



Practical Guide

For The Establishment
Of Supports For The Exercise
Of The **Legal Capacity**
Of Persons With
Disabilities



OAS

More rights for more people

COMMITTEE FOR THE
ELIMINATION OF ALL
FORMS OF DISCRIMINATION
AGAINST PERSONS WITH
DISABILITIES (CEDDIS)





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(CEDDIS).

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Preface



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The Committee for the Elimination of All Forms of Discrimination Against Persons with Disabilities (CEDDIS) of the Organization of American States (OAS) has the honor to present this “Practical Guide for the Establishment of Support for the Exercise of the Legal Capacity of Persons with Disabilities”, developed under the principles and guidelines of the Inter-American Convention for the Elimination of All Forms of Discrimination Against Persons with Disabilities (CIADDIS) and the United Nations International Convention on the Rights of Persons with Disabilities (CRPD).

The objective of this Guide is to support the Member states of the OAS and the international community interested in guaranteeing that persons with disabilities can effectively exercise their will and citizenship on equal terms with others. In this sense, this instrument is intended to propose guidance to national councils or secretariats for the inclusion of persons with disabilities (CONADIS/SENADIS); legislative bodies; organs of the judicial system; prison systems; public defenders; prosecutors; public policy makers at all levels; educators; government officials in charge of the provision of public services; registries and notaries; organized civil society; persons with disabilities and their families and the general public.

This Guide is the result of years of dedication by the national experts who were members of this Committee, with the valuable support of civil society organizations and international allies who provided their critical opinion as notable academic, scientific and practical references on the subject. This work also had the support of the Technical Secretariat of the Committee exercised by the Department of Social Inclusion (DSI) of the Secretariat for Access to Rights and Equity of the OAS. As a result of this multisectoral cooperation work we present the general notions, basic concepts, barriers, practical guidelines, reference models and applicable legal frameworks for the full exercise of the legal capacity of persons with disabilities in the following nine thematic axes: the right to make decisions; independent life; access to justice; sexual and reproductive rights; right to found a family; economic rights; free and informed consent; political and electoral participation and access to social protection.

CEDDIS invites you to use the contents developed in this Guide to promote the eradication of the model of substitution of the will of persons with disabilities, facilitate access to the support they may need in the exercise of their legal capacity, provide adequate and effective safeguards to prevent abuse, and ensure respect for the rights, will and preferences of all persons with disabilities.



Acknowledgements

To all the people who made up the Committee for the Elimination of All Forms of Discrimination against Persons with Disabilities (CEDDIS) and who participated in the ordinary or extraordinary sessions that took place since 2013 to define the objectives, structure and contents of this Guide.

The CEDDIS recognizes the special commitment of the Republic of Argentina to this project through the distinguished work of several of its experts before the Committee, such as Pablo Rosales, an expert in charge of preparing the first regional diagnosis on the exercise of the legal capacity of the persons with disabilities which served as a prelude to this guide; Valeria A. Monópoli, special accredited by the Argentine Secretariat for Human Rights, for the preparation, in 2014, of the first version of the conceptual framework of this instrument; Silvia Bersanelli, President of the CEDDIS from 2014-2015, for her leadership in promoting the subject within the Committee; Mariano Godachevich, Vice President of the CEDDIS for the period 2016-2021 and Susana Sequeiros, both for consolidating and presenting before the plenary session of the CEDDIS in 2016 the first results of the national surveys distributed in 2015, with the aim of detecting facilitating resources or barriers for the implementation of support and safeguards systems in the public sector and Civil society organizations.

To the staff of the Department of Social Inclusion (DSI) of the Secretariat for Access to Rights and Equity of the Organization of American States (SARE/OAS) in its capacity as Technical Secretariat of the Committee: Betilde Muñoz-Pogossian, Director of the Department, for her leadership in promoting this project and for expressing its importance to the Member states of the OAS; Mercedes Carrillo, Secretary of the Committee, for her continuous accompaniment and follow-up given to this project for over seven years; the preparation of the background of this document, and the technical support provided with the design of surveys that were distributed to the OAS Member states in 2015 and 2017 for the collection of data that contributed to feeding this Guide; Pamela Molina, DSI/CEDDIS Consultant, for her extraordinary technical support provided at the 2019 CEDDIS work tables; in the consolidation of all the recommendations that were received from experts and civil society organizations, and for writing proposals to reinforce content in each of its chapters.

