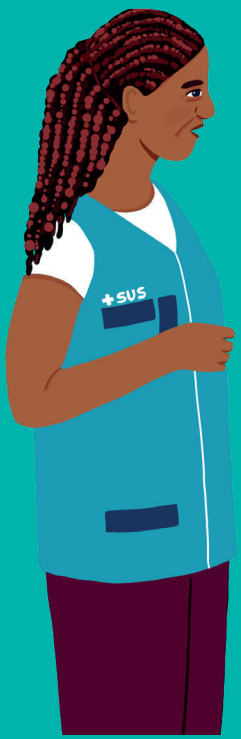
GUIDE TO PRIMARY HEALTH CARE FOR PERSONS WITH DISABILITIES

Guidance for healthcare workers and managers, persons with disabilities, carers and relatives.

All people, with or without disabilities, have the right to healthcare.

Some people face more barriers to exercise this right.

This guide discusses the barriers faced by persons with disabilities in primary health care and suggests solutions.



DID YOU KNOW?

- Every person has the right to make decisions about their care.
- There are support resources for persons with disabilities to take their own decisions.
- Workers should receive training to provide service with respect and dignity, and to favour autonomy.
- Persons with disabilities have the right to take part in drawing up healthcare policies.
- All people have the right to accessible communication.
- Persons with disabilities rank among the worst on social indicators.
- Social exclusion is one of the main causes of illness among persons with disabilities.

Learn about the healthcare rights of persons with disabilities in the BIL (Brazilian Inclusion Law: Law 13,146/2015, ch. III).

ABLEISM IN HEALTHCARE

Ableism means discrimination against persons with disabilities.
In healthcare, ableism results in:

- Dehumanization and reduction of a person to their disability.
- Invisibility of the person in universal policies and actions.
- Delayed and imprecise diagnosis.
- Lack of indicators linked to disability.
- Inadequate or inaccessible services and materials.
- Workers not qualified to provide inclusive care.
- Lack of knowledge of clinical guidelines and assistive technologies.
- Health needs not met.
- Social engagement actions that don't include persons with disabilities.

Ableism infringes the right to healthcare.

CARE MARKED BY STIGMAS

NOTE:
Markers such as race and color, ethnicity, gender, sexual orientation and poverty also affect access for persons with disabilities.

DID YOU KNOW?

- People under guardianship maintain their sexual and reproductive rights.
- Persons with disabilities become pregnant just like those without.
- Persons with disabilities have the right to respect, gender identity and sexual orientation.

DESPITE THIS

- Sexuality in all its diversity is made invisible.
- Sexual and reproductive health services for persons with disabilities are neither accessible nor humane.
- Healthcare workers are unfamiliar with the features of sexual and reproductive health for persons with disability, especially women.
- Illnesses that affect pregnant women, breastfeeding mothers or babies with disabilities remain poorly known and ill-served.
- There is a lack of support for reproductive planning and mother and child health.
- There is a lack of guidance for breastfeeding since prenatal care.

Discrimination based on disability is a crime (Art. 88, BLI).

SERVICE GAPS IN PRIMARY HEALTH CARE (PHC)

- Population with disabilities not identified in the area.
- Barriers to participation.
- Exclusion of persons with disabilities is seen as natural.
- Workers are unfamiliar with health needs.
- Healthcare guidance doesn't consider people's characteristics.
- Disability discussed and treated as an illness.
- Workers are unfamiliar with the care network for persons with disabilities.

Autistic people need reduced waiting times if there is no sensory space.

BARRIERS TO FORMING A BOND

- Contact marked by stigmas and prejudices.
- Focus on the carer rather than the person with disability.
- Failure to recognize that persons with disabilities belong to PHC.
- Direct referrals of people to specialist services.
- Lack of accessible communication.
- Use of inappropriate terms.

Persons with intellectual disabilities face more stigmas that result in disrespect for their autonomy and protagonism.

Access the Cards
using the QR Code

Visually impaired people face communication barriers when materials and information contain non-descript images.

BARRIERS TO COORDINATION OF CARE

- Workers lack knowledge about disability.
- Lack of accountability for care in PHC.
- Discontinuity of care (high worker turnover).
- Lack training to use the regulatory centres.
- Lack of knowledge about health and illness processes.

BARRIERS TO COMPREHENSIVE CARE

- Inaccessible health information and guidance.
- Patient not recognized holistically.
- Diagnosis and care hindered by barriers.
- Lack of knowledge about specific clinical services and protocols.
- Prevalence of the biomedical model.
- Lack of intersectoral action planning.
- Undersized, disjointed and inadequate services.

