, Delhi<br>• National Institute for Empowerment of Persons with Visual Disabilities, Dehradun<br>• National Institute for Empowerment of Persons with Intellectual Disabilities, Secunderabad<br>• Ali Yavar Jung National Institute for Persons with Speech and Hearing Disabilities, Mumbai<br>• Swami Vivekananda National Institute for Rehabilitation Training and Research, Cuttack<br>• National Institute for Locomotor Disabilities, Kolkata<br>• National Institute for Empowerment of Persons with Multiple Disabilities, Chennai<br>• National Institute of Mental Health Rehabilitation, Sehore, Madhya Pradesh<br>• Indian Sign Language Research and Training Centre, Delhi<br><br>There are **20** Composite Regional Centres under these National Institutes (as on 01-01-2020). |

The **Rights of Persons with Disabilities (RPwD) Act, 2016** in its **Section 25** on Healthcare provides for:

(a) Free healthcare in the vicinity especially in rural area subject to such family income as maybe notified;
(b) Barrier-free access in all parts of Government and Private hospitals and other healthcare institutions and centers;
(c) Priority in attendance and treatment;
(d) Undertake or cause to be undertaken surveys, investigations and research concerning the causes of occurrence of disabilities;
(e) Promote various methods for preventing disabilities;
(f) Screen all children at least once in a year for purpose of identifying "at-risk" cases;
(g) Provide facilities for training to the staff at the primary health centers;
(h) Sponsor or cause to be sponsored awareness campaigns and disseminate or cause to be disseminated information for general hygiene, health and sanitation;
(i) Take measures for pre-natal, perinatal and post-natal care of mother and child;
(j) Educate the public through pre-schools, schools, primary health centers, village level workers and *anganwadi* workers;
(k) Create awareness amongst the masses through television, radio and other mass media on the causes of disabilities and the preventive measures to be adopted;
(l) Healthcare during the time of natural disasters and other situations of risk;
(m) Essential medical facilities for life saving emergency treatment and procedures; and
(n) Sexual and reproductive healthcare especially for women with disabilities.

In the **Preamble of the RPwD Act, 2016**, respect to the evolving capacities of children with special needs and equality for women/girl-child with disabilities is highlighted. And the Act aims to uphold the dignity of every *divyangjan* in the society and prevent any form of discrimination. It also facilitates full acceptance of people with disability and ensures their full participation and inclusion in the society.

The **Section 92** of the Act specifies the punishment for atrocities against *divyangjan*, including: (a) intentionally insulting/intimidating with intent to humiliate within public view; (b) assaulting with intent to dishonor or outrage the modesty of a woman with disability;, (c) knowingly denying food or fluids to a *divyangjan*; (d) sexually exploiting a woman/child with disability; (e)

voluntarily injuring/damaging/interfering with the use of any limb/sense/ any supporting device of a *divyangjan*, and (f) performing/conducting/directing any medical procedure on a woman with disability which causes or can lead to termination of pregnancy, without her or her guardian's expressed consent, and without the opinion of a registered medical practitioner. **The imprisonment sanctioned under the legislation in such atrocities is 6 months, extendable to 5 years with or without fine.**

Additionally, the Central Government enacted **'The Mental Health Care Act, 2017'** which came into force from 07.07.2018. As per the Act, every person shall have the right to access mental health care and treatment from mental health service run or funded by the Central/State Government. The Act aims to provide for mental health care and services for persons with mental illness and to protect, promote and fulfil the rights of such persons during delivery of mental health care and services. As per **Section 115** of the Mental Health Care Act, 2017, attempt to commit suicide on account of severe stress will not be treated as criminal offence.

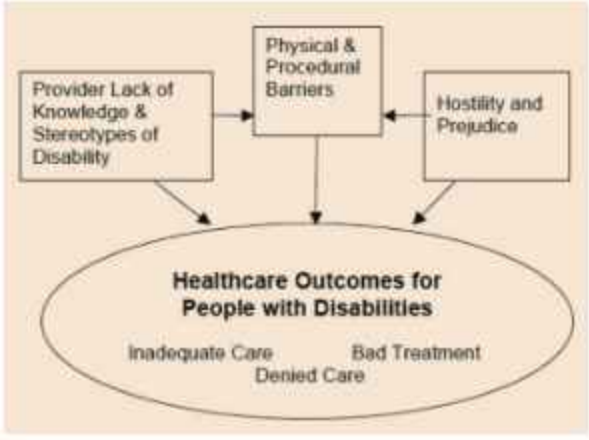
# 5. Significance of Inclusion in Healthcare

According to the **International Classification of Functioning, Disability and Health**, all people with disabilities have a health condition. However, having an impairment does not mean being unhealthy. Moreover, subjectively well-being of a person relates to her/his sense of being healthy. Regardless of impairment or illness, people can be in good health, because they eat a good diet, take exercise, get enough sleep, are in a good emotional state, and pursue other healthy behaviours. A richer understanding of health and disability is required to capture the lived experience of people with disabilities.

Due to this higher vulnerability of health concerns, on average, *divyangjan* are likely to require and use health services more than persons without disabilities. They require the same health services from promotion, prevention and treatment, to rehabilitation and palliative care. They may also require different types of specialists' services (eg. assistive devices) or adaptations in how services are offered (eg. sign language communication).

A key consideration is whether there is **equity in quality of health and healthcare** between *divyangjan* and those without disabilities. **Health equity** can be divided into **vertical health equity,** i.e. different groups of people with the same needs treated the same – and **horizontal health equity**, i.e. people

with different needs treated differently according to their health needs. The measure of this equity should be the extent to which the healthcare services meet the complex medical and rehabilitation needs of *divyangjan*.