To the international experts and civil society organizations who were so kind to participate in virtual sessions convened by the Committee for the exchange of information on the subject in 2017, answer questionnaires and/or review the preliminary contents of this guide in 2020 and formulate recommendations that contributed to enrich it widely:

Contributions from international experts

1. Alberto Vásquez, President of Society and Disability (SODIS).
2. María Graciela Iglesias, Expert in disability and Executive Secretary of the Mental Health Review Body of the Argentine Republic.
3. Monica Cortés, Executive Director of the organization Down Syndrome Association Colombia (Asdown); Coordinator of the Network of Families for Change and Representative of Inclusion International.
4. Silvia Quan, Guatemalan specialist in human rights of persons with disabilities. Independent expert of the United Nations Committee on the Rights of Persons with Disabilities for the period 2011-2016 of which she was its Vice-President.
5. Tina Minkowitz, President of the Center for the Human Rights of Users and Survivors of Psychiatry.
6. Valeria A. Monópoli, Argentine lawyer specialized in Human Rights.
7. Luis Fernando Astorga, Executive Director of the Inter-American Institute on Disability and Inclusive Development (IIDI).
8. Patricia Brogna, Researcher at the University Program for Human Rights and Disability at the National Autonomous University of Mexico (UNAM).
9. Luis Miguel Del Águila, Advisor to the Congress of Peru and President of the Muscular Dystrophy Association of Peru.
10. Claudio Espósito, Coordinator of the Disability Commission of the Bar Associations of the Province of Buenos Aires, Argentina.
11. Meg Mszyco, Coordinator of the Human Rights Watch Division of the Rights of Persons with Disabilities.
12. Chilean experts Francisca Figueroa and Marcela Benavides.
13. Francisco Bariffi, Coordinator of the Ibero-American Network of Experts on the Convention on the Rights of Persons with Disabilities.

Contributions from civil society organizations

1. Latin American Network of Organizations of Persons with disabilities and their Families (RIADIS).
2. Latin American Union of the Blind (ULAC).
3. Andar y Rodar Foundation.
4. Civil society organizations in Argentina: Network for the Rights of Persons with Disabilities - REDI, the Observatory of Mental Health and Human Rights of the province of Córdoba, and the Working Group on Disability and Human Rights of the province of Córdoba.
5. Peruvian civil society organizations from Metropolitan Lima, Ancash, Pasco and Moquegua whose contributions were consolidated by CONADIS-Peru.
6. Peruvian Down Syndrome Society.

Other contributions from government entities

1. National Council for the Integration of Persons with Disabilities (CONADIS) of Peru.
2. Peru Public Defender's Office.

A. ACCESSIBILITY

Accessibility:

It is a fundamental right, inherent to the human being and a transversal principle for the exercise of all other human rights. As a principal accessibility is the implicit condition which is part of the essential content of each of the fundamental rights. This implies that its absence or omission leads to the non-satisfaction of the right, that is its non-recognition. On the other hand, accessibility makes it possible to achieve equal opportunities, the exercise of citizenship and ultimately that persons with disabilities can exercise the right to independent life. It includes the right of access to the physical environment, transport, information and communications, including information and communication systems and technologies, as well as processes, goods, products, and other services and facilities open to the public or for public use, both in urban and rural areas on equal terms with the others.¹ It encompasses, in its concrete manifestations, both universal design and reasonable accommodation. Accessibility relates to groups of people, while reasonable accommodation refers to individual cases. This means that the obligation to provide accessibility is an ex-ante obligation. Therefore, States parties have an obligation to provide accessibility before receiving an individual request to enter a place or use a service.²

Reasonable accommodation:

These are the necessary and adequate modifications and adaptations required in a particular case that do not impose a disproportionate or undue burden, to guarantee persons with disabilities the enjoyment or exercise of all human rights and fundamental freedoms on equal terms with others.³

The “denial of reasonable accommodation” of a disability is disability discrimination:

The denial to admit an assistant, a support, or refusal to make accommodations in favor of a person with disability to equalize their opportunities to exercise their rights are examples of refusal of reasonable accommodation.

