

# SITUATIONAL ANALYSIS OF THE RIGHTS OF PERSONS WITH DISABILITIES IN ECUADOR



**UNPRPD** MPTF  
Partnership on the Rights of Persons with Disabilities



**UNITED NATIONS  
ECUADOR**



**FLACSO  
ECUADOR**

# Situational analysis of the rights of persons with disabilities in Ecuador

## DISCLAIMER

The data and information presented in the report are based on the situational analysis at country level and were drafted by the UN country teams. Data collection methodology included a desk review of relevant literature, key informant interviews and focus groups, stakeholder mapping exercises and consultative workshops with key stakeholders. UNPRPD has not edited the report or verified accuracy of findings. This report does not necessarily reflect the position of UNPRPD.

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# Acronyms and Abbreviations

AECID:	Spanish Agency of International Cooperation for Development
ANID:	National Agenda on Equality for persons with disabilities
CAI:	Juvenile Offenders Center
CCA:	Common Country Assessment
CEPAL:	Economic Commission for Latin America and the Caribbean
CNIG:	National Council for Gender Equality
CNII:	National Council for the Intergenerational Equality
CNIPN:	National Council for Equality of Peoples and Nationalities
CNREE:	National Council of Rehabilitation and Special Education
CONADI:	National Council for the Care of Persons with Disabilities (Guatemala)
CONADIS:	National Council for the Equality of Persons with Disability (Ecuador)
COORDINADEC:	National Disability Coordinator in Ecuador
CPPCS:	Council for Citizen Participation and Social Control
CRPD:	Convention on the Rights of Persons with Disabilities
DPE:	Ombudsman Office
EAP:	Economically Active Population
ECW:	Global Fund Education Cannot Wait
ENCC:	National Strategy of Climate Change in Ecuador
FAO:	Food and Agriculture Organization
FEDEDIF:	National Federation of Organizations of Persons with Physical Disabilities in Ecuador
FENASEC:	National Federation of Deaf in Ecuador
FENCE:	National Federation of Blind in Ecuador (by its Spanish acronym)
FENODIS:	NGO Federation for Disability in Ecuador (by its Spanish acronym)
FEPAPDEM:	Ecuadorian Federation for the Attention to Persons with Mental Disability
FLACSO:	Latin American Faculty of Social Sciences
GADs:	Autonomous Decentralized Provincial and Cantonal Governments
GBV:	Gender Based Violence
GTRM:	Working Group on Refugees and Migrants
ICTs:	Information and Communication Technology
INEC:	National Institute of Statistics and Census
INEN:	Ecuadorian Standardization Service
LGBTIQ+:	Lesbian, Gay, Bisexual, Transgender, Transsexual, Transvestite, Intersex and Queer
LOD:	National Disability Law (by its Spanish acronym)
LSEC:	Ecuadorian Sign Language

MAATE:	Ministry of Environment (by its Spanish acronym)
MD:	Ministry of Sports
MDT:	Ministry of Labor
MIES:	Ministry of Economic and Social Inclusion
MINEDUC:	Ministry of Education
MSP:	Ministry of Public Health
NGOs:	Non-Governmental Organizations
OPDs:	Organizations of Persons with Disabilities
PAHO:	Pan American Health Organization
PND:	National Development Plan (by its Spanish acronym)
PIIP:	Multiannual Public Investment Plan
RCO:	Resident Coordinator Office
RIADIS:	Latin-American Network of Organizations for Persons with Disabilities and their Families
SDG:	Sustainable Development Goals
SENESCYT:	Secretariat of Higher Education, Science, Technology, and Innovation
SENPLADES:	National Planning Secretariat
SNGRE:	National Secretariat of Risk Management and Emergencies
UN:	United Nations
UN Women:	United Nations Organization to promote gender equality and women empowerment.
UNCG:	UN Communications Group
UNCT:	United Nations Country Team
UNDIS:	United Nations Disability Inclusion Strategy
UNDP:	United Nations Development Program
UNESCO:	United Nations Educational, Scientific and Cultural Organization
UNFPA:	United Nations Population Fund
UNHCR:	United Nations High Commissioner for Refugees
UNICEF:	United Nations International Children's Emergency Fund
UNPRPD:	United Nations Partnership on the Rights of Persons with Disabilities
UNS:	United Nations System
UNSDCF:	United Nations Sustainable Development Cooperation

## Executive Summary

The *Situational Analysis of the Rights of Persons with Disabilities in Ecuador* is a joint effort to shed light on the living conditions of persons with disabilities in the country, within the framework of the implementation of the Convention on the Rights of Persons with Disabilities (CRPD). In this sense, its objective is to outline and identify gaps in legal and regulatory frameworks, access to government social services, and social practices that will be the basis for the development of an innovative and participatory proposal to the UN Country Team. The Situational Analysis will also serve as a basis for programming beyond the proposal and for OPDs' advocacy.

Based on the expression of interest submitted by the UN country team in Ecuador, the United Nations Partnership on the Rights of Persons with Disabilities (UNPRPD) invited Ecuador to participate in the inception phase of its 4th Call. The UNPRPD Fund aims at supporting and financing programs for the adequate implementation of the CRPD in the signatory countries.

The research was performed by an interdisciplinary team of consultants from FLACSO Ecuador, with the support of the United Nations Population Fund in Ecuador. Moreover, actors from organizations of persons with disabilities (OPD) and individual activists joined the effort and representatives of governmental institutions and the United Nations Country Team supported the initiative.

In this research process, UNPRPD's preconditions to include persons with disabilities are used as analysis categories, i.e.: a) equality and no discrimination, b) accessibility, c) inclusive services, d) budget and financial management, and e) accountability and governance. Key cross-cutting issues for CRPD implementation are f) participation of persons with disabilities and their organizations, g) gender equality and, h) targeting underrepresented groups of persons with disabilities (intersectionality), such as women and girls with disabilities, persons from the LGBTIQ+ community, especially the ones living in rural areas, in situations of poverty or extreme poverty; indigenous peoples, including Afro and *Montubios*; refugees with disabilities; persons with psychosocial, intellectual and hearing disabilities; and persons that are not yet organized in formal OPDs.

The main finding of the research is that Ecuador has developed legal and institutional mechanisms and public policies on disabilities, but the implementation of such commitments remains a challenge.

After the interviews with OPD representatives and persons with disabilities, it is possible to conclude that disability-related national laws and guidelines have not been translated into concrete actions. This is noticeable in the daily aspects of their lives, which demonstrate a range of obstacles related to their inclusion in different aspects of society.

Thus, the following key gaps have been identified in systems, structures, policies and practices, among others:

- Cultural and attitudinal barriers persist due to the lack of knowledge about the human rights of persons with disabilities and their right to be included in all aspects of society. As a result, persons with disabilities are subject to patronizing/charitable and discriminatory attitudes in all spaces and relationships (with their family, with society, and with the State).



- Persons with disabilities and their organizations do not have sufficient knowledge and skills to demand and uphold their rights. The voices of some underrepresented groups of persons with disabilities are not heard and they are not yet organized in OPDs. Self-recognition and self-representation of persons with disabilities is limited.
- There are no measures to enable the social and political participation of persons with disabilities, particularly from underrepresented groups.
- Ecuador's legislation is not completely CRPD-compliant, for example, the Civil Code and the Organic Code of General Procedure need amendments to ensure the legal entitlements of Persons with disabilities are addressed properly.
- Ecuadorian state and local government institutional weaknesses are evident in the lack of continuity of public policies in the medium and long term. This affects the disability inclusion in public policies and limits the institutional capacity of CONADIS to guarantee the rights of persons with disabilities.
- There is limited access for persons with disabilities to both general services and to disability specific support services, especially GBV and SRH services. This is exacerbated for persons with disabilities from rural, frontier, and underrepresented groups.
- Accessibility standards have been adopted but they are not implemented or monitored. The engagement of persons with disabilities is poor and stakeholders working on accessibility do not consider the perspective of persons with disabilities.

The coordination mechanisms between and among governmental, international, and academic institutions, civil society organizations, and OPDs are weak both at national and local levels.

There is not enough accurate data on the numbers and the conditions of persons with different disabilities and there is no coordination between stakeholders on disability data management.

In order to fill the gaps, this situational analysis makes mid- and long-term recommendations for actions and processes to ensure the optimal implementation of a human rights-based approach to disability and to meet the CRPD goals. Besides, it specifies the actions with catalytic potential to be developed in short- and mid-term, for the UN country team to consider, such as:

- Supporting CONADIS in the revision of the regulatory and public policy framework necessary to guarantee the full inclusion of persons with disabilities, from a rights-based perspective with emphasis on underrepresented groups.
- Supporting CONADIS to develop processes that enable the full social and political participation of persons with disabilities in national and local decision-making bodies, promoting leadership skills development and processes that include persons from more marginalized groups, as well as the creation and strengthening of OPDs in Ecuador.
- Supporting CONADIS and the Ombudsman's Office to monitor and enforce existing laws and policies that guarantee accessibility with an inclusive universal design approach, in terms of infrastructure, information and communication.
- Providing technical support to CONADIS and other ministries on the implementation of specific and time-bound targets, indicators and budgets and follow-up mechanisms to monitor effective access to both general and special support services for persons with disabilities, especially in rural areas.
- Supporting government entities to strengthen access for women and girls with disabilities to health care and justice services in rural areas, with emphasis on sexual and reproductive health care services and gender-based violence.

- Developing participatory coordination mechanisms between OPDs, public institutions, academia, and UN Agencies to share situational analysis with emphasis on underrepresented groups, to enable disability mainstreaming in the CCA, the UNSDCF, and the Humanitarian Country Team Response Plan.
- Supporting government institutions to strengthen in a coordinated manner the National Disability Registry, providing for the mainstreaming of the human rights of persons with disabilities.

It is worth mentioning that the research findings were disseminated and validated in July 2023 by OPDs, State institutions and UN Agencies that co-participated in developing this research and this report reflects such recommendations.



# 1. Background

## 1.1. Rationale

The United Nations Partnership for the Rights of Persons with Disabilities Multi-Partnership Trust Fund (UNPRPD MPTF) promotes CRPD implementation and disability inclusion in the Sustainable Development Goals (SDG) plans and processes among all the State Members and under the joint programming of the United Nations.

According to the UNPRPD, there is still an inconsistency between the rights set forth in the Convention on the Rights of Persons with Disabilities (CRPD) and its effective enforcement in the policies and programs of the signatory countries.

In order to support countries with effective policies for CRPD implementation, it is necessary to identify the main difficulties and strengths of the country's policies, systems, structures, and capacities of stakeholders to address this issue. With this objective in mind, the present situational analysis is developed, using the UNPRPD's theory of change as a basis for the analysis.

## 1.2. Introducción a la discapacidad en Ecuador

Disability inclusion in the Ecuadorian context has developed under three main paradigms: the moral model, the medical model, and the social model of disability.

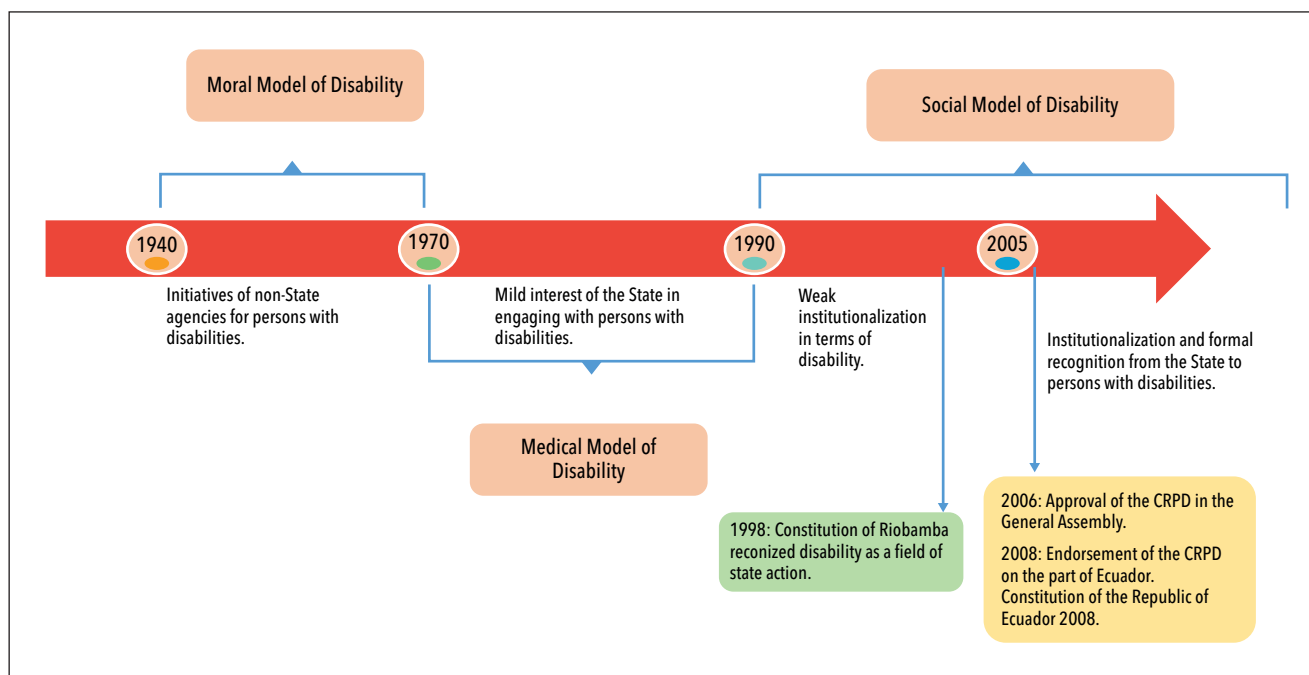
Until the 1970s, disability was considered a family and social organization concern with a charity-based vision. As of that decade, civil society organizations started to grow in strength and visibility before the State. As one of the key informants of this analysis (Interview to Torres, Quito, March 223) highlighted, these organizations were mostly created by relatives of persons with disabilities (and, in smaller percentages, by persons with disabilities themselves). It was the way they found to manage care and rehabilitation services and to claim human rights from the State. In this phase, disability was handled exclusively as a "medical problem" that must be treated first, in order for the person to be included in society.

As Figure 1 shows, it was only in the 1990s when the social model and a human rights-based approach were applied to disability. The first milestone in terms of legislation was evident in the Constitution of Riobamba in 1998, where disability was recognized as a field of state action.

One of the most important milestones within the Social Model in Ecuador is undoubtedly the signing and ratification of the CRPD (in 2006 and 2008, respectively). By adhering to this international legal framework, the country expresses its commitment to achieve full rights and social participation of persons with disabilities through innovative and transformative policies, programs and plans that involve all areas of daily, social and political life.

The ratification of the 2008 Convention represented legal and regulatory advances to provide protection to persons with disabilities and to institutionalize the provision of services to meet their basic needs. The 2008 Constitution of Ecuador formally recognizes all persons with disabilities as rights

Figure 1. Evolution of disability inclusion in Ecuador



Source: Valarezo (2017)

holders and a priority population (Constitution of the Republic of Ecuador 2008, art. 35), moving them –at least formally– from the welfare arena. In practice this is still not happening.