*Divyangjan* are more likely to receive a range of poor responses when seeking healthcare, from outright denial of care to inadequate care and bad treatment, and the problem behind these responses can be rooted in the existence of physical or procedural barriers, poor attitude, ignorance about *divyangjan*, hostility and prejudice. The illustration frames the range of potential individual and systemic healthcare responses that can result in inaccessibility of healthcare system for *divyangjan*.

**Inclusion of people with disabilities involves:**

(a) Getting fair treatment from others (**non-discrimination**);
(b) Making products, communications and the physical environment more usable by as many people as possible (**universal design**);
(c) Modifying items, procedures, or systems to enable a divyangjan to use them to the maximum extent possible (**reasonable accommodations**); and
(d) Eliminating the belief that *divyangjan* are unhealthy or less capable of doing things (**stigma, stereotype**).

**Achieving disability inclusive healthcare requires three key elements:**

1. **Accessibility** – All environments, products or services must be able to meet the needs of all persons. For example, providing clinics with ramps and other features of accessibility, sign language interpreters, and Braille materials, increase the level of accessibility of health services, etc.
2. **Participation** –Meaningful engagement of people with different disabilities in the design, implementation, monitoring, evaluation of all programs and policies affecting their lives.
3. **Equality and Non-Discrimination** – Specific and systemic action to challenge the factors (attitude, actions, policies, etc.) which discriminate against people on grounds of disability, gender, age or any other criteria.

# 6. Specific Healthcare Needs of *Divyangjan*

There is good evidence that ***divyangjan* are more likely to have poorer health** than general population, due to a variety of possible reasons, which may be different for people with different impairments. **Many *divyangjan* in addition to the primary impairment, are at a greater risk of secondary health conditions, where there is a causal link to their primary diagnosis.** For example: people with Down's Syndrome are more likely to experience congenital heart disease, impaired hearing and early onset dementia; people with spinal cord injury are at increased risk of pressure sores and urinary tract infection; people with cerebral palsy may develop osteoporosis, etc.

Additionally, ***divyangjan* are also at a higher risk of co-morbidities, where the cause is less direct**. Often, a co-morbidity might result from the increased risk of **poverty** and **social exclusion** that the person may face. **Barriers** and **isolation** can impact *divyangjan* in diverse ways. For example: people with long-term physical conditions are 2-3 times more likely to have a mental health condition such as anxiety or depression; people with mental health conditions are more likely to experience premature mortality due to higher levels of obesity, smoking, heart disease, high blood pressure, respiratory disease, diabetes and stroke, etc.

Following are some more examples of these co-morbid conditions:

- Bowel or bladder problems
- Fatigue
- Injury
- Mental health and depression
- Overweight and obesity
- Pain
- Pressure sores or ulcers, etc.

Therefore, **annual health-checks are important**, as many *divyangjan* regularly have difficulties recognizing illness or communicating their needs in an easily understood manner. Additionally, using health services can be challenging for them and their families. Annual checks can help combat their unmet health needs and ensure effective treatment plans, as well as preventive measures, to improve health outcomes.

A comprehensive health check necessarily should involve exploring the following issues:

- Mental and Physical Health
- Skin
- Blood Pressure
- Bone Strength
- Eyes
- Teeth
- Epilepsy
- Pain
- Urine
- Medication
- Specific Syndromal Concerns
- Thoughts, Feelings and Moods
- Sexual Health
- Heart Health
- Breathing
- Hearing
- Swallowing
- Blood Tests
- Diabetes Sleep
- Age-Related Issues, such as Dementia

**Once the annual health check has been completed, a plan of action, for referral onto other health practitioners, health education, promotion and surveillance should be developed that is accessible and that can be easily understood.**

A lot of *divyangjan* are confined to their homes and ignore their health issues because they cannot travel to clinics/hospitals. They need to be provided home based health services.

# 7. Access to Health for *Divyangjan*: Areas of Concern

The health status of *divyangjan* is often poorer than that of the general population. In the context of health, stigma and prejudice gives rise to additional barriers faced by *divyangjan*. These barriers may include:

- **Physical Barriers** that prevents access to hospitals and health clinics.
- **Information & Communication Barriers** that prevent access to health literacy and information brochures/material on health promotion, prevention and protection.
- **Attitudinal Barriers** that give rise to discrimination that can have severe implications particularly for those with psychosocial disabilities.
- **Institutional Barriers** that includes policies, practices and processes that prohibit access to health services.

Following are some **examples of accessibility issues & barriers to health services**:

- **Privacy and confidentiality may be compromised** for *divyangjan* seeking medical treatment or counselling owing to the presence of personal assistants or sign-language interpreter;
- **Lack of information and communication material** (eg. lack of materials in braille, large print, simple language, and picture format; lack of sign-language interpreters, lack of materials for individuals with hearing impairment)
- **Lack of physical access, including transportation**, within hospital/clinic, lack of ramps, adapted examination tables, suitable weighing machine, accessible washroom and similar facilities;
- **Lack of suitable water sources, toilets, washroom and restroom facilities**;
- **Lack of awareness, knowledge and understanding of the needs of *divyangjan*** among healthcare service providers;
- **Negative attitudes, prejudice and imposed stigma**, etc.

It is important both to enhance the capacity of *divyangjan* to access the healthcare system and also to ensure that the system is able to respond in an appropriate and timely manner to address their needs.