Lack of coordination of the care flow, lack of interest in forming a bond, disregard for the needs and invisibility of the individual put the health of persons with disabilities at risk.

PERSONS WITH DISABILITIES AND THEIR BODIES ARE DIVERSE, AS ARE THE BARRIERS TO THEIR PARTICIPATION

BARRIERS	DESIRABLE INITIATIVES
Lack of accessible communication in contact with healthcare workers and guidelines.	Use **simple language, augmentative and alternative communication, sign language, the written word and describe supporting images.** **Allow more time for the appointment** as the interaction between worker and user may take longer than usual.
Lack of accessibility at facilities.	Ensure wheelchair access, **have a tactile floor**, a **sensory space** and **accessible information**.
Lack of accessible equipment.	**Equipment** needs to be **compatible with all bodies**; if it doesn't exist on the market, it needs to be adapted.
Failure to recognize protagonism.	Eliminate attitudinal barriers, strengthen the bond and act to favour supported decision-making.
Service directed at the carer.	**Person-centred care** requires listening to the user, even when it is necessary to involve a carer.
Inattention to transition periods in life cycles (adolescence, adulthood and ageing).	Periods associated with worsening health and well--being require more frequent preparation and care. **Promote conversation circles and awareness-raising activities in the area, and get closer to users to see how to support them.** **Produce accessible information about transition periods.**

BARRIERS TO PARTICIPATION ALSO VARY ACCORDING TO DISABILITY TYPE

BARRIERS	DESIRABLE INITIATIVES
Stigma and prejudice.	People are more than their disability! Persons with disabilities must benefit from all lines of primary health care (e.g. adolescents, women, elderly people, etc.).
Lack of knowledge of needs, social determination and specific clinical protocols.	PHC is able to map persons with disabilities in the territory, monitor them due to their greater vulnerability to violence and know their health conditions. Support the development of specific clinical protocols and unique therapeutic projects.
Infantilization.	Get rid of prejudice! Functional diversity does not reduce the right to a full and adult life, with a greater or lesser degree of support to exercise autonomy and independence. **Don't begin by assuming incapacity.**
Ableism in healthcare.	Accessible campaigns to: fight body **normativity***, eliminate **stigmatizing terms**, tell parents the baby has a disability humanely, **eliminate notions of grief** and mourning associated with disability, include **representation in educational materials** of the diversity of persons with intellectual, psychosocial, sensorial and physical disabilities, social participation and community mobilization to promote **inclusion in the territory.** * See page 18 of the glossary

PHC CHARACTERISTICS THAT MOST AFFECT PERSONS WITH DISABILITY

- Insufficient funding.
- Lack of participation in formulating public policies.
- Fragmentation of care.
- Precarious employment relationships.
- Reduction in dedicated PHC workers.
- Workers not trained for inclusive care.
- Inaccessible PHC facilities.

DESIRABLE INITIATIVES

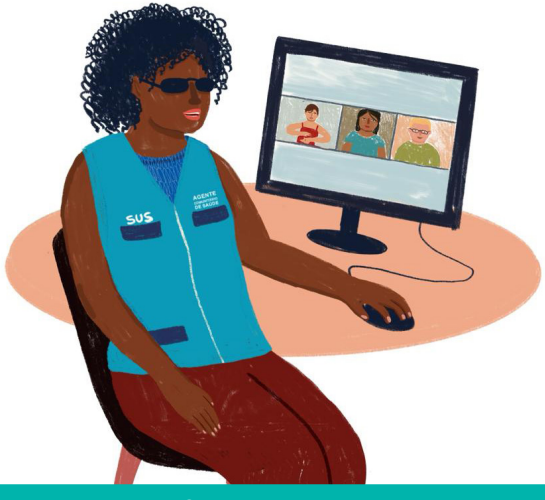
Training for workers:

- Based on scientific knowledge and subjective, common and empirical aspects.
- Exercise listening, welcoming, promotion of conversation circles.
- Adaptive strategies, appropriate equipment and support.
- Inclusion of the theme in subjects, supervised internships and residencies.
- Communications skills, including non-oral.
- Formation of a network of people with similar issues. (connection to share strategies and support).
- Welcoming and support for family members and carers from an anti-ableism perspective.
- Guidance centred on the person, the family and carers.
- Identification of people in the area and mapping of the necessary assistive technologies.

DESIRABLE INITIATIVES

Research and development:

- Produce equipment and knowledge to adapt services.
- Develop technological, methodological and pedagogical means.
- Diversify the forms of communication: 3D-printing, high-relief, *cordel* literature, gamification.
- Develop techniques for family safety.
- Ensure participation of persons with disabilities at every stage of the research.