This is evidenced by the ongoing marginalization faced by persons with disabilities and their families, combined with the poverty of a large part of the households in which a person with a disability lives (CONADIS 2017) resulting in difficulties in accessing health services, education, work, social protection and; recreational activities such as sports, art and culture.

To better understand the reality of persons with disabilities in the country, it is important to consider official data from the National Council for Disability Equality. Up to April 2023, 471 205 persons with disabilities are registered at national level (representing about 57% of the number identified in the 2010 population census and probably even less of the actual number of persons with disabilities)<sup>1</sup>. From this population group, 45.66% has a physical disability, 23.12% an intellectual disability, 14.12% a hearing impairment, 11.64% a visual disability, and 5.55% a psychosocial disability (CONADIS 2023).

The majority of the population is in the age group between 36 and 64 years old (40.72%) followed by 25.12% of people aged 65 and over, then by 13.44% of people between 25 and 35 years old and, finally, 7.81% of people between 19 and 24 years old. On the other hand, children and adolescents with disabilities represent 12.9% of all persons with disabilities officially registered (CONADIS 2023). The above allows us to infer that the majority of people with disabilities (61.97%) are part of the Economically Active Population (EAP) and, of this, 35.52% are women and 64.48% men; most of the conditions of disability are acquired, either by work or traffic accidents (Interviews CONADIS and

<sup>1</sup> More information in the chapter on Inclusive evidence and Data gathering Systems.

MD, Quito, April 2023), or as a result of diseases or poor medical practices (Interviews with Asopleji-ca and Acuerdo por la Discapacidad, Guayaquil and El Coca, March 2023)<sup>2</sup>.

Out of the total number of persons with disabilities registered in the country, 31.49% live in poverty, according to CONADIS statistics (2023). The 43% who are not registered are presumably even poorer. This population group faces discrimination and a lack of access to education and work, which translates into a lack of equal opportunities and a greater likelihood of continuing to live in highly vulnerable situations.

Generating data on girls and women with disabilities is essential. The National Institute of Statistics and Census collects data on gender-based violence and live-born babies, but there is no breakdown by disability, even though a disability question was added to the population census survey (INEC 2022).

According to the results of the 2010 population census, 80% of Ecuadorian women who are mothers and have a disability had their first child in adolescence or youth, while 3% of them had their first child between the ages of 10 and 14. Following this, 43% had their first child between the ages of 15 and 19 (INEC 2010). It should be noted that, according to Ecuadorian law, pregnancies of girls aged 15 or younger are considered a consequence of sexual violence.

Although these figures are disaggregated by gender, they do not include qualitatively relevant variables on the specific conditions, vulnerabilities, and difficulties faced by women with disabilities, who end up disappearing in the data, within homogeneous categories such as “women” or “persons with disabilities”.

On the population census in 2022, questions from the Washington Group were included to get more updated information on persons with disabilities. However, official results are still in process for their corresponding release.

The last World Bank’s study on disability, updated in March 2021, reiterates the dire situation: persons with disabilities are more likely to face adverse socioeconomic events, with less education, worst health results, lowest levels of employment and higher poverty rates (World Bank 2021).

It is necessary to mention that COVID-19 pandemic aggravated the situation for persons with disabilities in terms of lack of opportunities and inequality (UN 2021). This was the case also in Ecuador and it was clear that there was a need of taking a disability inclusion perspective in risk and emergency management.

In summary, it can be concluded that although there have been regulatory advances in the country that mark the path towards the implementation of the CRPD, these legal tools have not yet had a direct impact on the lives of persons with disabilities.

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<sup>2</sup> The interviews are part of the sound evidence gathered from primary sources in the research work conducted in March-April 2023.

## 2. Approach

This research is focused on the preconditions necessary to guarantee a decent life and full social participation of persons with disabilities within the framework of the Convention on the Rights of Persons with Disabilities (PRPD 2021):

1. Equality and non-discrimination.
2. Inclusive services delivery
3. Accessibility.
4. CRPD-compliant budgeting and financial management.
5. Accountability and governance.

In addition to these five preconditions, three cross-cutting approaches are incorporated: participation of persons with disabilities and their organizations, gender equality and, targeting underrepresented groups of persons with disabilities (intersectionality). The analysis of these areas is driven by three main theoretical-methodological approaches: human rights approach<sup>3</sup>, gender mainstreaming approach, intersectional approach. (Annex 1)

### 2.1. Guiding principles

All research is governed by ethical principles considered essential for the development of an equitable and inclusive society (Annex 1). Such principles are in line with international and United Nations System principles and Ecuadorian regulations, but were reformulated in this way by Magdalena Herdoíza in her study *Construyendo igualdad en la educación superior* (Constructing equality in higher education) (2015):

1. Equality and equity
2. Comprehensive and inclusive development
3. Community Grassroots development relations
4. Biocentric development<sup>4</sup>

### 2.2. Methodology used

A participatory methodology was used in the research. It was developed jointly with representatives of key government institutions and organizations of persons with disabilities. Through discussions with stakeholders, and, particularly, with the involved OPD in the analysis, priority areas for attention and the gaps for the realization of the rights of persons with disabilities were identified.

<sup>3</sup> This analysis is based on the human rights approach, which aims to ensure the realization of the legal entitlements of persons with disabilities, defined as the acknowledgment that a person has the right to make decisions in all aspects of his or her life. In addition, it goes beyond legal frameworks to the actual exercise of rights. Different activists, organizations of persons with disabilities and experts agree with this integral perspective: Plena Inclusión Organization; Human Rights Watch; a Mexican Collective Decidir es mi derecho; Inclusion International and others.

<sup>4</sup> Biocentric development is an ethical point of view that extends inherent value to all living things. All living beings (humans, animals, plants, etc.) have the same value and the same right to respect and autonomy.



Different data collection techniques were used:<sup>5</sup>

- a. Desk Review of documents and regulations: a historical review of disability regulations from the 1990s onwards (when the disability social model started). Likewise, other types of documentary sources were reviewed as potential useful materials for context analysis: for example, the statistical production of the National Institute of Statistics and Census (INEC) on disability; and the annual statistics published by CONADIS (National Council on Disability and Development).
- b. A survey to persons with disabilities: an online survey was launched through the Google Forms platform to all the OPDs that were part of the data collection process. A total of 26 OPDs were invited<sup>6</sup> but only 21 responded<sup>7</sup>. Additionally, the five national associations of disabilities known in the country were invited to take part: the National Federation of Organizations of Persons with Physical Disabilities in Ecuador (FEDEDIF by its Spanish acronym); the Ecuadorian Federation Pro-Attention to the Person with Mental Disability (FEPAPDEM by its Spanish acronym); National Federation of Deaf in Ecuador (FENASEC by its Spanish acronym); National Federation of Blind in Ecuador (FENCE by its Spanish acronym); Federation of NGOs working on Disability in Ecuador (FENODIS by its Spanish acronym). However, only FEPAPDEM and FENODIS responded and a total of 23 surveys were collected. It is worth mentioning that members of FENEDIF, FENCE, and FENASEC participated in some of the focus groups.
- c. Strategic focus groups<sup>8</sup> with socially underrepresented sectors from three geographical areas of the country (jungle, highlands, coast): the focus groups were organized based on contacts established in the training workshop on the rights of persons with disabilities, “Taking ownership of the CRPD”, which was held in February 2023. With the collaboration of some of the OPDs that participated in the workshop, it was possible to include more representatives of other OPDs in the focus groups. They also facilitated contacts for individual interviews with persons with disabilities. In total, nine face-to-face focus groups were held in the cities of Ibarra, Otavalo, Guayaquil, Coca, Tena and Quito, plus two virtual ones with OPDs in Esmeraldas.
- d. Semi-structured interviews with persons with disabilities, OPDs representatives, government institutions and United Nations cooperation agencies. The semi-structured interviews were designed as tools to gather specific and experiential information. A total of 33 interviews were carried out among the following stakeholders:

Eight interviews to OPDs leaders and representatives of Advisory Committees for Rights of Persons with Disabilities: two representatives of Advisory Committees (Quito and Guayaquil); five OPDs representatives (Quito, Guayaquil, El Tena, Orellana); and one representative from a Special Education Unit (Otavalo).

<sup>5</sup> The online interview, focus groups and survey questions have been developed according to the *UNPRPD* guidance for conducting a situational country analysis of rights of persons with disabilities.

<sup>6</sup> The majority of these organizations participated in the Induction Workshop, therefore, as a result of an initial screening process, it was ensured that these organizations met qualitative indicators of representativeness, according to *UNPRPD*’s training guide. The guide considers the following characteristics: a. they have members from underrepresented groups; b. They focus on several types of disabilities and not just one; c. they are small and local or multi-local organizations. In addition, representatives of these organizations referred to other organizations that met the aforementioned criteria, and therefore also participated in this survey.

<sup>7</sup> In fact, 20 surveys were responded to since two people responded from one group (Comunidad Di(s)loca). These two persons represented two very different country areas: one is a semi-rural zone and in the border; and the other is an urban zone in Quito. Due to these two different approaches, these two responses were registered separately.

<sup>8</sup> To see the associations names that were involved in the focus groups, go to Annex 1.

Ten interviews with persons with disabilities belonging to underrepresented groups (some of them associated with OPDs), in Guayaquil, Cuenca, Yambiro and San Pablo (Imbabura), El Tena and Quito. Among them, women, and girls from rural areas and from indigenous peoples and nationalities are included; an elderly person with severe physical disability of the rural area; women with hearing impairment, and a lesbian woman with psychosocial disability.

Eight interviews to representatives from State institutions: CONADIS; CNIG; Ministry of Public Health; Ministry of Education; Ministry of Labor; Ministry of Sports; Secretariat of Higher Education, Science, Technology, and Innovation; National Secretariat of Risk Management and Emergencies.

Seven interviews to representatives of UN cooperation agencies: The United Nations High Commissioner for Refugees (UNHCR); UN Women; UN Volunteers; Resident Coordinator Office (RCO); United Nations Development Program (UNDP); United Nations Educational, Scientific and Cultural Organization (UNESCO); Pan American Health Organization (PAHO).

## 2.3. Scope and limitations

This study aims at identifying progress, opportunities, challenges, and main gaps in CRPD implementation in Ecuador. Therefore, the research has a mainly exploratory, analytical<sup>9</sup> and descriptive scope, since it seeks to identify the characteristics of the disability scenario in the country and to analyze the current situation in the exercise of the rights of persons with disabilities, through the collection of existing information and data, as well as experiential information from persons with disabilities and OPDs.

The idea is to show the reality regarding the full enjoyment of their rights for the persons living with disability and the perception on CRPD implementation from the governmental institutions, as duty bearers, and their inclusion in the programming of the United Nations System.

This research provides an overview of the country situation, taking into account the geographical, cultural, and political differences of provinces<sup>10</sup>. Meanwhile, the findings will be the pillars to build a comprehensive proposal that enhances government and OPDs actions to implement the rights of persons with disabilities.

An important methodological limitation of the research must be highlighted: the difficult access to nationally representative data and statistics containing all the variables that would be useful for the analysis. Ecuador presents a critical situation in terms of statistical compilation of the major social problems, including disability. In addition, there is no single data collection registry on disability; rather, each institution has its own database, which is difficult to access due to personal data protection issues.

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<sup>9</sup> This study is analytical in nature in terms of addressing the underlying causes of the gaps and the intention to propose catalytic recommendations.

<sup>10</sup> This document will be shared with the OPDs that have actively participated in the situational analysis in order to follow up on the joint efforts to strengthen partnerships and create national networks.



This lack of implementation and coordination of data collection is also reflected in the mapping of OPDs at the national and territorial level. To make up for this deficiency, the study has focused on a representative group of associations with which we have worked through surveys, qualitative interviews and focus groups. Despite not being able to count on statistical representativeness, we were able to access representativeness, limiting the urban bias of the analysis and exploring rural and culturally diverse territories, belonging to the three representative zones of the country: coast, highlands and Amazon.

The lack of an efficient and inter-institutional single disability registry also represents a limitation in relation to institutional actions and initiatives on disability, whose information is fragmented and difficult to obtain. Because of this, we requested qualitative interviews with most of the governmental bodies in the social sector, although we did not receive a response from some of them.

## 3. Findings

### 3.1. Section 1: Stakeholders and coordination analysis

#### 3.1.1. Outline of Key Stakeholders

- **Government**

The fundamental principles and values of the Ecuadorian State are established in the 2008 Constitution of the Republic of Ecuador, which recognizes the human rights of all persons under the principles of equality and non-discrimination, equity, participation and inclusion; it makes specific reference to the rights of persons with disabilities (art. 47-50), in accordance with the CRPD.

Accordingly, the Government implements these provisions of the constitution through the following equality councils: National Council for Gender Equality; National Council for Intergenerational Equality; National Council for Equality of Peoples and Nationalities; National Council for Disability Equality.

The National Development Plan is the primary programming and management instrument of Ecuadorian public policy of each government and is prepared with the active participation of all equality councils. This planning instrument has 16 objectives comprising 52 policies for their effective implementation and execution; likewise, they are aligned to the Sustainable Development Goals (SDG)<sup>11</sup>. Among these policies, three make specific reference to persons with disabilities and are related to the areas of health, education and labor.

After the elaboration of the National Development Plan, each Equality Council prepares the directives of the public policies of reference. The following is a brief description of the institutions most involved in the issue and details of their respective roles and functioning.

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<sup>11</sup> For further reference, refer to "Alignment matrix: National Plan of Development 2021-2025. Agenda 2030" (SENPLADES 2022).

- **National Council for Disabilities Equality (CONADIS by its Spanish acronym)**

CONADIS is the governing body for disability public policy, planning and designing the National Agenda for Disability Equality (ANID by its Spanish acronym) –that defined the National Plan of Disabilities for the period of the current Government, 2021-2025– and accounts for the implementation of actions with different coordination and supervision mechanisms.

The National Council for Disability Equality<sup>12</sup> is responsible for verifying compliance with constitutional and legal obligations to guarantee the rights of persons with disabilities in Ecuador and for the affirmative actions or reasonable adjustments in this field. (CONADIS, 2022).

This National Council is formed by ten representatives: one representative from each of the five State functions (Executive, Legislative, Judicial, Electoral and Transparency) and five civil society representatives<sup>13</sup>. They are appointed after a merit-based process for a period of 4 years (CONADIS, 2022); and report to the government bodies and civil society.

Although CONADIS is the governing entity on disability issues, its main role is to ensure compliance of governmental institutions (MIES, MSP, MDT, MD, MINEDUC, among others) with the disability-mainstreaming policy, based on the Constitution's mandate. The National Council does not have the power to impose sanctions, but rather to recommend full respect for the rights of persons with disabilities.

- **National Council for Gender Equality (CNIG by its Spanish acronym)**

The CNIG is the body in charge of enforcing the full exercise of the rights of women and LGBTIQ+ persons, The target population of this entity's activities includes women and girls with disabilities and people from gender-diverse groups living with disabilities.