## Health and Persons with Psychosocial/Mental Health Disabilities

People with psychosocial or mental health disabilities often face particular challenges in accessing healthcare along with facing abuse like arbitrary detention in prisons, forced treatments and medication, verbal and physical abuse, poor conditions and overcrowding, physical restrain like chaining for long periods of time, etc.

Abuses have also been documented at community level where due to false perceptions about persons with mental health disabilities, local health providers – including traditional healers – sometimes engage in abusing practices, often including confinement, even of children.

## Sexual and Reproductive Health of Persons with Disabilities

*Divyangjan* have the same sexual and reproductive health needs as other persons. However, there are many barriers that are created or sustained as a result of stigma, ignorance and negative attitudes of society and individuals, including healthcare providers.

The need for sexual and reproductive health services for women with disabilities is often heightened owing to their increased vulnerability to abuse. Women with disabilities experience higher rates of gender-based violence, sexual abuse, neglect, maltreatment and exploitation than women without disabilities.

Persons with disabilities are sometimes placed in institutions, group homes, hospitals and other group living situations, where they may not be prevented from making informed and independent decisions about their sexual and reproductive health, but also face an increased risk of sexual abuse and violence. People with intellectual and mental health disabilities are particularly vulnerable in this regard.

Violence against women with disabilities can also take the form of forced medical treatment or procedures, including forced sterilization. Women with disabilities have also been often denied the right to establish relationships and to decide whether, when and with whom to have a family, in some cases being forced to marry. As a result of the increased risk of sexual violence, women with disabilities are also at risk of becoming infected with HIV and other sexually transmitted diseases.

## Disability Inclusion in HIV and AIDS Response

Evidence suggests that *divyangjan* are at equal, if not more, risk of exposure to HIV. Barriers faced by *divyangjan* in this regard are similar to those faced in relation to access to health services, including:

- **Lack of Availability of HIV related facilities/services** including HIV prevention, treatment, care and support are often not available to *divyangjan*, in terms of disability-specific support and accommodation needed.
- **Barriers to Accessibility:** Accessibility requires attention to stigma and discriminatory attitudes as well as to physical, economic and informational barriers.
- **Unacceptable HIV and AIDS facilities, goods and services:** *Divyangjan* often experience disrespectful treatment, informed consent procedures are often not respected; and their confidentiality and privacy are often breached.

**Important**

*Just as disability should be mainstreamed across health services generally, the rights and needs of divyangjan should be mainstreamed in national responses to HIV and AIDS, including national strategic plans.*

# 8. Disability and Health Inclusion Strategies

To respect, protect and ensure the right to health of *divyangjan*, States in cooperation with *divyangjan* and their representative organizations should conduct a review of all relevant policies and identify areas in need of reform or improvement.

Following are some measures that can be taken by stakeholders to ensure the rights to health services for *divyangjan* and inclusive healthcare practices:

## (a) Understanding the Role of Doctors, Nurses and Administrators

The members of healthcare professionals have a particularly important role, their awareness about the needs of *divyangjan* in healthcare setting is, therefore, of paramount importance. Beyond understanding the rights and concerns of *divyangjan*, it is commonly reported that the attitudinal barriers in healthcare including patronizing, ignorance of front-line staff, negative attitudes, etc. create significant barriers to the provision of health services for *divyangjan*, and their quality of life in the long run.

It is important to raise awareness among frontline healthcare providers involved in daily contact with *divyangjan*. To build the organizational and individual capacity for delivering the range of health services by raising awareness will enable *divyangjan* to live fully inclusive lives in their community.

## (b) Ensuring Physical Accessibility

*Divyangjan* with health problems are unable to visit hospitals or health clinics if the buildings and spaces are physically inaccessible to them. The ensure that *divyangjan* are able to enjoy their right to health services, accessibility must be addressed in relation to entrances to buildings/facilities, appropriate equipment, adapted examination tables, restroom facilities, and to transportation to healthcare facilities.

Accessibility must also be focused on the difficulties of orientation to healthcare settings, including registration forms, location of a seats in the waiting area, and realization of when to enter the medical examination room with proper accessible signages.

## (c) Removing Information and Communication Barriers

Health service and related information is rarely available in formats that are accessible to *divyangjan*, which limits their understanding of what services are available and how to access them. This raises questions about:

- Whether the uptake of disability, mental health and general services by divyangjan is an accurate reflection of the real need; and
- The quality of informed consent to treatment that is being secured.

Health outreach and health promotion efforts also often fail to reach *divyangjan* due to the barriers of information and communication.

## (d) Overcoming Economic Barriers

*Divyangjan* are likely to experience disproportionately high rates of poverty due to poor access to education and employment. They may also experience additional disadvantages in their health and wellbeing due to the economic and financial factors as they are more likely to spend furthermore in other resources and services like therapies, assistive aids and devices, adapted equipment, etc.

## (e) Ensuring Participation of NGOs/Disabled People Organizations/Parent Associations

Health and social services support should be provided, organized and designed around what is important to service users from their own perspectives. Active participation of *divyangjan* and their representative organizations should be consulted in law, policy and programming decisions, as per the mandate of UNCRPD.

To ensure a fully inclusive health sector, it is essential to consult with and ensure the participation – at all stages of health-related policy development, implementation, monitoring and evaluation – of *divyangjan* across the full range of disabilities, along with their representative organizations. NGOs, Disabled People Organizations (DPOs) and Parent Associations (PAs) may have valuable contributions in the areas of:

- Training of doctors, nurses and other health professionals;
- Design of accessible health services;
- Advice on accessibility to the created environment;
- Advice on information and communication access;
- Identification of strategies for inclusion; and
- Provision of support to families of *divyangjan*.

