HEALTHCARE GUIDE FOR PERSONS WITH DISABILITIES

Guidance for Community Healthcare Workers

According to the 2010 IBGE[1] census, almost ¼ of the Brazilian population have some sort of disability.

Persons with disabilities are those who have long-term physical, mental, intellectual or sensory impairments which, interacting with one or more barriers, may hinder their full and effective participation in society on an equal basis with others.

Barriers means 'any hindrance, obstacle, attitude or behaviour that limits or prevents a person's participation in society'

Law 13.146/2015 – Brazilian Law on Inclusion (LBI*)

This guide was developed to share guidance for Community Healthcare Workers (ACS*) to improve healthcare for persons with disabilities.

[1] *Brazilian Institute of Geography and Statistics.*
[*] *Acronym in Portuguese.*

DISABILITY & HEALTHCARE

Preventing disability and reducing functional impairment depend on timely access to high-quality health services.

Stigmas, conflicts, inequalities and **ableism*** prevent the development and autonomy, cause illness and increase the risk of premature death of persons with disabilities.

*** ABLEISM IS THE NAME FOR DISCRIMINATION BASED ON DISABILITY. IT MANIFESTS IN THE DENIAL OF THE PERSON'S ENTIRENESS, ACCESS AND ACCESSIBILITY TO HUMAN-CENTRED AND HIGH-QUALITY HEALTH SERVICES.**

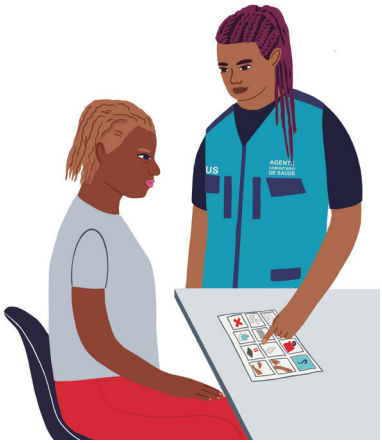
PERSONS WITH OR WITHOUT DISABILITIES ARE ENTITLED TO TREATMENT ON THE BRAZILIAN NATIONAL HEALTHCARE SYSTEM (SUS*)

Health services must ensure:

- → High-quality accessible information about your health.
- → Habilitation and rehabilitation services.
- → Human-centred assistance.
- → Respect for specifics, gender identity and sexual orientation.
- → Access to public policies and care pathways (child, adolescent, woman, man, sexual and reproductive, etc).
- → Accessible services, equipment and care.
- → Workers capable of welcoming and caring who are attentive to healthcare needs and human rights.

Persons with disabilities must be included in all public healthcare actions and also in specific actions, according to their disability or condition.

COMPREHENSIVE HEALTHCARE FOR PERSONS WITH DISABILITIES OF ANY SORT IS GUARANTEED THROUGH THE SUS (...) LBI, art.18



PRIMARY HEALTHCARE (APS*)

APS focuses on the user, the family and the community.

The teams are made up of diverse professionals and community healthcare workers who live in the area. This facilitates the connection between those who provide and those who receive healthcare.

APS should be able to resolve 85% of basic health issues. Primary healthcare workers refer the patient to other services, while maintaining their link to the Local Health Centre (UBS*).

* *Acronym in Portuguese.*

PRIMARY HEALTHCARE PROFESSIONALS ARE RESPONSIBLE FOR COORDINATING THE CARE PLANS FOR PERSONS WITH DISABILITIES.

REGISTRATION OF FAMILIES

Identify and register persons with disabilities to:

- Plan and develop public policies and actions to take care of and deal with social issues.
- Make them aware of and able to use their rights.
- Create a database for study and research.

Specific health factors should be taken into account. Remember that persons with disability may have:

- Higher prevalence of certain health conditions.
- Premature ageing.
- Greater vulnerability to abuse and violence.

Registration should be up-to-date with information regarding: family composition, education, age, disability, race, ethnicity, sexual orientation, housing conditions, employment, etc.

REGISTRATION IN THE TERRITORY IS REQUIRED TO PLAN AND REALIZE THE UNIVERSAL HEALTHCARE RIGHTS OF PERSONS WITH DISABILITIES.

HOME VISITS (VD*)

For some users, the VD is the only point of contact with healthcare services. The VD allows us to:

- Identify the person, their disability, whether they were born with it, when they acquired it and the main cause.
- Understand their living conditions (activities, social benefits, occupation, bond with the territory, friendships, values, etc.).
- Identify the accessibility at the environment/place, arrangement of furniture, access to objects and autonomy in their daily lives.
- Check the need for and access to assistive technologies (equipment or techniques for accessibility).
- Establish a bond between the team, user and family.
- Monitor the situation of families at risk.