- **Ombudsman Office (DPE by its Spanish acronym)**

The DPE is responsible for promoting and protecting human rights, including communities, peoples, nationalities and collectives in the country, as well as Ecuadorians abroad, and the rights of nature, to promote decent life and good living (Ombudsman's Office, 2023). The Ombudsman's Office has a mechanism for monitoring the rights of persons with disabilities that has two objectives:

- To reduce the recurrence of infringement of the rights of persons with disabilities, through advice and support to its local offices providing support to the citizens, as well as the generation of strategies and guidelines for the identification and management of such situations.

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<sup>12</sup> In accordance with Article 88 of the Organic Law on Disabilities (2012), this Council is considered part of the first level of the National System for the Comprehensive Protection of Persons with Disabilities, in addition, it is part of the National System for the Protection of Rights, therefore, it articulates actions with the Ombudsman's Office, Public Defender's Office, Attorney General's Office, among other institutions of the Judicial System (CONADIS, 2022).

<sup>13</sup> Correlated with the 5 types of disabilities legally recognized in Ecuador: physical, sensory (hearing and vision conditions), psychosocial and intellectual.

- To expand the ombudsman actions for the prevention, monitoring, protection, and guaranteeing the full enjoyment of the rights of persons with disabilities, through the accompaniment of local offices, and monitoring of the exercise of the rights of persons with disabilities. (Defensoría del Pueblo, 2023).

- **Ministry of Education (MINEDUC by its Spanish acronym)**

The MINEDUC through the National Directorate of Specialized and Inclusive Education works in the generation of public policies for the sustainability of inclusive practices aimed at facilitating and guiding the care of students with specific educational needs associated with a disability and of any student in a situation of vulnerability, such as: students with catastrophic diseases and students who are in the Centers for Adolescent Offenders (CAI).

- **Ministry of Economic and Social Inclusion (MIES by its Spanish acronym)**

In the MIES, the Undersecretariat for Disabilities is responsible for the formulation of policies that fully promote inclusion through the care of persons with disabilities, their families and caregivers, living in situations of vulnerability, poverty and extreme poverty, throughout their life cycle. (MIES 2023b).

- **Ministry of Public Health (MSP by its Spanish acronym)**

The MSP is the national health authority in Ecuador and the National Directorate of Disabilities, Rehabilitation and Palliative Care, is part of its structure. They have the duty to implement disability assessments in the country and to provide technical aids, according to the needs of persons with disabilities. The National Registry of Disabilities, which provides data to the different governmental institutions involved in public policy making is under its scope. (Ministry of Public Health 2023).

- **Ministry of Sports (MD by its Spanish acronym)**

As part of the MD's management, the Directorate of Sports for People with Disabilities promotes adapted and inclusive sports so that this target group can have access to different sports activities. Its role is to articulate directly with the Paralympic Committee and in turn with the National Federations of Adapted and Paralympic Sport; it also coordinates actions with adapted and Paralympic sport clubs for their proper development (Ministry of Sport 2023) (Ministry of Sports 2023).

- **Ministry of Labor (MDT by its Spanish acronym)**

The MDT is the body responsible for the creation and implementation of public policies regarding the country's labor sector; it also regulates and controls compliance with labor obligations in the public and private spheres. It has a Directorate of Attention to Priority Groups, which is responsible for "designing, articulating, evaluating and monitoring public policy for compliance with labor rights of persons in conditions of vulnerability and priority attention" (Ministry of Labor 2023, para. 2); among these population groups are persons with disabilities.

## • Council for Citizen Participation and Social Control (CPCCS by its Spanish acronym)

The CPCCS is an entity that promotes the rights to participation and social control. In addition, it establishes control and accountability mechanisms, investigates corruption cases, and monitors the appointment of authorities in accordance with the Law (CPCCS, 2023). Control mechanisms in place are: citizen oversight processes, citizen observatories, and user committees. These mechanisms promote citizens' participation in different areas of action, including disability (CPCCS, 2023).

## • Citizen's observatories of the rights of persons with disabilities

Citizens' observatories for the rights of persons with disabilities are spaces established for the purpose of monitoring, evaluating, and controlling compliance with public policies on disability. According to the list of Observatories accredited by the CPCCS (2023), there are currently the following Citizens' observatories that focus, in different ways, on monitoring the rights of persons with disabilities:

- Citizens' observatory for the fulfillment of public policies on the rights of persons with disabilities, in the areas of health, education, labor, housing, accessibility and elimination of architectural barriers in the province of Imbabura.
- Citizens' observatory for public policies related to disability in the province of Azuay.
- Citizens' observatory to monitor compliance with public policies on disabilities in the province of Loja.
- Citizens' observatory to monitor compliance with public policies on mental health in Ecuador.
- Citizens' observatory to monitor compliance with the right to occupational health in relation to the prevention of psychosocial risks.

Although these Observatories are listed with CPCCS, any report of activities is produced and each one works in isolation. Imbabura Observatory took part on the situational analysis data collection.

## • Rights protection councils in local governments

The Councils for the Protection of Rights in the local level governments (provinces, municipalities and cantons) are collegiate bodies of law that are responsible for the formulation, mainstreaming, observance, follow-up and evaluation of municipal public policies for the protection of rights, in coordination with the public policies of the National Councils for Equality, including CONADIS.

## • Consulting Councils on the rights of persons with disabilities

The Consultative Councils for the Rights of Persons with Disabilities are consultative and participatory bodies, with an advisory role and made up of representatives of civil society that are convened through the local governments' Councils for the Protection of Rights and work voluntarily<sup>14</sup>. Their main role is to advise, receive and channel information on the problems and needs of persons with disabilities and to make proposals for their resolution.

<sup>14</sup> Even though these spaces do not imply full-time work, consideration could be given to compensating a minimum fee and providing reasonable adjustments when possible.

- **Organizations of persons with disabilities and civil society organizations that provide services and support on disability issues**

The Movement of Persons with Disabilities in Ecuador has traditionally been represented by five national federations of and for disability, among them: FENASEC, FENEDIF, FEPAPDEM, FENODIS and FENCE. Although these federations bring together associations located in the country's largest cities, on many occasions they have not been able to consolidate the representation of grassroots organizations located in peripheral areas and involving persons with disabilities from underrepresented groups, including girls and women, persons of ethnic diversity, of gender diversity, and persons with intellectual or psychosocial disabilities.

In recent years, groups, communities, and independent individual activists seeking to influence on public and political issues of their interest in order to claim their right to decide have emerged. In addition, many OPDs bring together other smaller groups or even individual activists with the intention of building a more solid representativeness.

In the context of the COVID-19 pandemic, and thanks to the virtual modality, which facilitated collaboration through different technological platforms, some of these organizations emerged and others were strengthened. Among the most renowned at the national level are the following: Fundación Comparlante and the Red Latinoamericana de Organizaciones de Personas con Discapacidad y sus Familias (RIADIS) -both regional in scope-; Sordas Feministas; Acuerdo por la Discapacidad; and the Coordinadora Nacional de Discapacidades Ecuador (COORDINADEC by its Spanish acronym).

It is worth mentioning that, as seen in many countries, most organizations are led by males. As a result, women within these organizations are gradually organizing themselves and forming their own gender-specialized organizations with specific needs that transcend the disability movement as in the case of Colectiva Sordas Feministas (Feminist Deaf Collective)<sup>15</sup>.

In addition, there are several civil society organizations<sup>16</sup> that implement projects in favor of people with disabilities and provide services and support for them and their families, filling in for the institutional absence in the territories, particularly in rural and border areas.

- **International Cooperation: donors, UN agencies**

International cooperation focused on the development of persons with disabilities in Ecuador has been increasing in recent years, although often the contributions of various donors are crosscutting to all citizens.

At present, CONADIS, the governing body for disability policy, has two cooperation projects underway. On the one hand, CONADI of Guatemala is supporting different disability issues by exchanging knowledge and technical experiences, for example, accessible tourism, labor inclusion and accessibility to the physical environment for persons with disabilities. On the other hand, CONADIS signed

<sup>15</sup> The organization "Feminist Deaf" was established in 2019, and it is formed by more than 50 deaf women living in various provinces in Ecuador. The organization seeks to manage sessions with different professionals and "constructing support networks for deaf women by sharing information on gender violence, self-care and empowerment in Ecuadorian Sign Language" (National Museum in Ecuador 2021).

<sup>16</sup> The specialist focus of these foundations has been inherited from those that were established between the 1970s and the 1990s, and has set the path to continue with their services - many of them aimed at persons with "severe" disabilities - although they are not always led by persons with disabilities, but rather by parents or family members who have sought alternatives that impact on the development and progress of this sector of the population.

a Letter of Understanding with UNHCR, with the objective of promoting public policies that allow the inclusion of persons with disabilities in a situation of human mobility in the country.

The United Nations is committed to disability inclusion in its programming, using the Convention as a powerful tool that promotes the recognition of the rights of this population, as well as those of any other, to achieve a decent life, respecting their autonomy and independence, as fundamental pillars for their development and participation in society.

Thus, the agencies of the United Nations System in Ecuador (UNS) implement a number of actions for disability inclusion, taking the United Nations Disability Inclusion Strategy (UNDIS) as a framework<sup>17</sup>.

It should be noted that under the framework of collaboration between UNFPA and the Spanish Agency for International Development Cooperation (AECID), since 2017, the Ecuador Office has been part of the We Decide Project, that provides technical and financial assistance for the formulation of disability inclusion public policies. Also, OPDs have been strengthened so that women and young people with disabilities can access sexual and reproductive health services and a life free of gender-based violence.

#### • Other relevant stakeholders such as the academia, arts, and sports

In recent years, Ecuador has witnessed new forms of disability activism that have brought about cultural and social transformations in the academia, sports and arts fields as well. These transformations do not evenly spread throughout the nation, but continue to be specific to urban centers, where artistic and experiential exhibitions of persons with disabilities have flourished; as well as, high-performance sports programs for persons with disabilities and social neighborhood sports programs, with a particular focus on the participation of persons with disabilities (Ministry of Sports, interview, April 2023).

Disability in the academic world has been primarily studied under the medical-rehabilitation model, focusing on the cure and rehabilitation of “affected bodies”; consequently, the condition of disability has been placed on the person. However, with the partial application of the social model of disability, and with the active inclusion of persons with disabilities in research projects, new perspectives have been implemented to study disability as a social construction, from a human rights and gender approach.

Thus, it is worth mentioning that the Faculty of Disability Sciences, Pre-hospital Care and Disasters from Universidad Central del Ecuador has offered a Master’s Degree in Disability. But, the curriculum is based on a medical-rehabilitation approach, showing the challenge of migrating towards a person-centered social model.

Another initiative to highlight is the management of the Observatory of Inclusion and Disability<sup>18</sup>. This is a space within the headquarters of Universidad Politécnica Salesiana in Guayaquil which aims at monitoring the compliance of accessibility through the ICTs and support products

<sup>17</sup> It includes three approaches: two-way, intersectionality, and coordination.

<sup>18</sup> The scope of work of this observatory is within the university, so that reasonable adjustments required by the students with disabilities are made timely.

enhancing inclusive education of persons with disabilities depending on particular and individual needs of each student.

### 3.1.2. Key Stakeholder Coordination mechanisms

CONADIS is also in charge of designing and implementing inter-institutional coordination mechanisms and civil society participation. The council determines what and how coordination mechanisms will work, although their success depends mostly on other stakeholders.

Roundtables with OPDs and civil society to disseminate actions, get feedback, and strengthen citizen participation are the most visible and immediate coordination mechanisms. However, the current National Agenda for the Equality of Disabilities (ANID) identifies other types of coordination mechanisms promoted by CONADIS, but implemented through inter-ministerial coordination. These are detailed below:

- Mainstreaming of disability in public policy proposals: CONADIS coordinates with governmental institutions at central and local levels to ensure disability inclusion is part of governmental plans, programs, projects and actions.
- Monitoring and evaluation of public policy proposals implementation: tracking the progress in the achievement of ANID goals and indicators by the governmental institutions responsible for public policy.
- Compliance of public policy proposals implementation: specific issues or problems related to persons with disabilities are identified and verified (ANID, 2021).

Undoubtedly, the current ANID 2021-2025 has been significantly improved, both in terms of the coordination, participation, and mainstreaming mechanisms and the identification of goals and indicators for monitoring and evaluation. This allows for much more efficient implementation and follow-up of the agenda as a guiding instrument for public policy on disability-mainstreaming.

The current ANID sets out an inter-institutional coordination process, where officials from CONADIS and from the ministries share information, according to their lines of action for each thematic area of public policy. The 14 thematic areas are the following:

- Health.
- Education and training throughout life.
- Comprehensive protection and social security.
- Accessibility, mobility and housing.
- Access to justice and life free of violence.
- Work and employment.
- Access to information, technological development and innovation.
- Promoting citizen, political and social participation.
- Risk situations, humanitarian emergencies and migration or individual mobility.
- Accessible tourism.
- Art and culture.
- Sports.
- Sensitization and awareness.
- Inclusive communication.



In addition, CONADIS has a local office for each of the provinces where a specialist is responsible for establishing coordination mechanisms for each thematic area, creating alliances with the provincial and cantonal local governments (GADs) and other decentralized State functions. They are also responsible for coordinating actions and agendas with the Cantonal Councils for the Protection of Rights, organizations of persons with disabilities and civil society organizations that implement actions in favor of the rights of persons with disabilities.

### 3.1.3. Stakeholder Capacity Gaps

Although there is a good level of design of institutional mechanisms, the perception of persons with disabilities and the OPDs is that they do not materialize in actions in the territories. The information gathered shows that there is a lack of trust in the institutions, including CONADIS. Despite the construction of a planning and coordination instrument such as ANID and its specific mechanisms, this institution has a weak acceptance by civil society, which represents a difficulty in implementing public policy.

Within this general framework, the following inter-institutional and intersectional gaps are identified:

- There is an **institutional weakness in the Ecuadorian State**, evidenced by the constant changes of authorities and the lack of continuity of public policies in the medium and long term. It can be said that in Ecuador there are government policies but no State policies. This lack of institutional strength affects the disability inclusion in public policies but also limits the institutional capacity of CONADIS to guarantee the rights of persons with disabilities, especially in rural areas and in poverty.
- **Consultative Councils on the rights of persons with disabilities are weak entities, due to the lack of financing systems that enable sustainable processes.** The lack of economic resources allocated to these councils forces their members to work on a voluntary basis, which implies that they must pay for traveling and reasonable accommodation from their own pocket, which is not possible for most persons with disabilities.. Due to the same lack of resources, the members of the Consultative Councils do not have access to training processes and cannot guarantee medium or long-term processes. This leads to instability in local coordination mechanisms.
- **Lack of a single inter-institutional and intersectoral system of disability related data** that is fed by institutions and OPDs on a regular and coordinated basis. The institutions have statistical sources that are not easily accessible and the OPDs do not systematize their own information, which leads to inefficient data collection processes on persons with disabilities and their realities.
- **Internal communication between OPDs and governmental institutions, do not comply with accessibility standards.** This implies the failure to include persons from the deaf community –mostly those who do not know LSEC and communicate by non-verbal systems–, as well as persons with visual and intellectual disabilities.