A disability access focal point could be designated within each hospital or

health clinic to serve as a resource and to interface with the *divyangjan*, their families and others. DPOs/PAs should be included in all outreach to NGO/civil society organizations in relation to health service utilization.

## (f) Gaining Access to Supportive Devices and Technologies

In accordance with UNCRPD, State Parties must promote the availability, knowledge and use of supportive devices and technologies for *divyangjan*, as they relate to habitation and rehabilitation. In recent years, there have been significant improvements in supportive technologies available for *divyangjan*; some of these include:

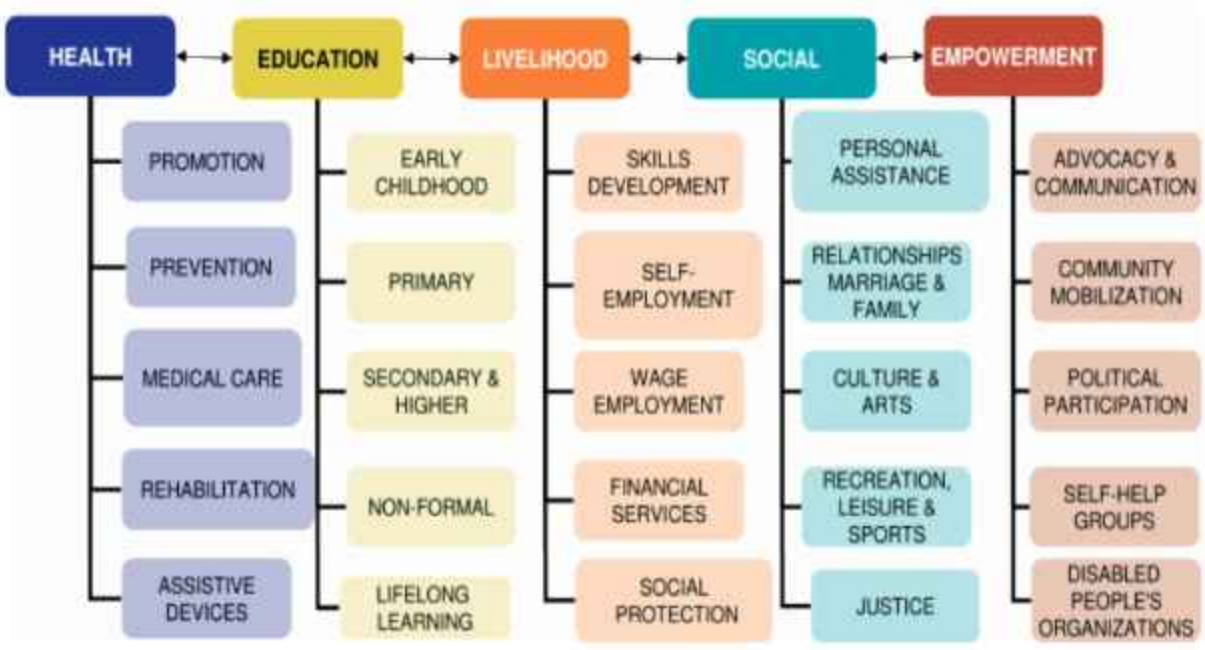
- Mobility aids like electric wheelchairs, scooters, walkers, laser canes, crutches, prosthetic devices, orthotic devices, etc.
- Cognitive assistance like computer or electronic supportive devices;
- Computer software and hardware, voice recognition programmes, screen readers and screen enlargement applications, etc. to use computer technology;
- Supportive devices like automatic page-turners, book holders, adapted pencil grips, etc.
- Closed captioning to allow people with hearing Impairment to access TV programs/resources and information;
- Improving physical access of buildings through automatic door openers, grab bars, wide doorways, ramps, etc.
- Adaptive electric switches to improve access of people with limited motor skills; and
- Medication dispensers with alarms, extendable reaching devices to reach items on shelves, devices to help dressing/grooming, cushioned grips for equipment, etc. to facilitate independent participation.

## (g) Community Based Inclusive Development (CBID)

This focuses on enhancing the quality of life for *divyangjan* and their families, meeting basic needs and ensuring inclusion and participation. It is a multi-sectoral strategy that empowers *divyangjan* to access and benefit from education, employment, health and social services. It is a strategy within general community development targeted on rehabilitation, equalization of opportunities and social inclusion of all children and adults with disabilities.

It is implemented through combined efforts of *divyangjan*, their families and communities; and the appropriate health, education, vocational and social

services. However, since all communities differ in their socio-economic conditions, terrain, cultures and political systems, no single model of CBID is appropriate for all parts of the country. Following is the matrix that describes different sectors which can make up a CBID strategy, and are also an essential component of community development.




Community care and personalized services can be broadly designed to enable people to remain living in their community, especially when they have difficulties in doing so because of illness, disability or age.

**The key to ensure non-discrimination and equal access to health and personalized services is raising the level of awareness of the needs and rights of persons with disabilities.**

# 9. Early Intervention

0-6 years of age being the initial developmental phase are critical for the proper development of the cognitive and physical abilities of a child. As such, identification of 'risk cases' and timely rehabilitation during this period of life is key to reduce the disability burden.