Guide-Interpreter:

The guide-interpreter is the person who knows the language or communication system, both of the deafblind person and their interlocutors, and transmits the messages expressed bidirectionally in a tactile, textual and objective way, making thus communication possible. They must contextualize the messages by offering the relevant visual information so that they are adequately expressed and understood, and guide the deafblind person in their movements, providing security, when requested or necessary.⁴

Clear and simple language.

It is a communication style based on simple words and short phrases, which allows processes, procedures, concepts and documents to be easy to understand by anyone (adults who did not have access to quality education, foreigners, children, persons with disabilities, among others), ensuring the understanding of the message. “A statement is written in simple language, if its wording, structure and design are so transparent that the target readers can find what they need, understand what they find and use that information.”⁵

1 See: Articles 3 and 9 of the United Nations Convention on the Rights of Persons with Disabilities (UN-CRPD): <https://www.ohchr.org/SP/HRBodies/CRPD/Pages/Disabilitiesconvention.aspx>. See also: General Comment # 1 of the United Nations Committee on the Rights of Persons with Disabilities, pp. 2 and 10, and General Comment # 2, paragraph 14, of the same Committee, both available at: https://conf-dts1.unog.ch/1%20SPA/Tradutek/Derechos_hum_Base/CRPD/00_Observaciones%20generales%20CRPD.htm#GC1

2 General Comment # 2 of the United Nations Committee on the Rights of Persons with Disabilities: Accessibility, paragraph 25. Available at: https://conf-dts1.unog.ch/1%20SPA/Tradutek/Derechos_hum_Base/CRPD/00_Observaciones%20generales%20CRPD.htm#GC2

3 United Nations Convention on the Rights of Persons with Disabilities, UN-CRPD, Article 2, “Definitions”. Available at: <https://www.ohchr.org/sp/hrbodies/crpd/pages/disabilitiesconvention.aspx>

4 Definition of the National Association of the Deafblind of Spain. Available in: http://www.asocide.org/solotexto/servicios/apoyo_interpretes.htm

5 Cfr: International Federation of Plain Language: <https://www.ifplfederation.org/plain-language/>. Also see Plena Inclusión, publication of December 7, 2019, available here: <https://>



Sign Language:

It is the natural language of the Deaf People community, which is part of their cultural heritage and is as rich and complex in grammar and vocabulary as any oral language. Sign Language is characterized by being visual, gestural and spatial.⁶

Macro type:

It is the format with a font and font size between 16 and 20 points per inch, to be used by people with low vision.

Accessibility measures:

These are measures that guarantee the detection and elimination of existing barriers in the environment -both physical and digital- so that persons with disabilities can have access to goods and services to live independently and participate fully in all aspects of life on equal terms with other people.⁷

Augmentative or alternative modes, media and formats of communication:

It is “a set of tools and strategies that an individual uses to solve everyday communication challenges, as defined by ISAAC, the International Society for Augmentative Alternative Communication. Communication can take many forms: language, a shared look, text, gestures, facial expressions, touch, sign language, symbols, images, speech generating devices. Whenever something limits the effectiveness of our use of speech, we use an augmentative form of communication”. When an individual has complex communication needs and their use of speech is limited in many settings, it is helpful to use a well-planned system, tailored to the individual’s needs and environment.”⁸

Guide dog. Animal assistance:

It is a professionally trained dog to guide people with visual disabilities in their movements in the physical environment with greater safety and confidence. It contributes to strengthening the autonomy, independence and mobility in the physical environment, and in the development of activities of daily life of the persons with visual disabilities.