In addition to the fragmented institutional context, there are also internal cultural gaps within the OPDs themselves:

- **OPDs** have created internal **coordination mechanisms** that enable local coordination and emerging of national organizations. However, the lack of knowledge about the legal framework



and participatory instruments, and the difficulties to reach agreements on political positions and competition for funding sources **weakened these mechanisms**. Also, there are limited efforts to ensure the involvement of all members of these organizations.

- **OPDs face difficulties participating in cross-sectoral coordination processes**, as do leaders with disabilities from underrepresented groups. For example, women and girls with disabilities, persons with disabilities from native and Afro-descendent peoples and nationalities, from LGBTIQ+ groups, persons with psychosocial disabilities, persons with hearing impairment and persons with intellectual disabilities, who are living in poverty or in extreme poverty conditions, face barriers that prevent them to be part of OPDs' political participation and coordination mechanisms. This is because they are not supported and encouraged enough by the movement to develop their capacity and political engagement. National federations and organizations of urban areas are the most common members of these participation and coordination mechanisms, where the same individuals often appear as OPDs representatives.

## 4. Section 2: Equality and non-discrimination

Persons with disabilities consulted during the research process expressed that discrimination takes a variety of forms. It is expressed in the disability stereotypes that still persist in society; the treatment they get or are denied when they try to access general and support services; the inaccessible way in which spaces, infrastructures, objects, and information are designed; among other realities. Their stories show that there is a gap between a protectionist regulatory framework and their experiences in everyday life.

In this sense, discrimination refers both to the perceived treatment of persons without disabilities and to structural and cultural barriers. The situation thus remains with no change, despite the fact that the United Nations Committee on the Rights of Persons with Disabilities issued its recommendations in 2019 on the need for awareness and compliance with article 8 of the CRPD<sup>19</sup>.

There is a widespread perception among the persons with disabilities that there is a very big gap between the rights they should have access to and the rights they actually have access to. In other words, there is a gap between equality as expressed in the law and equality in real life. Their stories told us about common discriminatory practices that diminish their possibility of action, decision-making, and independence.

The persons with disabilities surveyed stated that their experiences can be described as a "circle of discrimination". For them, the multiple daily experiences of discrimination and the lack of access to the exercise of their rights (services, spaces, information, work, education, etc.) are the cause and perpetuate a social devaluation of the body, affections, economy, and autonomy of a person with disabilities. This social devaluation, in turn, results in greater limitations in accessing their rights (Personal interview, El Tena, March 2023). For many OPDs, naming the circle of

<sup>19</sup> The Committee recommends that the State party strengthen and increase intensive human rights-based training on the rights of persons with disabilities, aimed at students, judges and staff of the judiciary, health professionals and the community in general. Meanwhile conducting media campaigns to eliminate prejudices, stereotypes and harmful practices, especially of persons with disabilities with psychosocial or intellectual disabilities. In addition, measures should be taken so that municipal governments discourage the use of welfare-based campaigns. (Committee on the Rights of Persons with Disabilities 2019, 4).

discrimination represents the possibility of making visible the system of structural exclusion that reinforces discrimination.

Respondents agree that the greatest barriers to equity are mainly cultural/attitudinal, structural, and budgetary. The lack of concrete actions to ensure compliance with laws and public policies, and the lack of investment in fundamental public services, such as health, education, and employment are evidence of this. These gaps are followed, in order of importance, by: unawareness of the disability inclusion, which represents a reason for exclusion, restricting possibilities for real social participation; lack of knowledge on the part of OPDs and persons with disabilities about their own rights and how to demand them.

## 4.1. Legislative & Policy Context

As already mentioned, a national public policy on disability was developed in the 1990s. In 1994, the Law for the Social Integration of Persons with Disabilities was published, which also established the National Council for Rehabilitation and Special Education (CNREE) as a support entity for the rehabilitation and inclusion of persons with disabilities.

The Ecuadorian Constitution of 1998 identifies disability as a social problem, a public health problem, of priority attention and, in short, as a field of state action (arts. 23, 47, 53, 57, 66, 82).

In 2007, a national strategy was developed to comply with the CRPD (Convention of the rights of persons with disabilities). The “Ecuador without Barriers” strategy, whose governing body was the Vice-Presidency of the Republic, resulted in a new institutional era for disability policy. Equality became a cross-cutting theme to be considered in all phases of public policy design and management and in all sectors. This strategy led to the development of the first labor registry of persons with disabilities.

In 2008, the new Constitution of the Republic was approved, which is still the main legal instrument that promotes priority actions for persons with disabilities. Thus, in 2009 and 2010, respectively, the “Manuela Espejo” mission was created to create a geographic, economic, and social mapping of persons with disabilities, and the “Joaquín Gallegos Lara” mission to provide specific support services in situations of severe disability and disadvantageous socioeconomic conditions (based on the principles established in the 2008 Constitution).

In 2012, the National Law on Disabilities (LOD by its Spanish acronym)<sup>20</sup> and its Regulation were enacted which rule the path that public and private entities, as well as society in general, must follow to achieve the inclusion of persons with disabilities, allowing their full recognition as right holders, and, thus, the enjoyment of their rights, such as comprehensive health care, inclusive education, dignified work, active participation in all areas. These regulations also grant equal recognition as persons before the Law and their legal protection, always taking into account the principles of accessibility, equality, and non-discrimination. This regulatory framework supports the mainstreaming of disability inclusion in all laws and public policies, in alignment with the 2030 Agenda for Sustainable Development.

In 2021, the ANID (National Agenda for the Equality of Disabilities 2021-2025) was adopted. It outlines how to implement the policy commitments and it has 14 framework pillars that encompass 69

<sup>20</sup> Amended in 2016 and 2018.

public policy proposals with 236 indicators (CONADIS 2022, 92) for the fulfillment of the rights of persons with disabilities. It also considers the necessary reasonable modifications needed in the different spaces and which are the responsibility of the different State institutions, as part of their planning and programming.

Legislative and political instruments, such as those mentioned here, prove to be a great advance in the protection of the rights of persons with disabilities for Ecuador, which has been an example of good practice for the Latin American region. However, in many occasions, the essence of the medical-rehabilitative paradigm still persists in the treatment of persons with disabilities by state service providers and the general society, becoming a persistent gap to achieve the goals described in the CRPD.

Also, the lack of institutionalization of processes on disability issues, in addition to the high turnover of technical staff in the public sector significantly hinders the effective and efficient mainstreaming of disability inclusion, making it difficult to create real impacts on the lives of persons with disabilities in Ecuador. In addition, there is a lack of knowledge on human rights and disability issues among technical staff.

The following section describes the discrimination that persons with disabilities face in their family and community relationships and when seeking care from service providers.

## 4.2. Barriers to Equity

### 4.2.1 Discrimination in the family and the community

The people interviewed in the Analysis shared the experiences of discrimination they have suffered in their family relationships. This is expressed in the forms of feeling rejected, singled out, excluded, infantilized, and overprotected (Focus groups and individual interviews, March and April 2023). In this way, it is pointed out that the family is the first place where persons with disabilities perceive to experience differential treatment, even if it is also their first space of support.

These forms of discrimination interact with gender roles, type of disability and economic status. Men with physical, visual, and hearing disabilities from rural settings feel discriminated against, for example, when their ability to be providers (economically and sexually) is undermined because of their disability (El Tena, El Coca, Guayaquil, March 2023). These discriminatory attitudes identified in the treatment of friends and family may appear in a joking tone (Personal interview, El Coca, March 2023).

In the case of women with disabilities in urban settings, the discrimination is often related to over-protection, which limits their ability to be, to do, and to decide. Gender and disability intersect, a critical point in which disability appears as a justification for the patriarchal mandate. Thus, women with disabilities (of all types) are questioned or singled out for wanting to leave their homes, for the way they dress or for their sexuality. (Personal interviews, March and April 2023).

Persons with psychosocial and intellectual disabilities are discriminated against when they try to make decisions about their daily life. For this group, the diagnosis itself constitutes a mechanism that

weakens the exercise of their rights and their right to make decisions<sup>21</sup> (Personal interview, Quito, May 2023). This is exacerbated for women and persons from the LGBTIQ+ community with psychosocial disabilities whose agency of choice is pathologized.

Women interviewed who live in rural areas of the Ecuadorian Amazon identify the discriminatory behavior in collective mockery directed at persons with hearing disabilities. Thus, they shared an experience in which a group of hearing people made gestures and signs to tease a child with a hearing disability from the Shuar community who knew Ecuadorian sign language (LSEC) (El Coca, March 2023). They also refer to exclusion as a form of disciplining persons with disabilities, whose behaviors and expressions are perceived as a kind of voluntary rebellion and not as part of the disability itself (Imbabura, March 2023).

Likewise, in cases of descendants with intellectual disabilities and wives who have acquired a disability, there is a pattern of abandonment by men. According to the women, abandonment is caused by their cowardice since “taking care” of persons with disabilities has its challenges (Imbabura, El Coca, El Tena, March 2023). It is evident how caregiving is still thought of as a female responsibility.

In conclusion, persons with disabilities interviewed identify experiences of discrimination in the context of family and community relationships. Discrimination is expressed in caregiving practices; for example, overprotection is a way of preventing decision-making. It is also manifested in practices of collective exclusion. These expressions are forms of “minor ableism”, i.e. the discrimination of and social prejudice against persons with disabilities based on the belief that typical abilities are superior. In the face of this, it is possible to affirm that families and communities are imbued with the imaginary of disability as an impairment.

#### 4.2.2. Discrimination in service providers

The persons interviewed stated that the institutional spaces where they have most perceived discriminatory attitudes and treatment are the institutions providing health, education, justice and labor services. These perceptions relate to the type of attention that persons with disabilities have been given when they have approached these institutions. They have felt that the exercise of their rights and their recognition as persons are weakened because they have a disability. Persons with disabilities face discrimination in their daily lives as a consequence of the perceptions and ideas that society has developed about disabilities. For this reason, it is necessary to focus on the transformation of these perceptions, both at individual and at collective level.

Health personnel’s behavior is what is considered to be the most discriminatory (Field diaries, 2023). This is consistent with one of the challenges of the Ministry of Health: raising awareness among medical personnel about the rights and priority care for persons with disabilities (Personal interview, May 2023). For the people interviewed, this treatment can become insensitive, indifferent, and rude, and is the expression of institutional discrimination (Guayaquil, Esmeraldas, March and May 2023).

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<sup>21</sup> This is related to the recommendation of the Committee on the Rights of Persons with Disabilities of 2019, regarding article 19, on the right to live independently and to be included in the community. It stated that the State should (...) review the actions envisaged in public policies and programs aimed at persons with disabilities, including the Manuelas Mission, the disability pension and the “neighborhood doctor” strategies, to ensure the right to independent living of persons with disabilities and their inclusion in the community” (Committee on the Rights of Persons with Disabilities 2019, 9).

Persons with a hearing disability interviewed affirm that health personnel have demanded on more than one occasion that they be accompanied by a person without a disability, who answers questions and receives the doctor's recommendations, instead of the person with a disability. During the medical appointment, this person plays the role of an improvised tutor, since the person with disabilities is not considered capable of communicating his or her experience and is infantilized. This demonstrates how decision-making by persons with disabilities is prevented in daily practices in healthcare institutions. (Focus group and personal interviews, El Coca, Guayaquil and Babahoyo, March and May 2023). Persons with psychosocial disabilities agreed with the comments, they said they "are prescribed medication according to what a third person considers correct, and their health situation is thought of as part of a delirium" (Personal interview, Quito, May 2023).

Likewise, women with disabilities interviewed for the Analysis, indicated that when they were seeking sexual and reproductive health services, they were denied care and were required to return for a medical consultation with their mother or a representative (Personal interview, Quito, May 2023).

Another example, a woman from the deaf community refers to discriminatory treatment as an expression of violence, when upon requesting an emergency contraceptive pill she was forced to take it in front of health personnel (Personal interview, Guayaquil, May 2023). In a different context, a woman with a physical disability talks about the abusive and violent manner in which she was treated by a doctor who yelled at her and shouted at her and used offensive words about her disability (Focus group, Guayaquil, March 2023). This shows that women and girls with disabilities are doubly vulnerable, because they face barriers to making decisions about their bodies, due to their gender and disability.

Regarding the discrimination perceived in educational institutions, the mothers caring for children with intellectual disabilities who are in mainstream schools expressed that they have perceived differential treatment and have experienced delays in the development of curricular adaptations and reasonable adjustments for their children (Focus group, Quito, April 2023).

In the rural context, mothers of children with disabilities state that the teaching staff of the educational institutions where their children study gets upset and criticizes their ways of communicating or censures them, including physical violence (El Coca, Imbabura, March 2023).

In another context, the experiences of persons with hearing disabilities are highlighted. Among them, were non-signing hearing impaired women received refusals from their teachers when they requested adequate material to take language exams. The women consulted affirm that they have felt discriminated against because there has been disbelief in educational institutions about their disability and therefore they have been denied their right to reasonable adjustments (Personal interviews, Cuenca, Guayaquil, May 2023). Regarding discriminatory attitudes and treatment in access to justice, persons with blindness and deep low vision have been asked to present witnesses in order to be able to carry out procedures that generally do not require them (Quito, Workshop, February 2023). This type of discrimination is echoed in cases of women with blindness who

report gender violence and who are not considered authentic witnesses of the violence against their bodies, because “they cannot see it” (Personal interview, Quito, 2023).

Also, the experiences of women with psychosocial disabilities who have been victims of sexual violence, and whose testimony is questioned because of their disability, are made visible (Personal interview, Quito, May 2023). In addition, some of the women with hearing disabilities interviewed stated that it is difficult to communicate situations of abuse or sexual violence, both in their families and in the institutions that provide access to justice. They perceive that they cannot trust the sign interpreters summoned by the institutions, because when trying to file a complaint for gender-based violence, they feel that their message has been underestimated or misrepresented by the interpreter, and in this way, their testimony has been lost (Personal interview, Babahoyo, May 2023).

Regarding discrimination at work, persons with disabilities interviewed stated that they perceived a change in the treatment of their superiors and colleagues after having experienced a crisis or having reported that they are persons with disabilities. In other cases, this has been a reason for being fired or forced to sign a resignation (Focus group and personal interviews, Quito, March and May 2023). Generally, psychosocial health conditions are defined in terms of intellectual performance and are used to challenge the performance of the person with disabilities (Personal interview, Quito, 2023).

Persons with visual, hearing, physical, and psychosocial disabilities from the middle class and the urban sector who were consulted in the analysis perceive discriminatory treatment because they are only required for services and customer service roles; even if their interests and academic preparation are not in line with these activities (Focus groups and personal interviews, Quito, Guayaquil, Cuenca, March, April and May 2023). In contrast, persons with visual, physical, and intellectual disabilities from the low-income sector perceive discriminatory treatment since they cannot access any formal job because the hiring institutions do not consider them capable. This is a reason for them to look for an informal activity, which is generally carried out in the streets, even if this means a risk to their integrity (Guayaquil, March 2023).

