Drafted by Rising Flame

Introduction

We, the civil society members from across India, would like to take this opportunity to appreciate the government for releasing an important manual around accessibility standards for healthcare of persons with disabilities in the country. Despite The Rights of Persons with Disabilities Act, 2016 (RPD), the ratification of the United Nations Convention on Rights of Persons With Disabilities, and after India being a signature to the Sustainable Development Goals, persons with disabilities are struggling to access healthcare, which was spotlighted and further exacerbated during the pandemic. To ensure nondiscrimination as a legal and constitutional right, larger systemic and structural changes need to be facilitated and instituted. To achieve this, the 'Accessibility Standards for Healthcare' manual is extremely important. Therefore, it is also imperative that the manual be representative and inclusive of all 21 disabilities recognised in the RPD legislation and to have a nuanced definition of accessibility and more robust standards in implementing it.

After a national consultation for persons across disabilities facilitated by Rising Flame and an open input process, we have drafted the following recommendations to strengthen the document published by the Ministry of Health and Family Welfare.

- The manual should institute an accountability mechanism as well as a short term and long term implementation strategy including a feasible timeline for these measures to be put in place.
- The manual should clarify the budgetary allocation which is mandatory to make significant changes required in healthcare access.
- The manual should focus and include accessibility needs of all persons across all disabilities including those with high support needs, and not have more weightage on visible or otherwise accepted disabilities.
- The manual should actively include and account for the unique accessibility needs of and barriers faced by women and gender marginalised persons with disabilities.
- The manual should include the accessibility needs of children with disabilities.
- The manual should have language and terminology with regards to disabilities in strict compliance with UNCRPD and the RPD Act. The rights based language and terminology should be used uniformly throughout the document. Replace words like hearing problem, speech problem, mental problems, psychological / psychiatric disability with rights based language of hearing disability, speech disability, psychosocial disability.
- Many of the recommendations of altering equipment and infrastructure are urban in nature. Given the context of our country and the high prevalence of disability in rural areas, the manual should have specific implementable solutions to ensure access to health care at village, taluka and district levels.

 Over 70% of the healthcare services in India are provided by the private sector. Therefore the standards should be mandated for both existing and upcoming government facilities as well as private health facilities.

For ease of navigation the recommendations have been clustered into 5 groups to ensure full access and accessibility of healthcare spaces, systems and services.

Infrastructure Accessibility

For ease of understanding, this area will be split up into sections.

Environmental Accessibility:

(This refers to areas around all medical facilities.)

- Clearly designated parking and loading zones for individuals with disability to be available around medical facilities. The same to be made visible on navigation systems as well.
- Adequate accessible lighting and contrasting lighting in and around areas leading to the medical facility and/or parking zone in accordance with the relevant recommendations from British Standard EN 12464-1 and Lighting Guide 5 (produced by Society of Light and Lighting, UK)
- Pathways to be curbless with tactile markings for ease of navigation on foot.
- Anti-skid flooring with tactile markings in areas leading to the medical facility.
- All entry and exit points to the hospital/medical college/ medical facility to be clearly marked with sign boards and to be accessible across disabilities.

Navigation Inside the Medical Facility:

- Clear labelling in simple language, large font, clear signages, and tactile markings on all floors and outside all rooms/clinics/entry/exit/washrooms/waiting rooms etc.
- Elevators to be accessible in terms of assistive devices like wheelchairs and crutches. They also must have braille markings and audio outputs for each floor.
- Height adjustable and comfortable chairs clearly designated seating in waiting rooms.
- An accessible digital navigation guide to be made available via an app or the website will help navigate the medical facility for individuals with sensory concerns and psychosocial disabilities.
- Provision of human assistance for those with blind and low vision disabilities and other disabilities to navigate the medical centres/ hospitals.
- The railings given for staircases and ramps should extend a little below the step and should not end abruptly one step above.

- No pots /ornamental plants should be placed next to grab railings to prevent injuries during usage.
- Clear information about the location of a quiet room where children and adults with disabilities who experience sensory overload can go during the duration of the healthcare setting visit.