Access to health care is challenging for children with disabilities, especially those with intellectual and developmental disorders. It is evidenced that there is an increasing trend of disabilities noticed in children, including those of Autism Spectrum Disorders, Muscular Dystrophy, Cerebral Palsy, Specific Learning Disabilities. After their diagnosis by medical authorities, there is an urgent need for such children to be given proper and timely rehabilitative care.

Under the National Health Mission, Ministry of Health & Family Welfare has setup District Early Intervention Centres (DEICs) to provide referral support, management and follow up of screened children.

**The Department of Empowerment of Persons with Disabilities is also setting up Early Intervention Centres initially at 7 National Institutes (NILD, Kolkata; PDDNIPPD, Delhi; SVNIRTAR, Cuttack; NIEPID, Secunderabad, NIEPMD, Chennai; NIEPVD, Dehradun and AYJNISH, Mumbai) and 7 Composite Regional Centres (CRCs) at Rajnandgaon, Kozhikode, Bhopal, Sundernagar, Nellore, Patna and Lucknow. These centres will work as contiguous units for providing rehabilitative services for children with various types of disabilities. Each National Institute, despite its present given specialisation and focus of disabilities that they currently deal with, has also been tasked to set up Early Intervention Units which can cater to cross-disabilities. Each such Early Intervention Centre will have rehabilitation professionals such as clinical psychologists, audiologists, speech language pathologists, occupational therapists, community workers, counsellors, etc.**

The District health authorities need to work in concert with Early Intervention Centres at the NIs and CRCs whenever possible for providing early identification, intervention and rehabilitation services effectively.

# 10. Certificate of Disability & Unique Disability Identity (UDID) Cards

- Certificate of Disability is the primary document required for PwDs for availing the benefits of government schemes and programmes.
- Competent Medical Authority as notified by States/UTs can issue Certificate of Disability.
- The Guidelines for assessment of various specified disabilities included under the RPwD Act 2016 except Autism Spectrum Disorder was notified by the DEPwD on 04.01.2018. Details of these guidelines are available on the website of the Department http://disabilityaffairs.gov.in/content/page/guidelines.php.
- Guidelines for assessment of Autism Spectrum Disorder were notified on 25.04.2016.
- These assessment guidelines notified by the DEPwD inter-alia provides for composition of Medical Authorities for assessment and certification based on nature of disability.
- Chapter VII (Rule 17-20) of Rights of Persons with Disabilities (RPwD) Rules 2017 notified on 15.06.2017 deals with Certificate of Disability.
- Any person with specified disability may apply for certificate of disability in Form IV as notified under RPwD Rules 2017 and submit to competent medical authority.
- The PwD may also apply for certificate of disability under Unique Disability ID (UDID) Portal (www.swavlambancard.gov.in).
- The application of certificate of disability shall be accompanied by proof of residence, two recent passport size photographs and Aadhaar number or Aadhaar enrolment number, if any.
- The Medical Authority shall issue the certificate of disability within a period of one month from the date of receipt of application.
- If an applicant is found ineligible for certificate of disability, the medical authority shall have to convey reasons for rejection in writing within a period of one month
- If a person is not satisfied with the decision of the certifying medical authority, he may approach the Appellate Authority as constituted by the States/UTs.
- The Persons with Disability having the certificate of disability can apply for the UDID card through the website(www.swavlambancard.gov.in)
- The PwDs having a temporary certificate can apply for renewal of certificate through the UDID portal (www.swavlambancard.gov.in)
- Medial Authorities have to adhere to the timeline of one month for issuance of certificate of disability, else they are liable to penal action as per Section 89 of the RPwD Act 2016.

# 11. Mental Health and other Helpline numbers

**Mental Health Rehabilitation Helpline (KIRAN) (1800 599 0019 – Toll Free)**

- A 24x7 Mental Health Rehabilitation Helpline (KIRAN) launched by the DEPwD for enabling persons in distress develop effective coping strategies.
- This Helpline operates through various Institutions of the Department in English, Hindi and other regional languages.
- The Helpline is supported by 640 clinical/rehab psychologists and 668 psychiatrists volunteers.
- Confidentiality of the identity of the person seeking help of this Helpline is maintained.

❖ The National Institute of Mental Health and Neuro-Sciences (NIMHANS) also runs a Mental Health Helpline 08046110007 (Toll Free).

| Other Toll Free Helplines for PwDs | | |
|---|---|---|
| **All India Institute of Medical Sciences, Delhi** | 24x7 Helpline No 1800 - 11-7776 | For understanding and identified symptoms of Autistic Disorder |
| **National Institute of Empowerment of Persons with Intellectual Disabilities, Secunderabad** | Helpline No 1800 -572-6422<br><br>(9.00 AM to 5.30 PM from Monday to Friday) | For Mental Health related issues, Special Education, Occupational Therapy /Speech Therapy/Physiotherapy and Vocational Counselling |
| **Artificial Limbs Manufacturing Corporation (ALIMCO)** | Helpline Number 1800-180-5129<br>(9.00 AM to 5.30 PM from Monday to Saturday) | For information related to aids and assistive devices and services thereof |