Braille Literacy System:

It is the Universal Reading and Writing System based on points in high relief for blind people who interpret it by using touch, and write by using manual, mechanical or computerized means.

B. LEGAL CAPACITY

Personal Assistant (PA):

it is an adult person, freely chosen by persons with disabilities, who assist them in carrying out activities of their daily life,⁹ with the aim of ensuring the right to autonomy and independent life.¹⁰ The term “Personal” implies that assistance must be personalized to individual needs, wishes and preferences; the user with a disability decides which activities require support, and who, when, how and for how long the assistance tasks will be carried out.¹¹ These personal assistants (PAs) can be temporary or permanent.

www.plenainclusion.org/noticias/cual-es-la-diferencia-entre-lectura-facil-y-lenguaje-claro/

⁶ Law 982, 2005, Colombia


⁷ See: Regulation that results in the granting of reasonable accommodations, decision of support and implementation of safeguards for the exercise of the Legal Capacity of Persons with Disabilities. Article 2: Definitions. Republic of Peru., In: Official Gazette of the Bicentennial, Lima, August 23, 2019. Available here: <https://busquedas.elperuano.pe/normaslegales/decreto-supremo-que-apruestra-el-regdamientos-que-regula-el-otor-supreme-decree-n-016-2019-mimp-1801069-5/>

⁸ Watch: <https://www.isaac-online.org/english/what-is-aac/>; . “<https://www.isaac-online.org/english/what-is-aac/who-benefits/>”. In Spanish: <http://www.ceapat.es/InterPresent2/groups/imserso/documents/binario/comunicacionaumentativayalternativa.pdf>. Also see: Government of Aragon: <http://www.arasaac.org/aac.php>; American Speech Language Hearing Association <https://www.asha.org/public/speech/disorders/Los-Sistemas-Aumentativos-y-Alternativos-de-Comunicacion/>

⁹ Regulation that regulates the granting of reasonable accommodations, designation of support and implementation of safeguards for the exercise of the legal capacity of persons with disabilities, of Legislative Decree No. 1384 of the Republic of Peru, which recognizes and regulates the legal capacity of the persons with disabilities on equal terms. Article 9 of the Regulation. Available at: <http://www.gacetajuridica.com.pe/boletin-nvnet/ar-web/DSN-016-2019-MIMP.pdf>

¹⁰ General comment no. 5 (2017) of the Committee on the Rights of Persons with Disabilities on the right to live independently and to be included in the community

¹¹ Training Manual for Personal Assistants, Government of Spain, State Representative Platform of People with Physical Disabilities (PREDEF).



The role of a PA is to promote autonomy and to exercise the concept of independent life. It can be a single person or a service agency. It may include a variety of home care services, and other personal support services for the exercise of basic activities (getting up, getting dressed, eating, etc.), which are necessary to facilitate the autonomy and inclusion in the community of the person with disability. If the person with disability decides to, the PA can also facilitate decision-making processes in the legal and other aspects of daily life. Personal assistant is not the same as “reasonable accommodation,” although policies related to the latter should include them.

Legal capacity:

It is the right of all people to be recognized as persons before the law (as rights holders) and to act legally (exercise the right to make and execute decisions before the law). The legal capacity to be the holder of rights grants the person full protection of all their human rights by the legal system. The law recognizes that person as an actor empowered to carry out transactions and to create legal relationships, modify or terminate them.

Criteria for the interpretation of will and preferences.

When it is not possible to determine the will of a person with disability, despite considerable effort, including the provision of decision support, and the application of reasonable accommodation, the “best possible interpretation of will and preferences” should be applied as a measure of last resort. This implies considering the life trajectory of the person, the previous manifestations of will in similar contexts, the information that the people of confidence of the right holder have, the consideration of their preferences, instead of making a decision considering only the criteria of “best interests”. In this process, taking preferences into account means what the person would have wanted, values, attitudes, arguments¹² and previous acts.¹³

Undue influence.