Accessibility of Documents and Payment:

- Accessible digital mediums to be used in order to fill medical forms and consent-related documents.
- All diagnostic reports (blood tests, sonography and ultrasound among others)
 prescriptions, pre/post procedure instructions, bills to be made available on
 the same accessible digital medium.
- Data privacy laws to be taken into account when designing/administering such digital mediums to patients.
- Ensuring that payment interfaces and other such services are accessible across disabilities as part of digital infrastructure. For example, having an alternative to touch screen card machines, having talking ATMs in accessible locations, if any, within the medical centre.

Accessibility with Regards to Medicines and Medical Equipment:

- Equipment provided for recovery/ monitoring (e.g thermometer, spirometer, Oxymeter, blood pressure machines, glucometers etc) must be made accessible.
- Measuring cups for liquid medication must have braille markings and/or audio outputs to enable self- consumption of correct dosage.
- Medicines to have barcodes in universal formats and accessible with barcode readers, to help blind and low vision users to scan to know details of the medicines procured including drug ingredients, side effects of medicines, recommended dosage etc.
- Design of home tests (COVID antigen test, pregnancy test etc) should be universally accessible, so that persons across disabilities could use them on an equal basis with others.
- Essential healthcare services for people with disabilities including
 physiotherapy, aqua therapy, should be made available from taluk and district
 level (CHC and PHC). Similarly district hospitals must be equipped with
 equipment and skills to provide calipers, prosthetics and crutches to reduce
 the additional cost of travel for people with disabilities.
- Medical stores should also be counted within the healthcare system and therefore should be fully accessible across disabilities.

Accessibility in Times of Emergency:

(This refers to emergency response service.)

- Ambulances should be accessible as per the accessibility standards laid down for public transport vehicles.
- Maximum occupancy requirement in an ambulance may require to be waived in cases of individuals with high support needs and/or intellectual disabilities to make way for interpreters and/or personal assistants to also be present along with one person.
- Interpreter support must be available along with ambulance services in case it is sought by deaf or deafblind people who might need support to communicate with the medical professionals in the ambulance.

Accessibility of Information & Communication

- Websites which have information related to healthcare should be fully accessible with adjustable font size, accurate colour contrast and access to screen reader for JAWS/talkback/refreshable braille device. Language must be simple, easy to understand and also demonstrated with use of images and sign language. Audio-video transcriptions and image descriptions should be available throughout the website.
- Digital medical platforms like e-pharmacy, e-consults should make all information/communication/announcements on their platforms in plain language and made available in a range of accessible formats including sign language, braille, audio versions, text only and easy to read versions and in languages used by the local population.
- All medical digital platforms are mandated to design/ develop online platforms in line with W3CAG (web accessibility guidelines).
- Health settings which have TV screens with informational content must make the content accessible in a range of accessible formats including sign language, braille, audio versions, text only, with captions and easy to read versions.
- Health settings like hospitals, clinics, primary healthcare centres must hire or empanel fluent Indian Sign Language interpreters to support independent interaction of deaf persons with the doctors and other staff in the centre.
- Health settings must provide text support options or alternatives to verbal communication to deaf and hard of hearing persons accessing services and use of Augmentative and Alternative Communication (AAC) for others who may be non-verbal.
- Teletypewriters to be made available wherever possible.
- All medical documents (pre/post test or procedure guidelines, prescriptions, test results, medical notes, consent form, liability waiver etc.) be available in audio form, braille form, accessible electronic formats, in sign language.
- Information about nearest grievance cell, contact details for organisations that provide medical assistance or financial aid, social schemes etc. are available in multiple accessible formats as detailed above.
- Informed Consent for all medical procedures from diagnostic tests to medications to surgery to any other medical therapy / procedure - should be

mandated. For this consent forms and relevant instructions / information must be provided to the patient in an accessible format for full comprehension, and direct patient consent should be ascertained.