# 12. Milestones of Growth and Development of Child with Age

A child passes through many developmental stages while growing. These stages involve physical, mental, social, communication and emotional growth & development. However, the time and pace for these developmental stages may vary child to child. Ministry of Health & Family Welfare under the National Health Programme has indicated age-wise milestones of growth and development of a child. The health authorities especially at the primary health centres and village level health workers need to keep a tab on the developmental milestones in a child and counsel/suggest the parents accordingly for corrective steps. **The milestone of a child in the first 12 months is given in the following table:**

| Parameters | Milestone | | | | |
|---|---|---|---|---|---|
| | 2 Months | 4 Months | 6 Months | 9 Months | 12 Months |
| Physical Development | • Cannot support head from birth till 1 month.<br>• Sleeps 20 hours a day till a month.<br>• Around 2 months, able to hold head.<br>• Begins to push while lying on your tummy at 2 months.<br>• Makes easy movements with hands and legs. | • Keeps head steady<br>• Senses colour, visuals and oral exploration.<br>• Controls eyes' movement.<br>• Lifts head when lying over your stomach.<br>• May roll from tummy to back<br>• Can hold a toy and shake it. | • Rolls from front to back & back to front.<br>• Supports self and starts sitting with round back.<br>• Carries weight on legs when stands and may bounce.<br>• Pushes backward before going ahead. | • Stands with support.<br>• Starts crawling.<br>• May get into sitting position by self and sits without support with straight back. | • Starts sitting and standing without any help.<br>• May take few steps without holding anything as support.<br>• Walks while holding furniture or sidesteps around furniture |
| Mental/Cognitive Development | • Starts paying attention to faces.<br>• Acknowledges you from a distance.<br>• Follows things through eyes.<br>• Cries if gets bored with an activity. | • Expresses mood (happy or sad)<br>• Starts using hands and eyes together to see & reach for toys.<br>• Watches faces with focus.<br>• Acknowledges affection. | • Starts looking around for things<br>• Shows curiosity about things and tries to get them.<br>• Passes things from one hand to another | • Seeks the things you hide.<br>• Plays peek-a-boo.<br>• Starts picking things with thumb and index finger.<br>• Puts things in her/ his mouth. | • Likes to mess up by shaking, banging and throwing things away.<br>• Copies gestures like clapping or dancing.<br>• Follows directions like 'pick up your toy'. |

| | | | | | |
|---|---|---|---|---|---|
| Social/Emotional Development | • Starts smiling in response to your voice.<br>• Brings hands to mouth to calm self for a short while. | • Smiles impulsively or may laugh.<br>• Cries if no one plays with her/him.<br>• Copies some acts like smile and frown. | • Knows when sees a stranger.<br>• Loves playing, especially with parents & other babies.<br>• Grasps things with palm on purpose.<br>• Reacts to your emotions, usually remains happy.<br>• Enjoys being cuddled | • Emotional attachment to mother.<br>• Clings to familiar people.<br>• Afraid of strangers.<br>• Chooses some favourite toys. | • Feels shy and nervous in front of strangers.<br>• Gives and takes objects.<br>• Makes sounds and repeats actions in order to get attention.<br>• May ask you to do something like holding out both hands to get picked up.<br>• Cries when any of the parents leave the house. |
| Communication/ Language Development | • Starts cooing and purling.<br>• Recognizes sounds and tries to turn head towards it | • Cries if angry, hungry or tired.<br>• Starts babbling with expressions.<br>• Begins speaking vowels. | • Starts responding when hears own name.<br>• Starts making sounds of vowels together like "ah", "eh", "oh" etc.<br>• Begins speaking consonants like "m", "b" etc.<br>• Shows emotions by making sounds. | • Starts making sounds like "mamama" or "bababa" etc.<br>• Starts waving and understands that it is connected to "bye-bye".<br>• Points at things with finger.<br>• Understands "no" | • Uses gestures like shaking head to say "no".<br>• Says "mama" or "dada" or "uh-oh".<br>• Tries to repeat words you say. |

Source: https://www.nhp.gov.in/developmental-milestones_pg

# 13. Major Disability Prevention Programmes of MH&FW

**Disability Prevention Programmes of MH&FW**

- Universal Immunisation Programme
- Rashtriya Bal Swasthya Karyakarm
- National Programnme for Control of Blindness
- Pulse-Polio Programme
- National Mental Health Programme
- National Iodine Deficiency Disorders Control programme
- National Programme for Prevention and Control of Deafness
- National Programme for Prevention and Control of Fluorosis

**Universal Immunisation Programme:** It is one of the key interventions 100% funded by the Central Government for protection of children from life threatening conditions by providing vaccination.

**Rashtriya Bal Swasthya Programme (RBSK):** It is an innovative and ambitious initiative of Central Government which envisages child care screening and early intervention services. It aims at screening of all children up to 18 years of age for early detection of 4 D's (birth defects, diseases, deficiencies and development delay including disabilities).

**National Programme for Control of Blindness:** This programme was launched in the year 1976 with a goal of reducing prevalence of blindness and also to foster eye health for all through provision of comprehensive universal eye-care services and quality service delivery.

**Pulse Polio Programme:** Polio was found to be one of the major causes of locomotor disability in India. Following World Health Assembly Resolution in 1988, Pulse Polio Immunization programme was launched in India in 1995, with an objective of achieving 100 % coverage under Oral Polio Vaccine aimed to immunize children in the age group of 0-5 years through improved social mobilization, plan mop-up operations in areas where poliovirus has almost disappeared and maintain high level of morale among the public.

**National Mental Health Programme:** This programe was launched by the Central Government in 1982 with the objectives to ensure availability and accessibility of minimum mental health care for all, to encourage application of mental health knowledge in general health care to promote community participation and to enhance human resource in mental health sub-specialties.