Finally, the interviews conducted with persons with disabilities for this situational analysis, have made visible the need to strengthen their knowledge and capacities to exercise their right to decide.

### 4.3. The key barriers to Equity

The conclusion of this analysis is that the main barriers to achieving equity for persons with disabilities in Ecuador are cultural/attitudinal, structural and budgetary.

- Cultural/attitudinal: The persistence of cultural barriers that link disability with incapacity and the overall lack of knowledge about disability inclusion means that persons with disabilities are constantly exposed to patronizing and discriminatory attitudes in all spaces and relationships (family, society, state). This means that persons with disabilities are treated as second-class citizens and not as rights holders capable of making decisions, which limits their power and autonomy.



- Structural: despite important advances in the inclusion of disability in the Ecuadorian legal and institutional framework, there are not enough mechanisms to guarantee the effective application of disability laws and public policies. This limits the access of persons with disabilities to services and spaces closely related to the exercise of their rights, such as health, education, justice and work.
- Budgetary: The general state budget does not have a specific and crosscutting budget line for disability. Only some institutions such as CONADIS, MSP, MIES and MINEDUC have a budget for disability, which is insufficient for the implementation of all the necessary actions to guarantee equity.

## 5. Section 3: Accessibility

### 5.1 Policy and practice in terms of universal design and accessibility

The possibility for persons with disabilities to enjoy independence is related to the accessibility of goods and services; that is, the elimination of barriers to access and use of public spaces, means of communication and information. In order to monitor compliance with the right to accessibility, at the national level there are the INEN Standards, a tool that sets regulations for standardization (Organic Law on Disabilities 2012, art. 58).

These standards interact with the logic of universal design that seeks to make objects, information and services accessible to all people in their diversity. According to CONADIS, there are currently “44 technical standards on accessibility to the physical environment, playing surfaces, recreational areas, information and communication, which have been officially published” (CONADIS 2022, 68).

Regarding access to information, accessibility refers to a series of formats for the design and circulation of information. Therefore, the LSEC, the Braille system, easy reading, as well as technological applications that facilitate access to information: audio, images, links, among others, are part of accessibility and guarantee the participation of persons with disabilities.

As affirmative action measures, the regulations refer to the right of persons with visual and hearing disabilities to demand adequate formats, as well as the obligation of institutions to generate easy-to-read material for persons with intellectual disabilities (Organic Law on Disabilities 2012, art. 63).

Despite this regulatory framework, the experience of persons with disabilities and the OPDs consulted shows that there is a weak implementation of the norm. Accessibility is a cross-cutting approach to guaranteeing access to all rights for persons with disabilities and is one of the preconditions for the inclusion of persons with disabilities, where there is a large gap.

Respondents agree that accessibility to physical spaces and information depends on the type of disability, location, gender, and technological skills of persons with disabilities. In general, the implementation of accessibility standards is better in larger cities. However, the focus is mainly on physical disability and less on access to information and services.

Physical accessibility in buildings and public transportation is better for persons with mild and moderate visual and physical disabilities, and in certain unique spaces in cities. In these places, there are ramps, Braille messages, and pod tactiles. However, physical accessibility tools are not always implemented correctly and can sometimes even hinder access.

According to the responses to the survey, most organizations recognize accessibility as a milestone still far from being met: 26.1% responded that there is no accessibility to transportation, public places and infrastructure, and 60.9% that it is very poor. With regard to the accessibility of information, 30.9% stated that they could not access it at all, while 56.5% said that they could access it very rarely.

In rural areas and in locations with higher poverty rates, accessibility does not exist at all (Focus groups and interviews, Imbabura, Quito, Esmeraldas, Guayaquil, March and May 2023). The following examples were provided: Women with physical disabilities in Esmeraldas have been excluded from access to institutions, public restrooms, and means of transportation due to the lack of accessibility (Focus group, Esmeraldas, May 2023). Persons with disabilities in Guayaquil and Quito state that it is difficult to move around in public spaces that are not constantly maintained; their canes cannot avoid potholes, manholes without covers, and other unplanned areas, which constitute permanent risks to their physical integrity (Focus group and interviews, May 2023).

Accessibility to information is even more limited, almost non-existent. There are few easy-to-read documents, documents with appropriate subtitles or those that include the use of LSEC (Personal interviews, Cuenca, Guayaquil, Babahoyo, May 2023). Persons with visual, hearing and intellectual disabilities are those who have the greatest difficulties in accessing information and, therefore, full participation in the different areas of daily life, in order to enjoy their autonomy and independence.

Clearly, the barriers to accessibility are even greater for people living in rural areas, considering that access to information is mediated by the availability of internet networks, mobile devices and skills in the use of technologies, not always easily accessible. Thus, the situation previously announced by the Committee in 2019 is reiterated, when it recommended the Ecuadorian State to implement a comprehensive policy of accessibility to the physical environment and transportation, which includes the entire mobility chain and ensures accessibility to information and communications in different formats (Committee on the Rights of Persons with Disabilities 2019, 5).

## 5.2. The key barriers to accessibility

The main barriers to accessibility are identified below:

- Accessibility planning is focused on access to physical spaces and urban architecture, while in rural areas it is nonexistent. In addition, it is aimed only at persons with mild and moderate physical and visual disabilities and is reduced to ramps, Braille, and tactile signs that do not always meet their objective due to deficient implementation.
- Accessibility to information is limited and a significant percentage of people consulted perceive that it is non-existent, due to the fact that they experience the scarcity of documents and messages in audible formats, easy to read, with subtitles, with LSEC interpretation, among others.
- Persons with disabilities such as hearing, visual, and intellectual disabilities are those who experience the greatest difficulties in accessing information. Even more so, if they are people from rural areas and have little access to information and communication technologies.



## 6. Section 4: Inclusive services

### 6.1. Disability Referral & Assessment Systems

In the Ecuadorian context, the Organic Law on Disabilities is the legal framework that establishes and guides actions related to the disability approach and the effective fulfillment of the rights of persons with disabilities.

The LOD provides that the national health authority (Ministry of Public Health) will be the entity in charge of the disability assessment/qualification and accreditation process, for which the National Subsystem for the Qualification of Disability will be created (Organic Law on Disabilities 2012, 8). In turn, it is defined that CONADIS has the power to oversee and monitor the proper functioning of the system throughout the Ecuadorian territory.

The Regulation for the Qualification, Re-qualification and Accreditation of Persons with Disabilities or with Impairment or Disabling Condition (2020) was issued to guide the actions of the Ministry of Public Health's staff. These regulations detail the singularities of the disability evaluation process, for which the following elements must be available:

- Specialized qualifying teams: made up of general practitioners or specialists, clinical psychologists and social workers, trained and accredited by the MSP to evaluate, qualify and requalify persons with disabilities.
- Manual de calificación "Valoración de las situaciones de minusvalía": Spanish document that establishes the conditions for defining disability in a person.

The disability qualification process goes through three phases: the general physician's evaluation, through which the body's functionality is evaluated; the psychological evaluation; and, finally, the evaluation of the social work area, which refers to a socioeconomic assessment of the person with a disability and his or her family<sup>22</sup>. The result is an average that calculates the percentage of disability of the person. This must be 30% or more for this to be valid and accredited as a disability (Reglamento a la Ley Orgánica de Discapacidades 2017, 3).

The process is expedited when the person with a disability presents his or her diagnostic tests endorsed by private medical specialists. If the disability diagnosis is requested within the authorized qualification centers, the scheduling of appointments can take months or even years, which is an obstacle for families in situations of poverty or extreme poverty.

From this scenario, it can be concluded that many persons with disabilities are not in official records due to a lack of access to the corresponding diagnostic and qualification services, and the barriers to access increase in peripheral and rural areas (Velasco, Hurtado, and Tapia 2020).

Finally, it is worth mentioning that the Organic Law on Disabilities and the Disability Qualification Manual are being updated, to ensure due compliance with the provisions of various international

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<sup>22</sup> The disability qualification process is the same for both children and adults with disabilities.

human rights instruments. Also in this process, the Committee's recommendation of 2019, on ensuring the harmonization of the criteria for disability qualification with the Convention, to view disability from the human rights perspective and not from a medical perspective, is being considered.

## 6.2. Disability Support Services (targeted efforts)

Three modalities of support for persons with disabilities with a focus on care are managed under the administration of the MIES. These are called: Comprehensive Day Care Centers, Inclusive Referral and Shelter Centers, and Home and Community Care (MIES 2023a). These systems are designed to provide, mainly, rehabilitation, medical, and support assistance in everyday activities. Also, the Ministry of Health distributes technical aids such as canes, orthoses, prostheses, wheelchairs, anti-decubitus cushions, among others, according to medical prescriptions.

Despite this institutional framework, according to information gathered through interviews and focus groups, families and communities bear the burden of care needs, its cost and management, without a State budget for it. As a result, their social, economic and emotional vulnerability increases, as well as the difference in access, determined by their economic stratum. Thus, there are persons with severe physical disabilities who have had to import from other countries tools such as cranes to improve their mobility, while others must remain in bed most of the time, and be carried by family members, when they have a care network (Guayaquil and El Tena, March 2023).

The persons consulted refer to the poverty surrounding the support systems and, as a result, there is an overload on the family care networks. This became more evident during the COVID-19 pandemic when the Day Care Centers and home visits stopped - something that has not yet been solved. This scenario becomes more complex because economic assistance, such as the Joaquín Gallegos Lara<sup>23</sup> voucher, has been systematically withdrawn from persons with disabilities who, the respondents consider, still need it (Focus group and personal interviews, Guayaquil, El Tena, Quito, March and May 2023).

Regarding technical aids, those that support persons with visual and physical disabilities are the most frequently distributed. Meanwhile, those requested by persons with hearing disabilities, such as cochlear implants and hearing aids, are not easily obtained (Personal interviews, Quito and Babahoyo, May 2023).

In addition, because of the low quality of these technical aids their durability is limited. For example, wheelchairs are not designed for a diversity of users of different sizes and body weights; their design is not suitable for different contexts and the possible difficulties of the terrain where they would be used (Imbabura focus group and Guayaquil focus group, March 2023). Persons with disabilities who are part of the informal labor sector use their chairs, canes, and other technical aids in their work in the streets, so they deteriorate even faster (Guayaquil, Quito, March and May 2023).

In addition to referring requests for technical assistance, organizations such as the Imbabura<sup>24</sup> Disability Observatory serve as intermediaries and make the referrals of specific cases to the corresponding

<sup>23</sup> This is a conditional cash transfer assistance program for Ecuadorians with disabilities (with severe, very severe and complete disability categories) living in poverty or extreme poverty.

<sup>24</sup> The Disability Observatory in Imbabura is a space for citizen participation that works as a social control mechanism and observation of public policy on disability, registered in the CPCCS.

institutions. These management systems are evidence of a community support system that the OPDs sustain, without support from the State. Along the same lines, organizational initiatives stand out, such as those of Grupo Fénix, which provides emotional support for persons with bipolar affective disorder; and Huertomanías, which provides a space for labor insertion and entrepreneurship for persons with psychosocial disabilities, among others.

Neglect and the frequent practice of institutionalizing children and adolescents with disabilities is one of the most important concerns noted by the Committee on the Rights of Persons with Disabilities (UN 2019). There is no official data on how many persons, children and adults with disabilities are institutionalized. A deinstitutionalization plan or policy is non-existent. The Ministry of Economic and Social Inclusion with the technical assistance of CONADIS are the bodies responsible for deinstitutionalization.

Likewise, OPDs consider that a system of community support services for persons with disabilities has not yet been constituted, which would be a response to this concern. Faced with the lack of access to these support services, OPDs have self-managed their own services, however, they are not part of the formal processes of deinstitutionalization or planned transition to a system of community support services (Focus groups and personal interviews in Guayaquil, Quito, El Tena, March and May 2023).

### 6.3. Mainstreaming services (inclusive efforts)

The Organic Law on Disabilities, in its second chapter, recognizes that it is the duty of the State to guarantee persons with disabilities the full exercise of their rights and, therefore, access to mainstream services through affirmative actions to achieve equality. Moreover, disability is (theoretically) mainstreamed in all public services.

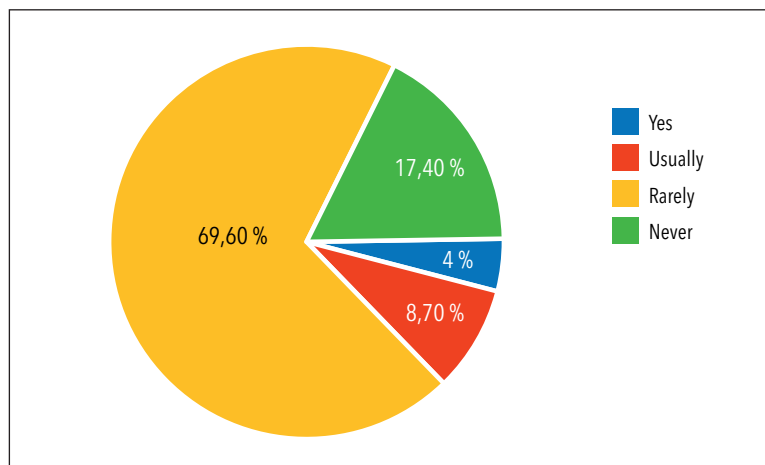
Additionally, there are sector-specific laws and regulations that concern people with disabilities but still require review to ensure they are in line with CRPD, such as: the Social Security Law (2022), the Labor Code (2021), the Organic Health Law (2022), the Organic Law on Intercultural Education (2021), the Comprehensive Organic Criminal Code (2013), the Organic Law of Human Mobility (2017) and the Comprehensive Organic Law to Prevent and Eradicate Violence against Women (2018). In addition to these laws, there are strategic programs such as the aforementioned “Ecuador sin Barreras” which sought the labor inclusion of persons with disabilities; “Educar Ecuador” which seeks to promote inclusion and equal opportunities in education and other specific support programs promoted by the Ministry of Health and the Ministry of Economic and Social Inclusion.

The OPDs and persons with disabilities interviewed all agree that there is little access to basic general services such as health, education, employment, and social inclusion. The situation worsens in rural and border areas, where it becomes very difficult even to interact with institutions and often they must travel long distances to access certain health or education services, excluding all people living in extreme poverty.

The responses to the survey reflect this reality: of the 23 participating associations, 16 expressed significant difficulty in accessing health services and four said that they simply do not have access.

Only three organizations responded that they do have access, two in the majority of cases and one in all cases (Figure 2).

Figure 2. Access to health<sup>25</sup>



When asked whether health services are designed in an inclusive and accessible manner, there is a consensus by stating that they very rarely and only for certain disabilities (60.9%), or never (39.1%). Similar responses are found in transportation, mobility, labor inclusion, and education services. For the education sector, however, it is recognized that there has been some small progress.