During Disaster/Pandemic

- Make all communications/ information/ announcements regarding healthcare during a disaster/ crisis in plain language and made available in a range of accessible formats including sign languages, braille, audio versions, easy to read versions and in languages used by the local population at the same time as it is available to the general population. The accessible information should be up to date and made available to even underrepresented groups among persons with disabilities such as the deafblind and persons with disabilities who continue to remain in group homes and institutions.
- All available helplines for healthcare services should be fully accessible. It should also have text based or message-based support available along with video support through sign language users.
- Sign language interpreters or guides and other persons trained to support persons with disabilities should be treated as essential frontline workers and given the same level health and safety protection as other healthcare workers in the time of a disaster.

Personnel Training and Engagement for Accessibility

- Disability specific sensitisation programmes to be designed for doctors and other healthcare staff (nurses, ward boys, paramedic staff, chemist, security staff, admin staff) covering all aspects of a medical experience (appointment booking, locating the doctor, history taking, physical examination, non invasive and invasive tests, medication prescriptions, communication during surgeries/ child birth etc.) These programmes must be mandatory in nature and with frequent refresher courses.
- Extensive training to be provided on the concept of consent in the disability context, so that informed consent should be patiently and consistently sought during all medical procedures especially for underrepresented or stigmatised disabilities like developmental, intellectual, and psychosocial disabilities.
- Disability specific access requirements and sensitisation training to be provided to paramedics and mobile health staff (ambulance drivers, at-home physiotherapists, at-home phlebotomists etc.) that provide healthcare at home.
- RPD legislation training to be mandatory for all healthcare and social protection agencies, along with disaster management agencies at a national level
- All persons responsible for handling emergency response services, including quarantine and testing centres, should be trained on the rights of persons with disabilities, and on risks and co-morbidities associated with persons with specific disabilities acquiring COVID-19.

 Training provided with regards to recognising violence, recording experiences, providing medical support to victim-survivors of sexual assault must include guidelines laidout in '<u>Guidelines and Protocols: Medico-legal care for survivors/victims of Sexual Violence'</u> for persons with disabilities.

Home Based Medical Facilities

- Home Based services to not be restricted to medical services alone, but be expanded to include personal assistance services, elder care services, psychosocial services, blood transfusion, chemotherapy and child care services as well.
- Expansion of psychosocial services at home to include therapeutic support, occupational therapy, counselling, rehabilitation services among others.
- Vaccinations (Child immunisations, adult immunisations and COVID vaccines) to be emphasised as an important component of home based medical facilities to be made available to people with disabilities.
- Holistic healthcare packages to be deployed at community level for people with disability having high support needs.
- Essential screening tests like sonography during pregnancy, X-rays in event of injuries or secondary prevention etc. to be made available at home for people with disabilities.

Social Protection and Healthcare Access

- Disability certification process to be streamlined and implemented in alignment with RPWD Act 2016. Certification process to be available in a range of accessible modalities like online, and at-home along with the inperson process to make acquiring a certificate and accessing subsequent health schemes and services accessible.
- Disability certification status to be linked with UDID and both to be acceptable universally.
- Cashless health insurance schemes providing adequate health coverage across domains such as OPD cover, accident cover, critical Illness, assistive devices and services, home healthcare services, and maternity cover to be designed for persons with disability.
- Government schemes and health insurances to be designed specifically for individuals with high support needs that cover social, medical and emotional aspects of condition management.
- Using disability certification to identify disabled people through the panchayat system to link social security support systems, state level health schemes and for these to reflect disability related added costs and implement without taking away choice, consent and autonomy.
- Insurance accident covers must include costs or replacement if there is damage to hearing aid, cochlear implants, prosthetics during accidents.

•	Strict guidelines on providing insurance to persons with disabilities, since insurance companies often deny insurance or charge high premiums resulting in further exclusion in accessibility to healthcare systems.

Inputs by OPDs, disabled activists, scholars and lawyers: (in alphabetical order of all attendees)

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