The visit should provide opportunities for contact with the unaccompanied person, to check their living conditions, and for signs of neglect, abuse or violence.

* *Acronym in Portuguese.*

REPORT SEXUAL ABUSE OR VIOLENCE!

MAPPING THE TERRITORY

ACS can enable persons with disabilities to participate in community activities and public spaces, which helps them to become socially active and prevents them being made invisible.

The mapping of the territory must take account of:

- Barriers that hinder the social participation.
- Barriers to access the UBS and community spaces.
- Viability of and participation in activities at the UBS.
- Community participation and attendance (meetings, councils, activities at church, school, sports and leisure centres, public spaces).
- Local civil society initiatives for their rights and demands from community leaders.
- More vulnerable families in risk areas and those who need specific support in environmental disaster situations.

OVERCOMING BARRIERS INVOLVES MAKING PERSONS WITH DISABILITIES VISIBLE AT THE UBS!

FIND THE BARRIERS TO ENFORCE PwD'S RIGHT TO HEALTHCARE

BARRIERS	TO OVERCOME THESE BARRIERS, IDENTIFY
Attitudinal barriers * ** attitudes or behaviours that prevent or hinder the social participation of persons with disabilities on equal terms and opportunities with others.*	**Invisibility of PwD in universal actions**. PwD should benefit from ALL healthcare pathways. *e.g. child, adolescent, women, men, sexual and reproductive healthcare, family planning, etc.* **Dehumanizing and underestimating persons with disabilities.** *e.g. interactions that assume PwD are incapable, have no or worthless opinions.* **Prejudiced attitudes and terminology.** *Disability is not a disease and does not imply a lower form of life.* **Ignorance of specific clinical protocols, risks and vulnerabilities**. **False idea that Primary Healthcare settings are not the place for PwD.** *The ACS should establish a link and take responsibility for the PwD's healthcare plans.* **Barriers to taking control and self-determination.** *Use methods to support decision-making.*
Urban Barriers* **that exist in streets and collective-use spaces.*	**Physical obstacles** that prevent or hinder people from travelling, occupying physical spaces and taking part in activities in the community or at the UBS. *Seek intersectoral coordination to eliminate barriers.*

FIND THE BARRIERS TO ENFORCE PwD'S RIGHT TO HEALTHCARE

BARRIERS	TO OVERCOME THESE BARRIERS, IDENTIFY
Architectural barriers * **that exist in public and private buildings.*	**Barriers to activities and spaces at the UBS and in referred healthcare services.** *E.g. lack of access ramps, working lifts, passable corridors, tactile flooring, accessible signals, adapted bathrooms, spaces that do not cause sensory overload, etc.*
Transport barriers* ** that exist on public transport systems.*	**Lack of accessibility of transport systems and connections between them.** **Physical or sensory impediments to use.** *E.g. absence of lift/lifting platform for wheelchairs, reserved seats, guaranteed entry with a guide dog, etc.*
Communication and information barriers* ** obstacles, attitudes or behaviour that makes it difficult or impossible to exchange information.*	**Obstacles to accurate diagnosis** and taking control make self-care and prevention actions infeasible. *E.g. prescriptions that lack accessibility.* **Lack of accessible communication** and staff qualified to communicate. *Use Augmentative and Alternative Communication (AAC) boards, simple language, easy read, easy-health; provide a Sign Language interpreter and materials with accessible information, in an easy-to-understand language.*
Technological barriers* ** that hinder or prevent persons with disabilities from accessing technologies.*	**Obstacles to communications technology flows.** *Locate people who do not have access to the internet or electronic devices, making it difficult to access any registration or healthcare.* **Inadequate health equipment and services.** e.g. mammography devices not accessible, technologies that cause sensory overload, etc.

HEALTHCARE EDUCATION IN THE COMMUNITY

Educational actions are very important for vulnerable populations with invisible healthcare needs.

Suggested topics:

- Self-care and autonomy.
- A sense of belonging to APS.
- Initiatives to encourage self-determination, emancipation of the person, taking control.
- Raising self-esteem.

For community mobilization:

- Deconstruction of myths and stigmas and anti-ableism actions.
- Respect for human diversity.
- Proper language used to refer to persons with disabilities.
- Social inclusion and literacy about rights.
- Topics suggested by persons with disabilities and their families.

Education is an exchange: listening is crucial for people to bond, welcome and come together.

COMBAT ABLEISM BY PROMOTING KNOWLEDGE ABOUT THE WAYS PwD LIVE THEIR LIVES.

SEEK SOCIAL PARTICIPATION, INTEGRATION AND INCLUSION

Involving people in community activities encourages inclusion.

Round-table discussions and suchlike afford learning opportunities for healthcare teams in tandem with persons with disabilities and their families.