Some barriers affect everybody, but have more severe effects on persons with disabilities.

DESIRABLE INITIATIVES

Qualification of services:

- Produce information (mapping and listening).
- Put service lines into operation with a specific focus on people.
- Review clinical protocols.
- Map the available support (services, information, family, etc.).
- Support that considers human interdependence.
- Establish humanized bonds and care.
- Offer psychological support.
- Follow-up services according to users' needs.
- Longer and more frequent visits and appointments to enhance effectiveness.
- Establish workflows and processes as needs dictate.
- Integrate PHC and other parts of the Healthcare Network with well-defined regulation flows.

GLOSSARY

Person with disability: "[a person] who has long-term physical, mental, intellectual or sensory [hearing, visual, autism] impairments which, interacting with one or more barriers, may hinder their full and effective participation in society on an equal basis with other people" (Art. 2 Law 13,146/2015). There are also people with more than one disability.

Accessibility: "chance to safely reach and use spaces, furniture, urban furniture, buildings, transport, information and communication, including its systems and technologies, as well as other services and facilities open to the public, for public use or private for collective use, in both rural and urban areas, by persons with disabilities or reduced mobility" (Art. 3(I), Law 13,146/2015).

Barriers: "any hindrance, obstacle, attitude or behaviour that limits or prevents a person's social participation, as well as the use, enjoyment and exercise of their rights to accessibility, freedom of movement, expression, communication, access to information, understanding, safe travel, etc. (Art. 3(IV), Law 13,146/2015.)

Body normativity is the culture that views the universal body as one without disability. Persons with disabilities are considered outside the norm, deviant and inferior, which results in their characteristics and needs being made invisible.

Ableism is a system of oppression that reproduces beliefs, processes and practices which class a certain standard body type as perfect, without considering all human diversity. This results in discrimination against persons with disabilities. Such discrimination is a crime (Article 88 of the BIL), punishable by 1 to 3 years imprisonment and a fine.

TECHNICAL INFORMATION

This work was developed within the scope of the research "PHC knowledge about disability: pathways of visibility or invisibility" supported by PMA/VPPCB/Fiocruz. It is the fruit of a collective effort with the participation of various institutions and people.

MINISTRY OF HEALTH
Nísia Trindade Lima

MINISTRY OF HUMAN RIGHTS AND CITIZENSHIP
Silvio Luiz de Almeida

NATIONAL DEPARTMENT FOR THE RIGHTS OF PERSONS WITH DISABILITIES
Anna Paula Feminella

OSWALDO CRUZ FOUNDATION – Fiocruz
Mário Moreira

VICE-CHAIR OF BIOLOGICAL RESEARCH AND COLLECTIONS – VPPCB
Maria de Lourdes Aguiar Oliveira

HEALTHCARE PUBLIC POLICY PROGRAMME AND MANAGEMET MODELS – PMA
Isabela Soares Santos
Roberta Argento Goldstein

FIOCRUZ COMMITTEE FOR ACCESSIBILITY AND INCLUSION OF PERSONS WITH DISABILITIESDEFICIÊNCIA

SÉRGIO AROUCA NATIONAL SCHOOL OF PUBLIC HEALTH
Marco Menezes
Luciana Dias de Lima

HEALTH ADMINISTRATION AND PLANNING DEPARTMENT – DAPS/Ensp
Carla Lourenço Tavares de Andrade

PREPARATION AND DEVELOPMENT
Laís Silveira Costa
Carolina Aguilar
Sônia Gertner
Maria Helena Mendonça
Danielle Bittencourt
Vitória Bernardes
Hellosman de Oliveira Silva

SUPPORT
National front for women with disabilitie
National Health Council
Acolhe PCD
Simples Assim
Office for policies for persons with disabilities - SEDSDH-RJ

ACCESSIBILITY FEATURES
Helena Werneck – SMPD-Rio
Flávia Cortinovis – SMPD-Rio
Patrícia Almeida – Gadim Brasil

G®APHIC DESIGN
dudesignartes@gmail.com

ART
Lys Portella

PUBLISHING
Dalila dos Reis

ILLUSTRATIONS
Janna Brilyantova

TRANSLATION
Timothy Cane

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WANT TO LEARN MORE ABOUT HEALTHCARE FOR PERSONS WITH DISABILITY?

Read the Brazilian Inclusion Law (Law 13,146/2015) and access our series of guides using the QR codes below:

Guide to rights and sexual health

Accessible communication guide

Guidance for community health workers

Guide to menstrual care for persons with and without disabilities

Guide to combating ableism

Guide to Inclusive Breastfeeding

If you witness discrimination due to disability, report it!
DIAL 100!