It is important to note that UN agencies such as the United Nations Population Fund (UNFPA) and the Pan American Health Organization have contributed with sexual and reproductive health strategies; rehabilitation and inclusion to manage disaster risks in hospitals; targeted at persons with disabilities. These strategies will be discussed in more detail in the section on support from UN agencies.

The lack of access to general services as well as specific support services for persons with disabilities is related to the low state investment in public services and social inclusion. In this context, the COVID-19 pandemic exacerbated the already complex situation of the country's essential public sectors, such as the health sector, which was finally declared in a state of emergency due to social pressure from the national demonstrations that took place in June 2022.

## 6.4 Key Barriers to Accessing Services

Finally, the most important gaps for accessing services are identified:

- 57.75% of persons with disabilities are not part of official registers due to the lack of access to assessment centers, and the access barriers increase in peripheral and rural areas.
- The Disability Assessment Manual of the Ministry of Public Health has not yet been updated to ensure compliance with international instruments that consider disability from the human rights model, and not from the medical model.

<sup>25</sup> Developed from the responses of the survey on rights of persons with disabilities.

- Lack of access to general and support services: Persons with disabilities, especially from under-represented groups, face difficulties in accessing health, education, work and social protection. Particularly, girls and women with disabilities in rural areas experience greater barriers in accessing sexual and reproductive health services and gender-based violence care. This is due to the centralization of services, lack of state attention to rural areas, lack of accessibility, and lack of affirmative action measures related to psychosocial disability.
- Lack of a state-level quality support system for persons with disabilities: This causes care work and its economic consequences to fall on the family and the community, especially on women due to socially imposed roles.
- Low-quality support products/technical aids: Respondents in this Analysis informed about the difficulties and poor quality of support products, such as wheelchairs, which must be used for a prolonged period of time.
- Lack of budget to develop deinstitutionalization initiatives for persons with disabilities, which would allow for a sustainable community support services system.
- The Informed Consent Manual for persons with disabilities of the Ministry of Health should be revised to strengthen adequate access to health services, as well as the right to decide of the aforementioned population.

## 7. Section 5: Disability inclusive budgeting

### 7.1. Financial Planning & Monitoring

Disability is one of the five cross-cutting themes of equality in the Ecuadorian law. However, the general 2023 State budget does not show a specific item for it, but it is up to the social sector institutions responsible for rights promotion to manage the budget to benefit the development of persons with disabilities. The following is a breakdown of which State entities have a specific budget for the disability inclusion, according to the Ministry of Economy and Finance published data as of 2023:

- CONADIS: this council has a budget line for the protection of persons with disabilities, and the initial budget allocated for 2023 was 1,707,513.78 USD. This budget is for CONADIS' own execution in terms of mainstreaming public policy proposals; monitoring, evaluation and enforcement activities related to its function.
- MINEDUC: In 2023, USD 505,851.84 has been allocated under the inclusive education budget line.
- MSP: In 2023, USD 6,222,218.95 has been allocated as a budget line for the provision of medical services for persons with disabilities.
- MIES: for this ministry, the budget line of protection for persons with disabilities has been diversified; the budget for 2023 has been 20,158,563.37 USD.

In the case of the MSP and the MIES, the budgets include a project under the heading of the annual investment plan, which is fed by international cooperation funding. The MSP manages the investment project "Support for early diagnosis, qualification and delivery of technical aids for persons with disabilities in Ecuador", which is financed by the Inter-American Development Bank. This represents 0.74% of the institution's total budget.

In the case of MIES, there are three investment projects financed by the Inter-American Development Bank: a) Capacity building for persons with disabilities and their families for the promotion and enforcement of rights; b) strengthening management and innovation in the care of persons with severe disabilities; and, c) innovation, diversification and expansion of social inclusion services for persons with disabilities and their families. These projects account for 27.24% of the institution's budget for disability issues.

## 7.2. Support from UN agencies

In financial planning around the disability area, the importance of international cooperation agencies must be recognized. In particular, the United Nations is committed to achieving disability inclusion in its programming, respecting the Convention as the main tool that promotes the recognition of the rights of persons with disabilities.

For example, the UN Volunteers agency has the category of service provider, so it does not implement projects and programs but has included affirmative action for persons with disabilities in its calls for proposals.

In the case of UN Women, the "Caminando" project has worked on disability as a cross-cutting issue, not as a specific project, and has focused on strengthening labor and entrepreneurial skills for women, considering that economic independence is vital for women.

UNESCO, UNHCR and UNICEF have come together in the Multi-Year Resilience Program (a project of 7,410,000.00 USD that UNESCO received as a guarantor). The program's focus is based on the attention to groups in vulnerable situations, where persons with disabilities stand out. It is worth mentioning that this program is financed by the Global Education Cannot Wait (ECW) Fund and its requirement is to involve persons with disabilities within the established actions of the program.

UNFPA has been implementing the We Decide Program (2017-2023), to work on strategies on sexual health and reproductive health and a life free of gender-based violence of persons with disabilities, with special attention to women and young people with disabilities (UNFPA 2020, 43). During the implementation period the investment has been USD 365,939.31.

Important achievements and lessons learned have been gathered from the program. For example, the strengthening of intersectoral collaboration on disability-related issues among different stakeholders and the capacity building of institutions such as the Ministry of Public Health, the CONADIS and the Council for Gender Equality in terms of knowledge generation, provision of technical assistance and development of guidelines on inclusive services for health staff. However, the implementation of the guidelines by health centers is still a challenge, as well as the empowerment of persons with disabilities so that they get to know and claim their rights. The guidelines also need to be updated.

For its part, the UNFPA Ecuador Office is implementing the Preparatory Phase of the UNPRPD Fund, which focuses on the implementation of the CRPD, guaranteeing the full development of persons with disabilities, and, for this purpose, 100,000.00 USD have been allocated.

The Pan American Health Organization in Ecuador is making efforts to implement the Plan of Action on Disability and Rehabilitation 2030 and the INGRID H Strategy "Inclusion for Disaster Risk Management in Hospitals". The budget for PAHO programming is USD 9,600,000.00, which includes actions related to disability.

The Resident Coordinator's Office has organized various consultation processes involving persons with disabilities, specifically the consultation process for the construction of the new United Nations Cooperation Framework for Sustainable Development 2022-2026, in which five organizations of persons with disabilities and seven activists participated.

In addition, as lead agency in human resources for the UNS, the Food and Agriculture Organization of the United Nations (FAO), between 2021 and 2022, was responsible for the Strategic Partnership Management Consultancy for the talent mapping of persons with disabilities.

As a result of these efforts, the Resident Coordinator signed letters of understanding with OPDs to promote the employment of persons with disabilities within the UNS. UNICEF is currently in charge of following up on these efforts.

It should be noted, however, that the disability marker has not yet been included in the budgets within the UNS, as well as in the catalog of international cooperation with reference to a specific line of disability. Therefore, the challenge is to mainstream the approach in order to better guide actions within this framework.

### 7.3. Key barriers to inclusive budgeting

In summary, the most important gaps around the inclusive budget are detailed in the following:

- There is no specific line item for disability in the general state budget. In the budget of the National Council for Equality of Disabilities, the Ministry of Education, the Ministry of Health and the Ministry of Economic and Social Inclusion, there are items aimed at programs that include disability mainstreaming.
- Despite the fact that the UNS is working on the development of programs that incorporate disability inclusion, there is no disability inclusive marker for the budgets.

## 8. Section 6: Governance and accountability

### 8.1. National Accountability Mechanisms

Accountability in the field of disability in Ecuador implies processes through which institutions working in the field of care and public policy on disability inform citizens about the programs established and their results. It includes mechanisms aimed at guaranteeing access to timely information, as well as spaces for observation, evaluation, control and participation of persons with disabilities and OPDs.

It is important to note that, in 2019, the Committee on the Rights of Persons with Disabilities recommends Ecuador (under Article 33), to establish an independent mechanism with a budget and



designated functions for monitoring the implementation of the Convention. The Committee also recommended that the Ombudsman's Office (DPE) be involved in the independent monitoring mechanism, and that persons with disabilities and their representative organizations participate in it effectively and independently (Committee on the Rights of Persons with Disabilities, 2019).

In view of this, as of April 2020, the Ombudsman's Office created the National Monitoring Mechanism for the Rights of Persons with Disabilities and its operation has been visible since mid-2021. The scope of the mechanism is nationwide, so the provincial delegations may refer cases of systematic incidents in order to issue directives and guidelines to address the violation of the constitutional rights of persons with disabilities.

Despite this effort, the DPE does not have sanctioning powers, which limits its ability to enforce its recommendations. In addition, due to the time of existence of this mechanism, it is not yet known by persons with disabilities and OPDs in the territories, so synergies have not been generated for proper implementation.

Currently, thanks to ANID 2021-2025, participatory mechanisms are being implemented for monitoring the results of public policies. A series of indicators are presented in this instrument to evaluate the progress of the institutions in terms of their action frameworks, in line with the recommendations of the Committee on the Rights of Persons with Disabilities (2019).

In turn, under Article 35 of the CRPD, signatory States are required to submit reports on compliance with the Convention, as well as on the recommendations received (CRPD 2012). Ecuador submitted the initial report in 2014, and the combined second and third periodic review report in 2018 -it was published in 2019-. As part of this accountability process, government institutions, through the leadership of CONADIS, report, respond to, and provide feedback on the Committee's recommendations, although exhaustive compliance with the different topics is not always evident.

For persons with disabilities and the OPDs consulted, there is a perception that accountability mechanisms, such as ANID, the DPE mechanism, or the possibility of participating in the preparation of reports, have not been disseminated in all the necessary accessible formats to get to know them in depth (Personal interviews, Guayaquil, Quito, March and May 2023).

Instead, the OPDs consulted have implemented citizen oversight processes to generate spaces for collective review of the documents made available to the public for the preparation of shadow reports. Despite this, there is a perception that their comments are not taken into account (Personal interviews, Quito, Guayaquil, March 2023).

The Council for Citizen Participation and Social Control has some citizen's observatories for the rights of persons with disabilities, but they do not interact with each other, and only the activities of the Observatory of the province of Imbabura are well-known (Personal interview, May 2023). The same lack of coordination is evident in the Consultative Councils that are part of the Cantonal Councils for the Protection of Rights and local governments (especially if there is no political alignment with the GADs). This hinders the fulfillment of the rights of persons with disabilities in the territory. (Interview, Ibarra, May 2023).

Regarding access to data, and according to the OPDs consulted, statistical information on the work of the government institutions circulates once a year and its formats do not comply with accessibility standards for all types of disability. They stated that the flow should be quarterly and should be improved with information collected by the OPDs.

## 8.2. Inclusive Evidence & Data Gathering Systems

For this section, the recommendations on the application of Article 31 of the CRPD, made by the Committee on the Rights of Persons with Disabilities and which were sent to the Ecuadorian State in 2019 have been taken into consideration. This is detailed below:

[...] the State party incorporate a human rights perspective into the information contained in the National Disabilities Register so that, in coordination with persons with disabilities and their organizations, the effective exercise of their rights is recognized; that it mainstream those rights in public policy and in policy follow-up and evaluation; and that it incorporate information on the participation of persons with disabilities in all areas of social life, such as education, paid work, recreation and political affairs. It also recommends that the State party disseminate the information contained in the National Disabilities Register widely once it has been reformed. (Comité sobre los Derechos de las Personas con Discapacidad, 2019).

In this regard, it should be mentioned that the country has not yet managed to strengthen the National Registry of Persons with Disabilities (which is currently generated and administered by the Ministry of Public Health). It is necessary to develop the registry to become a data collection system that meets accessibility standards and includes the necessary variables to create a public disability database, which truly represents the situation of the country.

The National Council on Disability Equality (CONADIS) is the governmental institution responsible for disability-related public policy. They collect and process official data to generate statistics on persons with disabilities registered in the country. It is important to consider that, according to data from the 2010 Population Census, 816.000 people self-identified as persons with disabilities (INEC, 2010).

However, CONADIS register shows that not all those persons with disabilities are formally registered, that is, only 57% of persons with disabilities identified in the census have a document qualifying their condition. Such a situation is due to the conditions of poverty or extreme poverty faced by people, especially those living in rural areas, which limit their access to a disability qualification process.

In addition, it should be mentioned that some of the government institutions have sub-registers of persons with disabilities to whom they provide services, but there is a lack of inter-institutional coordination of data. Thus, there is no clarity in the national figures of persons with disabilities nor their abilities and support needs, and it can be stated that this is an institutional criticality. It is very likely that there is a serious underestimation of this population group.

However, the National Institute of Statistics and Census (INEC) has already included questions on disability in the 2022 population census and in the surveys on living conditions, based on the Washington Group's questions. These are not yet published. The results of these population information gathering processes will be added to the statistical database that CONADIS publishes every year on

its web page and that is prepared based on some variables shared from the databases of sectoral institutions, such as the Ministry of Public Health, Ministry of Education, among others.

Additionally, it is important to mention that the UNFPA Office in Ecuador has promoted the generation of research on gender-based violence and disability “Pregnancy in adolescent women with disabilities, gender-based violence and challenges in care” in 2017 and “Bodies that do matter. Breaking down myths, the practice of incest in girls and teenagers with disabilities” in 2019; these studies have provided relevant results to understand the situation experienced by women and young women with disabilities.

### 8.3. Key gaps in governance and accountability systems

Given this context, the main gaps in accountability and governance mechanisms and inclusive data systems are presented below:

- The Committee on Rights of Persons with Disabilities’ final observations made to Ecuador’s periodic reports have not yet been totally fulfilled.
- During the Situational Analysis process, the consulted persons with disabilities affirmed that information about existing accountability mechanisms is insufficient and inaccessible and therefore these mechanisms are not effectively utilized by OPDs and persons with disabilities.
- Lack of a single inclusive data system through which institutions report information disaggregated by disability variables, in accessible formats and with a regular updating period.
- Organizations of persons with disabilities do not have the knowledge and tools to systematize the information on disability that they collect in the course of their work.
- Since 2020, the Ombudsman’s Office has begun to participate in the monitoring of human rights violations against persons with disabilities. However, the scope of its actions is still very weak.



## 9. Cross cutting issues

### 9.1. Section 1: Participation

CONADIS, the Ministry of Health, the Ministry of Education, the Ministry of Labor, among other state institutions, mentioned the existence of internal consultation initiatives, especially with members of the national federations of and for persons with disabilities and other large organizations (Personal interviews, April 2022). However, among the OPDs consulted there is a perception that their participation is undervalued (Focus groups, March 2023) and, on many occasions, they are simply not involved in a participatory manner, becoming objects of attention and not rights holders.

The existing opportunities to participate in coordination and monitoring mechanisms are largely unknown to OPDs on the ground, who are often not informed about ongoing planning or monitoring processes and tools in a manner that is accessible to them.

From the OPDs and non-associated persons with disabilities consulted for this analysis, there is a perception that the participation mechanisms proposed by the State institutions do not take into account a large number of persons with disabilities, mainly for three reasons: the information is not accessible to all, they are out of reach in rural sectors, and even, they are largely unknown in sectors with poverty indexes (Focus groups, Imbabura, El Coca, Esmeraldas, Guayaquil, March and May 2023).