**National Iodine Deficiency Disorder Control Programme**: The programme was initially launched as National Goitre Control Programme in 1962. Subsequently, it was renamed as National Iodine Deficiency Disorder Control Programme (NIDDCP) in 1992 with the objectives to conduct survey to assess the magnitude of iodine deficiency disorders, supply of iodated salt, laboratory monitory of iodated salt and urinary iodine excretion and health education and publicity. Iodine being an essential micronutrient for normal human growth and development, its deficiency may cause physical and mental retardation and deaf mutism.

**National Programme for Prevention and Control of Deafness (NPPCD)**: It was launched by the Central Government in January, 2007 to prevent avoidable hearing loss, its early identification, diagnosis and treatment of ear problems, rehabilitation, strengthening of inter-sectoral linkages and developing institutional capacity for ear-care services.

**National Programme for Prevention and Control of Fluorosis (NPPCF):** This programme was initiated in 2018-19 with the objective to have surveillance of Fluorosis in the community and schools, capacity building in the form of training and manpower support, enhancing diagnostic facilities and promoting health education management. Fluoride toxicity destroys the probiotics in the gut, resulting in vitamin $B_{12}$ depletion, an essential ingredient in haemoglobin (Hb) biosynthesis and cause disability.

Health officials need to publicise these programmes and ensure effective implementation to reduce the overall disability burden in the country.

# 14. Rehabilitation Professionals

- Access to rehabilitation is essential for persons with disabilities to achieve their highest attainable level of health.
- Rehabilitation professionals such as occupational therapists, physiotherapists, orthotics, prosthetics, community based social workers play vital role in improving physical and cognitive abilities of persons with disabilities.
- The Rehabilitation Council of India which regulates courses for various rehabilitation professionals (except occupational therapists, physiotherapists) also maintains a Register of Rehabilitation Personnel/Professionals in the country.
- These rehabilitation professionals include special educators, audiologists and speech therapists, speech and hearing technicians, prosthetics and orthotics, clinical psychologists/rehabilitation psychologists, community based rehabilitation personnel and sign language interpretors.
- Details of such registered rehabilitation professionals/personnel are available on the website of the RCI: http://www.rehabcouncil.nic.in/
- District Medical authorities including DEIC authorities can access the database of RCI and advise the parents/guardians of children/person with disability to get in touch with the nearest rehabilitation professional to improve his/her cognitive/physical abilities to live an independent life.
- District Medical Authorities may take the help of rehabilitation professionals while organizing community based sensitizing workshops for training of village level health workers.

# 15. Flagship Programmes and Important Schemes

There are various schemes under different ministries and departments, targeted at health care needs of our citizens.

The specific schemes for persons with disabilities, under the **Department of Empowerment of Persons with Disabilities (*Divyangjan*)**, **MSJE** are listed below. These are implemented through its Statutory Bodies, National Institutes, Composite Regional Centres (CRCs), and Central Public Sector Enterprises.

**Niramaya (Health Insurance Scheme):** The scheme envisages delivering comprehensive cover at an affordable single premium across age band. The insurance is offered for the disabilities covered under the National Trust Act, and provides a coverage of up to One Lakh Rupees, and the treatment can be taken from any hospital. It covers facility for OPD treatment including medicines, pathology, diagnostic tests, etc. Regular medical

check-up for non-ailing *divyangjan*, Dental Preventive Dentistry, Surgery to prevent further aggravation of disability, Non-Surgical Hospitalization, Corrective Surgeries for existing disability including congenital disability, Ongoing Therapies to reduce the impact of disability and disability related complications, alternative medicine and transportation costs. No pre-insurance medical tests are required. The details of the scheme can be accessed from http://www.thenationaltrust.gov.in/

**Accessible India Campaign (Sugamya Bharat Abhiyan):** It is a nation-wide Campaign for achieving universal accessibility for Persons with Disabilities (PwDs). It has three important components: (a) Built area accessibility, (b) Transport system accessibility, and (c) Information and communication eco-system accessibility.

**ADIP Scheme (Scheme of Assistance to Disabled Persons for Purchase/Fitting of Aids and Appliances)**: It is a major initiative of the DEPwD for assisting persons with disabilities in getting standard assistive devices. It covers persons with visual impairment, hearing impairment, orthopaedic impairment, leprosy, intellectual and developmental disabilities. The scheme is implemented through government and non-government agencies.

**Scheme for Implementation of Rights of Persons with Disabilities Act, 2016 (SIPDA):** It provides assistance to State Governments various implementing agencies to take a multi-sectoral collaborative approach towards implementation of the provisions of the RPwD Act. Financial assistance to various implementing agencies is provided for activities including creating of barrier-free environment, improving accessibility, skill development programmes, research on disability-related technology, products and issues, etc.

**District Disability Rehabilitation Centres (DDRC):** It is a joint venture between the Centre and the State, with a combination of financial and technical support by the Central government and infrastructural and administrative support by the State governments. The objective of the DDRCs is creation of infrastructure and capacity building at district level for awareness generation, rehabilitation, training and guidance of rehabilitation professionals. The rehabilitation services offered include early intervention, therapeutic services, counselling, support services for education and vocational training.

**Deendayal Disabled Rehabilitation Scheme (DDRS):** It offers grant to NGOs in support for model projects of: Early intervention, Home-based rehabilitation and home-management, Community-based rehabilitation programmes (CBR), etc that can cater to health needs of *divyangjan*, along with other projects for their education and training.

**Spinal Injury Centre and Deaf College:** DEPwD also supports the setting up of Spinal Injury Centres and Deaf Colleges in India.