HEALTH EDUCATION ACTIONS ON DISABILITY ENHANCE THE KNOWLEDGE OF PEOPLE WHO LIVE AND WORK IN THIS AREA SO THEY CAN HELP TO ADVANCE PwD ACCESSIBILITY, INCLUSION AND RIGHTS.

PERSONS WITH DISABILITIES' RIGHTS

The social exclusion of PwD led to the institutionalization of positive actions in Brazil. Knowledge about the rights of PwD is essential to support requests for these benefits:

Free travel: is granted to PwD on public transport.

Continuous Cash Benefit (BPC*): a minimum wage for persons with disabilities with a per capita family income of less than 1/4 of the minimum wage and registered in the single registry for social programmes.

Exemption from taxes and fees: IPTU* (municipal property tax), depending on the municipality, and discounts when purchasing cars, for example.

Reserved vacancies: vacancies are reserved for persons with disabilities in the labour market and also in public services' entrance exams.

Education: children with disabilities have the right to attend regular schools and receive the necessary support for effective learning and socialization. Be aware that it is forbidden to refuse enrolment due to disability.

Health: persons with disabilities are entitled to have their healthcare needs met like any other person. The State must provide the necessary conditions to access such rights.

Culture: half-price entry for the person with disabilities and one companion, depending on the rules and laws of the municipality.

Access to rights should be guided by biopsychosocial assessment, as determined by the Brazilian Law on Inclusion.

DENIAL OF THESE RIGHTS IS A CRIMINAL OFFENCE

Discrimination due to disability is a criminal offence!

Report it to the Police, the Public Prosecutor's Office, the Office of Persons with Disabilities of the Brazilian Bar Association (OAB).

When the victim of this crime is a child, Social Services should also be informed.

* *Acronym in Portuguese.*

TECHNICAL DATA SHEET:

This work was carried out with the support of the Program for the Promotion of Scientific and Technological Development Applied to Public Health - Ensp/Fiocruz and PMA/VPPCB/Fiocruz. It results from a collective effort with the participation of several institutions and people.

NATIONAL DEPARTMENT OF HEALTH
Nísia Trindade Lima

NATIONAL DEPARTMENT OF HUMAN RIGHTS AND CITIZENSHIP
Silvio Luiz de Almeida

FIOCRUZ PRESIDENCY
Mario Moreira

RESEARCH AND BIOLOGICAL COLLECTIONS VICE PRESIDENCY
Rodrigo Correa de Oliveira

PUBLIC POLICY PROGRAMS CARE AND MANAGEMENT MODELS OF HEALTH
Isabela Soares Santos
Roberta Argento Goldstein
Beatriz da Costa Soares
Edjane Alves de Santana
Glória Maria dos Santos Rodrigues
Laís Sousa Jannuzzi
Rosane Marques de Souza

NATIONAL SCHOOL OF PUBLIC HEALTH DIRECTION
Marco Menezes
Luciana Dias de Lima

ADMINISTRATION AND HEALTH PLANNING DEPARTMENT
Mariana Vercesi de Albuquerque

FIOCRUZ COMMITTEE FOR PERSONS WITH DISABILITIES, ACCESSIBILITY AND INCLUSION

CONCEPTION AND DEVELOPMENT
Laís Silveira Costa
Carolina Aguilar
Maria Helena Mendonça
Anna Paula Feminella
Luciana Lindenmeyer
Sônia Gertner
Isabella Koster

SUPPORT
NATIONAL HEALTH COUNCIL
EU ME PROTEJO

ACCESSIBILITY FEATURES
Helena Werneck – SMPD-Rio
FláviaCortinovis – SMPD-Rio
Patrícia Almeida – Gadim

GRAPHICAL DESIGN
dudesignartes@gmail.com

ART DIRECTION
Lys Portella

EDITING
Dalila dos Reis

ILLUSTRATIONS
Janna Brilyantova

TRANSLATOR
Timothy Came

Scan me

Persons with disabilities are responsible for their healthcare. Let them take control of it.

acolhe acessibilidade direito e saúde

Rio PREFEITURA SMPD

Programa de Fomento ao Desenvolvimento Científico e Tecnológico Aplicado à Saúde Pública ENSP/FIOCRUZ

PMA DISSEMINANDO CIÊNCIA EM SAÚDE PÚBLICA

Ministério da Saúde FIOCRUZ Fundação Oswaldo Cruz

Conselho Nacional de Saúde SUS

MINISTÉRIO DOS DIREITOS HUMANOS E DA CIDADANIA

MINISTÉRIO DA SAÚDE

GOVERNO FEDERAL BRASIL UNIÃO E RECONSTRUÇÃO