### 9.2. Section 2: Inclusion of underrepresented groups

Intersections between types of disability, location, race/ethnicity, and gender evidence differential access to participation.

Regarding the standard of information accessibility, the persons who have the greatest difficulty in participating in development initiatives are persons with visual, hearing and intellectual disabilities; even more so if we take into account the technological expertise of reading tools, as well as the low probability of having a multimedia device and access to the Internet.

In this sense, people in rural areas and poor sectors do not always have access to tools, channels and technological domains, in order to learn about the participation resources that can be found in social networks. Accessibility in rural areas does not meet universal design standards and this is evident in public spaces, where there is a lack of adequate planning.

According to the Imbabura Disability Observatory, persons with disabilities who are not associated, persons with disabilities in rural areas, especially women and girls, and those who know non-hegemonic languages such as Kichwa, LSEC and home sign language are less likely to be involved in participation processes (Focus group, Imbabura, March 2023).

The situation is even worse for persons with disabilities from indigenous peoples and nationalities, since they are not identified as persons with disabilities, but only on the basis of their medical conditions when they have been officially recognized. Not being named and not being officially registered,



generates an obstacle for the promotion of participation, and it is conceived as a unidirectionally planned mechanism by the institution. This calls for the urgent need to build spaces for horizontal participation that involve people as subjects of rights. In this way, the duty bearers must go to where their voices and realities are constructed and learn how to accept them.

In other contexts of poverty, for women with physical disabilities in Esmeraldas (Focus group, May 2023) and persons with physical, visual and intellectual disabilities in Guayaquil (Focus group, Guayaquil, March 2023) interviewed for this analysis, there is an institutional abandonment of certain territories: barriers are geolocalized. If they cannot participate in their OPDs and in other initiatives consistently, it is because their concerns are focused on food, rent payments and health expenses due to their disability conditions; they do not attend meetings due to lack of budget to travel (Guayaquil, March 2023).

In addition, persons with disabilities (at least in the sectors with the highest poverty rates) have a generalized perception that their knowledge is being co-opted by academic institutions and NGOs. They complain that they have given information and expertise to projects from which they have not received any return; therefore, they distrust the participation processes offered from the outside. They seek and demand to be actors in these processes and not only informants.

Furthermore, the historical number of recognized refugees in Ecuador is 75,000 according to the Norwegian Refugee Council<sup>26</sup> and there are around 502,214 migrants under regularization processes (GTRM, June 2023)<sup>27</sup>. However, there is no data on persons with disabilities in human mobility, despite the fact that the Organic Law on Human Mobility recognizes persons with disabilities as a group of priority attention (art. 20.A; art. 21). However, the ANID 2021-2025 includes actions and indicators for persons with disabilities in migratory situations. It is considered necessary to invest in research processes on disability inclusion and migratory conditions.

### 9.3. Section 3: Gender equality

The inequalities that women and girls with disabilities experience are shaped by the attitudes towards women in general and the stigmas around disability in particular. This intersection, in conjunction with other categories described in the previous section, adds up to extra vulnerabilities. Women and girls with disabilities are made invisible, even within their homes. This occurs because of patriarchal and ableist attitudes that limit their right to decide, to have a voice, and to participate.

During the participatory events that were organized as part of this situational analysis, which included mixed groups (men and women with different types of disabilities, and women caregivers without disabilities), the difficulty of women with disabilities to talk about their living conditions became evident, and therefore, the idea was clear and cannot go unnoticed: the initial silence conveys a message (El Tena, El Coca, Guayaquil, Quito, March, April and May 2023). At times, men with disabilities speak on behalf of women; just as caregivers without disabilities speak on behalf of the persons with

<sup>26</sup> <https://nrc.org.co/ecuador/#:~:text=La%20cifra%20hist%C3%B3rica%20de%20personas,y%20migrantes%20provenientes%20de%20Venezuela>

<sup>27</sup> Grupo de Trabajo Sobre Personas Refugiadas y Migrantes, agosto de 2023.  
<https://reliefweb.int/report/ecuador/ecuador-reporte-de-situacion-julio-2023>

disabilities under their care; thus, a type of subordinate relationship is established. These experiences show that women and girls in Ecuador face structural invisible violence in their lives (CNIG, UNFPA and AECID 2019). “It is a disguised reality since little or nothing is reported about the violation of their rights”. (Fundación ALDEA 2022, 30).

From individual interviews or moments set aside after the focus groups, situations of violence resulting from the intersection of sexism and ableism can be evidenced. For example, women from the deaf community report silenced sexual violence, difficulty in reporting it, and disbelief on the part of justice personnel and their families (Guayaquil, Babahoyo, Cuenca, March and May 2023). In addition, the women interviewed affirmed that the women with hearing, intellectual, and psychosocial disabilities have experienced unconsented sterilizations and their inheritance has been expropriated (Personal interview, May 2023).

Women with physical disabilities in Esmeraldas report situations of violence during childbirth<sup>28</sup>, expressed in statements that refer to their disability, as well as situations of sexist harassment in public transportation, with statements that refer to their non-obvious disability. Thus, when paying the preferential fare, they heard comments such as: “How could I think that such a beautiful woman would be disabled” (Focus group, May 2023).

Some women with blindness from the urban and rural sectors surveyed stated that their partners take away their canes to immobilize them, as a form of violence (Fundación ALDEA 2022; personal interview, Quito, April 2023). Others are questioned and blamed by their partners for having acquired a disability, arguing that they can no longer devote themselves to household chores as they did before. For example, they hear comments such as: “I didn’t tell you to be blind, I didn’t tell you to have diabetes” (Focus group, El Coca, March 2023). In this case, women’s value is shaped by the fulfillment of gender roles; the acquisition of a disability reduces that value.

For lesbian women with disabilities, there is a perception that vulnerability can be tripled due to intersecting stigmas about their sexual orientation and disability. Lesbian women with hearing and psychosocial disabilities who were interviewed and who have intimate partner relationships with a woman with a physical disability claimed that they experienced constant singling out for their expressions of affection in public (Personal interviews, Babahoyo and Quito, April and May 2023).

Kichwa-speaking women who are caregivers of girls with disabilities said that they are the only ones who can take care of their daughters, due to their role as women-mothers; they only rely on other women and girls for support (Imbabura, March 2023). One of them reported that she handles the menstruation of her adolescent daughter with a physical disability, and emphasizes the caution she takes in relation to the distance she must have with the men of the family and the community. This reflects that, in the absence of an inter-institutional care system, it is the women who assume this responsibility, and women with disabilities in rural areas, and others in low-income sectors, think of it as the only option, almost as a destiny; among other things, due to an implicit fear of sexual violence.

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<sup>28</sup> A specific form of violence against women that violates their human rights. Conducted by obstetric care providers regarding the body and reproductive processes of the woman, being characterized by dehumanized assistance, abuse of interventionist actions, medicalization, and reversion of the process from natural to pathological (BMC Pregnancy and Childbirth, 2022).

**The following challenges are identified** for women, girls, and persons LGBTIQ+ with disabilities.

1. Disability inclusion in certain legal frameworks related to the guarantee of citizens' rights, for example, in the Ecuadorian Civil Code and the Organic Code of General Procedure <sup>29</sup>.
2. Lack of self-recognition and self-representation of persons with disabilities from underrepresented groups. Women and girls with disabilities, people from rural areas, indigenous peoples and Afro-descendants, persons with disabilities, LGBTIQ+ community, persons with psychosocial and intellectual disabilities do not always name themselves in their identification processes. This is aggravated if the intersections add up to conditions of vulnerability, simultaneously, this produces weakness in the associative movement of these underrepresented groups.
3. In Ecuador, women and girls with disabilities are discriminated against and therefore are not considered as leaders, both by the movements of persons with disabilities and by feminist movements, so they face situations of double discrimination, both because of their gender and their disability.
4. Persons with disabilities in rural areas and living in poverty continue to face a lack of access to services. This is evidence of institutional discrimination due to the lack of operationalization of the Organic Law on Disabilities, because the officials in charge of its enforcement keep an ableist attitude.
5. General indifference and lack of knowledge about the conditions in which women and girls with disabilities live, especially in rural areas. This includes the positions of women's organizations, feminist organizations and OPDs.

## 10. Disability Inclusion in Broader Development, Humanitarian & Emergency Contexts

Considering what has been mentioned about the gap between the design and implementation of public policies, the following actions and national plans may be observed:

### 10.1. Section 1: National Development Plans

#### • National Development Plans "Creating Opportunities" 2021-2025

The policy implementation guidelines for 2021-2025 are the National Development Plan (PND by its Spanish acronym) titled "Creating Opportunities" and the National Agenda for Disability Equality, are aligned to Agenda 2030 for Sustainable Development (UN 2015).

The 2021-2025 Plan for the Creation of Opportunities is composed of 5 cross-cutting topics representing the roadmap for government policy programming: Economic, Social, Integral Security, Ecological

<sup>29</sup> This legal instrument regulates the procedure carried out in the different judicial processes between parties that correspond to the courts, chambers and tribunals of justice in the country. The Committee on the Rights of Persons with Disabilities in 2019 noted the persistence of the categories of guardianship and conservatorship within the Civil Code and the Organic Code of General Procedure with the purpose of aligning them with the CRPD. In view of this, it is important to promote their updating to include the legal entitlements of persons with disabilities.



and Institutional Transition. The objectives and goals of each cross-cutting topic are guided by the Pluriannual Public Investment Plan (PPIP). The PPIP is a public investment programming instrument. It includes the technical and budgetary description of priority public investment studies, programs, and projects for a 4-year period. It is a programmatic reference tool, subject to annual review.

There are two goals directly related to the inclusion of persons with disabilities in the National Development Plan. These are related to increased inclusion in the workplace and in high-performance sports. The National Planning Secretariat uses the “Open Data” platform to monitor compliance on these goals.

It sets goals for social action aimed at ensuring a life free of violence both in the private and public sphere, prioritizing women, boys, girls and youth, elderly persons, persons with disabilities, persons from LGBTIQ+ community and everyone in a disadvantaged or vulnerable situation (SENPLADES 2021, 39).

#### • **Cooperation Framework for Sustainable Development in Ecuador 2022-2026**

It should be mentioned that the Cooperation Framework for Sustainable Development in Ecuador 2022-2026, was built considering persons with disabilities as a target population group to develop consultation processes. This document reaffirms UNCT’s commitment to work to make the motto “Leave no one behind” a reality and comply with the 2030 Agenda.

Thus, its main focus is to support the strengthening of the National Statistical System to generate geo-referenced data to develop policies based on evidence and on the reality of persons with disabilities. Within the UNSDCF, the line of sexual and reproductive health is mentioned in general for all persons, but no specific reference is made to persons with disabilities.

It also points out the need for true disability inclusion at the level of the entire UN organization. In view of this, the UN Plan for Inclusion, Participation, and Visibility of Persons with Disabilities in the Workplace has been created, which allows the agencies to evaluate and report on what they are doing to make inclusion a sustainable goal. In this way, the agencies have delegated a focal point for the establishment of the Interagency Group on Disability, which is responsible for ensuring proper compliance with the annual planning.

Still more could be done to mainstream and monitor disability inclusion in the UN system – including a disability marker in the financial system.

## **10.2. Section 2: Disaster risk reduction & humanitarian action**

Both the SDGs and the CRPD emphasize the need to prevent, address and limit humanitarian risks arising from armed conflicts and, above all, from climate change and natural disasters. In particular, Goal 16 of the SDGs focuses on maintaining social peace, while Goals 13, 14 and 15 focus on the urgent need for transformations to counteract climate change and safeguard terrestrial and aquatic environments (ECLAC 2023).

Combating and managing climate change and humanitarian response must include a specific focus on vulnerable populations. In this regard, Article 11 of the CRPD provides that it is the obligation of States to take “necessary measures to ensure the safety and protection of persons with disabilities in situations of risk, including situations of armed conflict, humanitarian emergencies, and natural disasters” (UN 2006, 11). It should be noted that at the national level, disability is one of the five pillars of equality and is formally included in all processes and levels of development, humanitarian risk management, and emergency plans.

The different risk management and humanitarian response agendas include goals and objectives in the action plans that give special emphasis to priority groups, including persons with disabilities in a situation of human mobility. However, what is evident is that there is still a significant gap between the commitments made in the planning and the actual implementation of these strategies and plans. This gap exists in society in general, although it affects the most vulnerable groups such as persons with disabilities. Specific research on these issues is advised.

CONADIS is working on disability inclusion in risk management with the collaboration of the Risk Management Secretariat (SGR). The joint efforts of these two institutions are reflected in the “Guide for Inclusive Risk Management with a focus on persons with disabilities” published in 2019. The implementation of the plans is the responsibility of the GADs, which, however, do not have sufficient resources or training to do so.

### 10.3. Section 3: Climate change

In terms of climate change management in Ecuador, there is a planning document on this particular issue that refers to specific actions for persons with disabilities - the National Climate Change Strategy of Ecuador (ENCC 2012-2025), formulated by the Ministry of Environment in collaboration with CONADIS.

The ENCC focuses on two strategic lines for the fulfillment of its mission to 2025: Adaptation to climate change and Mitigation of climate change. The first line includes actions to reduce social, economic and environmental vulnerability to the impacts of climate change. The second line focuses on mitigation actions to reduce Greenhouse Gas emissions and increase carbon sinks in Strategic Sectors.

This strategy mentions persons with disabilities within the priority attention group together with other vulnerable population sectors and acknowledges, in a general way, the possible particular risk situations they may experience. However, there are no explicit targets, budgets, actions or indicators related to persons with disabilities.

### 10.4. Section 4: COVID-19

The COVID-19 pandemic hit a totally unprepared country where basic public services, such as health and education, were already experiencing a crisis due to low state investment.

CONADIS promptly promulgated the Guide for the Prevention and Care of COVID-19 Infection in Persons with Disabilities and Persons with Temporary Disabilities and their Families. However, many of the OPDs consulted expressed a feeling of total abandonment during the pandemic, with almost total absence of medicines and public support services. It should be emphasized that the disability qualification processes were also halted.

To date, there are no nationwide representative studies on the effects of the COVID-19 pandemic on the condition of persons with disabilities, which is necessary because some persons with disabilities claim to have suffered a deterioration of their health and living conditions as a result of the pandemic.

### 10.5. Key gaps in national planning

Development policies, risk management and humanitarian plans and actions do mention persons with disabilities as vulnerable groups that should be included in their agendas. However, disability inclusion is still very weak:

- The risk mitigation planned actions for persons with disabilities are not implemented, are insufficient or not shared with persons with disabilities.
- There is not enough information on the risk impact on persons with disabilities (such as climate change and the COVID-19 pandemic).

## 11. Conclusions

In Ecuador, the disability approach is a cross-cutting aspect of equality and is broadly recognized in the regulatory framework, although in practice it is not applied as such. Likewise, the cross-cutting approaches of participation, gender, and inequalities are addressed in the legal and public policy frameworks, but are not adequately applied.