**The schemes and programmes of other Ministries and Departments include:**

Under the **National Health Mission, Ministry of Health and Family Welfare** has launched several schemes. An effort in making them accessible and inclusive will go a long way for improving the health, wellbeing and quality of life of *divyangjan*.

**Reproductive, Maternal, Newborn, Child and Adolescent Health (RMNCH+A):** It is a programme which addresses the major causes of mortality among women and children as well as the delays in accessing and utilizing health care and services.

**Rashtriya Bal Swasthya Karyakram (RBSK)**: It is for early identification and early intervention of children from birth to 18 years to cover **4 'D's** viz. **Defects at birth, Deficiencies, Diseases, Development delays including disability**.

**Rashtriya Kishor Swasthya Karyakram**: It is for adolescent participation and leadership, equity and inclusion and gender equity, to help them realize their full potential by making informed and responsible decisions related to their health and well-being and by accessing the services and support they need to do so.

**Janani Shishu Suraksha Karyakaram:** It functions to motivate those who still choose to deliver at their homes to opt for institutional deliveries.

**National AIDS Control Organization (NACO):** It was set up so that every person living with HIV has access to quality care and is treated with dignity.

**Revised National TB Control Programme:** It is an initiative with a vision of achieving a TB free India. The program provides, various free of cost, quality

tuberculosis diagnosis and treatment services across the country through the government health system.

**National Leprosy Eradication Programme:** It is a programme for early detection through active surveillance by the trained health workers and to provide Appropriate medical rehabilitation and leprosy ulcer care services.

**Mission Indradhanush:** It aims to improve the coverage of immunization in the country.

**National Mental Health Program:** It aims to ensure the availability and accessibility of minimum mental healthcare for all in the foreseeable future.

**Pulse Polio Abhiyan**: It is an immunization campaign to eliminate polio in India by vaccinating all children under the age of five years against the polio virus.

**Pradhan Mantri Swasthya Suraksha Yojana (PMSSY):** It aims to correct regional imbalances in the availability of affordable/ reliable tertiary healthcare services and also to augment facilities for quality medical education in the country.

**Rashtriya Arogya Nidhi**: A programme for financial assistance to the patients that are below poverty line and are suffering from life-threatening diseases, to receive medical treatment at any government run super specialty hospital/ institution.

**National Tobacco Control Programme:** A programme to bring about greater awareness about the harmful effects of tobacco use and to facilitate effective implementation of Tobacco Control Laws.

**Integrated Child Development Service (ICDS):** It aims to improve the nutrition and health status of children in the age group of 0-6 years, that lays the foundation for proper psychological, physical and social development of the child.

**Rashtriya Swasthya Bima Yojana:** It aims to provide health insurance coverage to the unrecognized sector workers who are below poverty line, and their family members.

# 16. Summary

**Full inclusion and non-discrimination is an important aspect of promoting and supporting inclusive health services for meeting the needs of *divyangjan*.** This requires knowledge of rehabilitation needs of different categories of disabilities; an understanding of referral knowledge in both government and private institutions; duty of health functionaries for guiding and referral along with the skills for parent/family counseling and guidance/care. Thus, it is essential to create better understanding and awareness of the experience of *divyangjan* in accessing health services and of the impact of barriers on their independence, autonomy and well-being in order to realize the mainstreaming of health service provision, reorientation of health services towards a social model of disability and the inclusion of *divyangjan* as active participants.

Accessible India Campaign

Accessible India - Empowered India

Department of Empowerment of Persons with Disabilities
Ministry of Social Justice & Empowerment

# Building a Culture and Ethos of Accessibility

# Towards Universal Accessibility

## Accessible India Campaign

UNCRPD, 2007 (Article 26 Chapter 9) Incheon Strategy (Goal No. 3) → ACCESSIBILITY → AIC launched on 3.12.2015 for creating universal accessibility for Persons with Disabilities (PwDs)- Divyangjan → MANDATE → AIC - tool to actualize RPwD Act 2016 (Section 40 – 46)

CAMPAIGN COMPONENTS

- Public Buildings (Central and State Govt.)
- Information & Communication Technology (public websites, electronic media etc)
- Public Transport (Road, Rail and Air)

- Reasonable Accommodation
- Universal Design

Purpose is to bring about a **change in the ecosystem of public infrastructure**, to make it accessible for Divyangjan, but the **spirit** behind it is to make it **universally accessible**.

## Features of Accessibility in Built Environment

| OUTDOOR FEATURES | INDOOR FEATURES |
|---|---|
| i. Accessible route/approach;<br>ii. Accessible Parking – Reserved parking near entrance<br>iii. Accessible entrance to building – ramp; | iv. Accessible reception;<br>v. Accessible corridors and tactile flooring;<br>vi. Accessible lifts with braille; auditory commands;<br>vii. Staircases with durable handrails;<br>viii. Accessible toilets;<br>ix. Accessible drinking water provision;<br>x. Auditory and visual signage |

## 10 Key Accessibility Features in Buildings

OUTDOOR FEATURES

Accessible Route with tactile

Ramped Accessible Entrance

Reserved Parking

Double Height Reception

INDOOR FEATURES

Wide, Obstacle-free Corridors

Staircase (Colour strips, handrail)

Drinking Water Facility

Lifts (braille, Audio, Warning tile)

Accessible Toilet with grab-bars


Signage


**Rehabilitation Council of India**

Department of Empowerment for Persons with Disabilities (Divyangjan)
Ministry of Social Justice and Empowerment
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