The application of the rights-based approach in public policy should translate into a formal and real acknowledgment of people's legal entitlements, i.e., their capacity to exercise their rights and make decisions on all aspects of their lives. In this context, the current situational analysis shows that, although there is an effort to formally integrate a rights-based approach in public policy planning, there is no continuity in the implementation phase. This is reflected in the high level of institutional distrust expressed by the OPDs interviewed.

In everyday life, persons with disabilities are still not treated as rights holders, since their ability to make decisions about their own lives and bodies is not acknowledged. This not only restricts their autonomy, but also prevents their full social and political participation. In addition, persons with disabilities experience problems with accessibility to general and special support services, as well as to educational, work, participation, and recreational spaces.

From an intersectional perspective, the living conditions of persons with disabilities are more complex when several categories of vulnerability are considered and for certain types of disability.

For example, 66% of the OPDs consulted agreed that psychosocial disability is the most invisible type of disability, due to the strong stigma attached to “crazy” people and the lack of knowledge of some of the most common neuro divergences. The exclusion of persons with disabilities translates into the invisibilization of psychosocial disorders, even by the very people who experience them. It is important to note that people with other types of disabilities frequently experience some type of psychosocial disorder <sup>30</sup>.

Similarly, living in rural environments or belonging to indigenous peoples and Afro communities are other variables that lead to greater vulnerability due to the structural conditions of inequality and the lack of timely social, labor, and health measures.

The gender dimension cannot go unnoticed: women, girls and the LGBTIQ+ population with disabilities face a situation of invisibility and violence, even within the OPDs themselves. What became evident in the ethnographic phase of the research is that certain stereotypes are so naturalized that they are not identified as discrimination.

As for GBV situations, these have been mentioned only in private conversation, either at the insistence of the researchers or at the request of women themselves. Gender-based violence and discrimination are issues that are still hardly visible in the context of disability, and when they are addressed, they are treated as shameful secrets.

All the findings point to the need for institutional restructuring to enable the effective implementation of disability-related legal and public policy frameworks. Emphasis is placed on the need for investment in medium and long-term processes that guarantee real accessibility, in accordance with the universal design model. To this end, it is urgent that public policies have sufficient budget, infrastructure, and qualified personnel for their implementation. Finally, it is imperative that all disability-related actions and policies include intersectional and gender approaches as a crosscutting issue.

### 11.1. Analysis of key gaps

The main gaps identified throughout this research are framed in three types of problems: cultural/attitudinal, structural, and budgetary.

Those of a cultural/attitudinal nature refer to the existing stereotypes that relate disability with incompetence, whereby persons with disabilities are treated as second-class citizens and not as holders of rights, capable of making decisions, which limits their power and autonomy.

Those of a structural nature refer to the lack of mechanisms that guarantee the effective enforcement of disability laws and public policies, which limits the access of persons with disabilities to services and spaces closely related to the exercise of their rights, such as health, education, justice, and work.

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<sup>30</sup> 90% of the persons interviewed, both individually and in the focus groups, stated that they had thought of ending their lives on at least one occasion since the onset of their disability (or its progression). Suicide is perceived as the only way to escape from a marginal and dependent life in which one must try to adapt as much as possible to the ableism model in order to achieve a minimum degree of autonomy and participation and still feel “a human person”, as one quadriplegic man said (personal interview, El Tena, March 2023).

Those of a budgetary nature refer to the lack of a general State budget that does include a specific and crosscutting budget line for disability. The disability budget allocated to certain institutions (CONADIS, MSP, MIES and MINEDUC) is not sufficient for implementation to guarantee disability inclusion.

The most important gaps are listed below:

#### Cultural/attitudinal:

- Cultural and attitudinal barriers persist due to the lack of knowledge about the human rights approach and the inclusion of persons with disabilities. As a result persons with disabilities are subject to patronizing/charitable and discriminatory attitudes in all spaces and relationships (with their family, with society, and with the State).
- Persons with disabilities and their organizations do not have sufficient knowledge and skills to demand and uphold their rights. The voices of some underrepresented groups of persons with disabilities are not heard and they are not yet organized in OPDs. Self-recognition and self-representation of persons with disabilities is limited.

#### Structural:

- Ecuadorian state and local government institutional weaknesses are evident in the lack of continuity of public policies in the medium and long term. This affects the disability inclusion in public policies and limits the institutional capacity of CONADIS to guarantee the rights of persons with disabilities.
- There is still Ecuadorian legislation that does not comply with the CRPD (e.g., the Civil Code and the Organic Code of Proceedings); especially, the issue of legal entitlements has not been adequately addressed.
- Lack of a single inter-institutional and inter-sectoral system of data that is fed by institutions and OPDs in a constant and coordinated manner. Institutions have sub-registers that are not easily accessible.
- There are no measures to enable the social and political participation of persons with disabilities, particularly from underrepresented groups.
- There is limited access to general services and support services, especially GBV and SRH services. This is exacerbated for persons with disabilities from rural, frontier, and underrepresented groups.
- 57.75% of persons with disabilities are not included in official registries due to a lack of access to assessment centers and corresponding classification, and access barriers increase in peripheral and rural areas.
- Lack of affirmative action measures for people with psychosocial health conditions and diagnoses.
- Lack of public care services, which results in extra burden on the family, especially on female caregivers.
- Difficulty in accessing technical aids or support products, which are usually of low quality and do not take into account the particularities of each person.
- Accessibility standards focused on universal design exist in theory, but are not applied in reality. This includes access to public spaces and transport; and access to information, devices, and information technology tools.
- Failures in the coordination and implementation of intersectoral mechanisms at central and local levels. This includes cooperation between governmental institutions and between such governmental institutions and OPDs.

- Since 2020, the Ombudsman's Office has started to participate in the monitoring of human rights violations against persons with disabilities. However, the scope of its action is still very weak.

Budgetary:

- The general state budget does not have neither a specific nor a cross-cutting budget line for disability.
- Lack of a concrete plan for budget transformation that would support the setting up of a sustainable system of community support services and gradually reduce funding for institutionalization initiatives for persons with disabilities.
- Both UN and government programming (at national and local levels) lack inclusive budget classifiers and disability-centered monitoring and evaluation mechanisms; e.g., disaggregated targets and indicators.

## 11.2. Opportunities to improve the disability inclusion in government and UN humanitarian/emergency and development plans and processes

- Despite the institutional gaps in the country, there is a regulatory framework that protects the rights of persons with disabilities and facilitates the enforceability of their compliance.
- Through the historical struggle of the movements representing persons with disabilities, disability inclusion has become a priority in international action agendas.
- The situation is favorable for the emergence of new forms of political leadership, both individual and associative, which can strengthen the co-responsibility model. Currently, politicization among persons with disabilities is not necessarily expressed through traditional and institutional forms of political action but is based on each person's own lived experience, self-managed agendas, and the visibility of different bodies and voices.
- In Ecuador, within the framework of the UNDIS strategy, CSOs, the State, and UN agencies are willing to establish alliances and joint work. So, the Interagency Group on Disability has also been created to facilitate the implementation of cooperation actions.

## 12. Recommendations for UNCT action

The following are the most critical recommendations for medium- and long-term actions and processes that UNCT in Ecuador may implement to close the gaps identified in this study <sup>31</sup>.

UNCT could consider:

- Supporting CONADIS in the revision of the regulatory and public policy framework necessary to guarantee the full inclusion of persons with disabilities, from a rights-based perspective with emphasis on underrepresented groups.

<sup>31</sup> It should be remembered that all recommendations are built with the objective of complying with the provisions of the CRPD. In addition, the aim is to propose actions that contribute to the de facto recognition of the decision-making capacity of persons with disabilities and to achieve a model of co-responsibility. Finally, all recommendations should be understood from a human rights, gender and intersectional approach, which prioritizes the specific needs of underrepresented groups, where different categories of discrimination intersect.

- Supporting CONADIS to develop processes that enable the full social and political participation of persons with disabilities in national and local decision-making bodies, promoting leadership skills development and processes that include persons from more marginalized groups, as well as the creation and strengthening of OPDs in Ecuador.
- Supporting CONADIS and the Ombudsman's Office to enforce existing laws and policies that guarantee accessibility with an inclusive universal design approach, in terms of infrastructure, information and communication.
- Providing technical support to CONADIS and other ministries on the implementation of specific and time-bound targets, indicators and budgets and follow-up mechanisms to monitor effective access to both general and special support services for persons with disabilities, especially in rural areas.
- Supporting government entities to strengthen access for women and girls with disabilities to health care and justice services especially in rural areas, with emphasis on sexual and reproductive health care services and gender-based violence, building on the lessons learned, achievements and challenges of the We Decide project.
- Developing participatory coordination mechanisms between OPDs, public institutions, academia, and UN Agencies to share situational analysis with emphasis on underrepresented groups, to enable disability mainstreaming in the CCA, the UNSDCF, and the Humanitarian Country Team Response Plan.
- Supporting government institutions to strengthen in a coordinated manner the development of the National Disability Registry and a common database on disability data, providing for the mainstreaming of the human rights of persons with disabilities.

### 12.1. Issues that need further research to enhance the knowledge base

The following is a summary of the research topics that have been identified as priorities to advance and improve the knowledge base on the situation of persons with disabilities in Ecuador.

- Gender-based violence and barriers to access to Sexual and Reproductive Health services experienced by persons with disabilities, with special attention to girls and women with disabilities, and persons of sex- and gender diversity.
- The significance of disability among indigenous peoples and nationalities and the possibility of synergies with the Andean cosmovision <sup>32</sup>.
- Specific needs regarding support products for non-verbal forms of communication.
- Inclusion of persons with disabilities in the planning and management of plans for humanitarian risks, emergencies, and those related to climate change and natural disasters.
- Effects of the COVID-19 pandemic on persons with disabilities and disabling conditions generated by COVID-19.
- Specific needs of persons with disabilities in conditions of human mobility.

<sup>32</sup> The idea is to try to understand, on one hand, how indigenous peoples in Ecuador see and experience disability, and on the other hand, to investigate whether disability perceptions of the Andean Cosmovision could challenge some of the stereotypes and discriminatory practices that prevail in Ecuadorian society.



# ANNEX 1:

## Methodological approaches

The Situational Analysis of the rights of persons with disabilities in Ecuador has three approaches: human rights, gender and intersectionality.

### Human rights

This approach is based on international standards and is oriented toward the promotion and protection of human rights as inalienable and indispensable for all people (United Nations General Assembly 1948). Therefore, it focuses on inclusion, social justice and the eradication of structural inequalities and discrimination through the formulation of laws, rules and regulations in accordance with international law instruments.

In addition, it focuses on historically discriminated populations as subjects of rights, respecting the principle of participation, interrelation and equality among all people, without discrimination on the basis of age, sex, gender, sexual orientation, ethnicity, disability, religion, political orientation, among others.

### Gender

The concept of gender refers to the socially constructed roles attributed to men and women based on sexual differences and the meaning of the masculine as hierarchically superior to the feminine (Falanga 2014). This translates into structural inequality between men and women. In this regard, gender influences all aspects of private, social, and institutional life, and is therefore considered an important category for analyzing the relations of power and inequality that are established on the basis of the differences between the sexes (Scott 1996).

It is important, therefore, to consider the different opportunities that men and women have and to include actions to address this power differential. To this end, the concept of “mainstreaming” is included to indicate the need to apply a gender perspective in every socio-political-economic program and action, as well as in the integral dimension of the design, implementation and monitoring of a project or program.

### Intersectionality

The concept of intersectionality spreads from American black feminism, which shows how the experience of being a black woman cannot be understood independently in terms of being black or being a woman, but must be understood as a product of the intersection of the two categories.

This is how the concept of intersectionality begins to be defined as a relationship between systems of oppression: in order to analyze a situation of inequality, it is necessary to observe the specific life experiences that derive from the intersection of multiple categories of discrimination (Zapata Galindo, Cuenca and Puga 2014).

The development of public policies needs an intersectionality approach since it allows analyzing and addressing specific situations of discrimination.

## Guiding principles

All research is governed by ethical principles considered essential for the development of an equitable and inclusive society. Such principles are in line with international and United Nations System principles and Ecuadorian regulations, but were reformulated in this way by Magdalena Herdoíza in her study *Construyendo igualdad en la educación superior* (2015):

- equality and equity
- comprehensive and inclusive development
- community grassroots development relations
- biocentric development

Equality as a philosophical-political category arose in the 18th century when the principle of equality for all citizens was established. However, this universalizes the condition of all human beings and makes the subordination of historically excluded groups invisible (Cobo 2012). During the 20th century, there was a debate on how to understand equality and it was defined as “lack of discrimination” (Bernal 2012). In addition, the remedy for historically inequalities accumulated was considered, which became into the concept of equity (Arendt [1951] 1997; Cobo 2012; Sen 1979). There is no equality without equity.

The principle of integral development refers to the possibility that each person can develop their intellectual, physical, cultural, and artistic potential, and live a balanced life between times of work, care and fun. This principle becomes inclusive by understanding a participatory model of social construction under the significance of each person as a subject of rights. In this sense, the principle of integral and inclusive development has direct symmetry with the community grassroots development relations principle.

The community grassroots development relations are a basic principle for sustainable development and participation. The process is based on the self-organization from persons and their link with social, political and development dynamics. This principle goes beyond both the significance of participation as institutional political participation and a welfare vision towards excluded groups. On the contrary, it advocates a co-responsible and participatory construction among rights holders.

Finally, biocentric development focuses on human development, in a holistic vision of life as a harmonious relationship between individuals, nature, community and territory. It refers to the principle that, in Ecuadorian legal framework, is known as “Buen Vivir”.

## Members of the associations involved in focus groups

- Agreement for Disability.
- Club Association of Diabetic “*Amigos Dulces*”.
- Association of Entrepreneurs with Disabilities “*Juntos Somos Más*” (ASOPERDIS).
- Association of Hemiplegic, Paraplegic and Quadriplegic in Guayas (ASOPLÉJICA).

- Association of Parents with Children with Disabilities in Orellana (APANIDO).
- Association of Persons with Physical Disabilities in Esmeraldas (APDIFE).
- Association of Persons with Physical Disabilities in Napo (APDIFIN).
- Association of Persons with Visual Disabilities (ASODIV).
- Association of Persons with Visual Disabilities in the province of Orellana.
- Shuar Association *Nuevo Amanecer*;
- National Federation of Blind in Ecuador (FENCE).
- National Federation of Organizations of Persons with Physical Disabilities in Ecuador (FENEDIF) –members of the labor integration service in Tena and Esmeraldas–.
- *Grupo Fénix*: Support Group for bipolar disorder.
- Women in Movement <sup>33</sup>.

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<sup>33</sup> The Organization “Women in movement” is not an organization of women with disabilities, but an organization of women in mobility that integrates some women with disabilities. Due to the lack of organizations for women with disabilities, this study has considered working with women with disabilities who are not associated or who are associated with other types of organizations, as in this case.

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