It is a situation in which the person who is designated to be a support modifies, according to their interests, the manifestation of the will of the person who receives the support, by taking advantage of their role and exerting pressure, threat, manipulation or aggression.¹⁴

Decision Support Making Advisor (DSM):

This is a person who facilitates the decision-making of a person with disability. Its role is to support the process of decision-making by the person with disabilities, both those that have legal effects, as well as decisions made in daily life, depending on what the user chooses. The DSM advisor guides decision-making processes in acts that produce legal effects or not, within the framework of the rights of persons with disabilities. The processes that DSM advisor facilitates may include: a) obtaining and understanding information from the person with disability; b) that the person with disability evaluate the possible alternatives to a decision and their consequences; c) that the person with disability can express and communicate a decision; and/or d) execute a decision”.¹⁵

The Decision Support Making Advisor (DSM) is freely chosen by the person with disability, regardless of their age and individual or functional characteristics or conditions. The supported decision-making service may fall on one or more natural persons, non-profit or public legal entities, and may or may not coincide with the general Personal Assistance (PA) in the same person or entity. The support does not have powers of representation¹⁶.

Support refers to the decision-making process without interfering in value issues. This support can be temporary or permanent, as decided by the person with disability, and can be individual or through collective and community-based support networks. The person with disability is the one who decides whether or not to require supported decision-making.

¹² Cf. General Comment #1 of the United Nations Committee on the Rights of Persons with Disabilities, paragraph 11, p. 4. Available at: https://conf-dts1.unog.ch/1%20SPA/Tradutek/Derechos_hum_Base/CRPD/00_Observaciones%20generales%20CRPD.htm#GC1

¹³ See: Report of the Special Rapporteur for the Rights of Persons with Disabilities: A/HRC/37/56, para. 31, and see: General Comment #1 of the United Nations Committee on the Rights of Persons with Disabilities, paragraphs 15 and 18, page 5.

¹⁴ See: Regulation that results in the granting of reasonable accommodation, decision of support and implementation of safeguards for the exercise of the Legal Capacity of Persons with Disabilities. Article 2: Definitions. Republic of Peru. In: Official Gazette of the Bicentennial, Lima, August 23, 2019. Available at: <https://busquedas.elperuano.pe/normaslegales/decreto-supremo-que-apruestra-el-regdamientos-que-regula-el-otor-supreme-decree-n-016-2019-mimp-1801069-5/>

¹⁵ Cf. Devandas, Catalina (2017) Report of the United Nations Special Rapporteur on the Rights of Persons with Disabilities. A/HRC/37/56, par. 41.

¹⁶ See: Regulation that regulates the granting of reasonable accommodations, designation of support and implementation of safeguards for the exercise of the legal capacity of persons with disabilities, of Legislative Decree No. 1384 of the Republic of Peru, which recognizes and regulates legal capacity of persons with disabilities on equal terms. See Article 9 of the Regulations, available at: <http://www.gacetajuridica.com.pe/boletin-nvnet/ar-web/DSN-016-2019-MIMP.pdf>. Also see in relation to this topic the “Law for the Promotion of Personal Autonomy of Persons with disabilities” of Costa Rica, N° 9379/2016. <https://www.tse.go.cr/pdf/normativa/promocionautonomiapersonal.pdf>.



Trusted person:

A person who belongs to the same environment as the person with disability and who is freely chosen by them to facilitate their communication, their autonomy and their decision-making process. It may or may not coincide with your Personal Assistant or act as a Decision-Making Assistant, depending on the will and preferences of the person with disability who requires the support.

Safeguard:

It is a judicial or extrajudicial mechanism built to prevent abuses against persons with disabilities in their exercise of legal capacity, in order to ensure equal conditions with other people. There are two types of safeguards: a) General, which apply to the entire legal system. For example, safeguarding is the duty of notaries who must confirm the will of a person related to a particular legal act¹⁷. Safeguarding in these cases is about ensuring accessibility and the application of reasonable accommodations, including the support persons designated by the person with disability. b) Particular safeguard, included in an agreement of a person’s particular support systems. This type of safeguard is conditioned to the will and preferences of the user. There are, for example, minimal safeguards that must be included in each supporting agreement, such as the periodicity of renewal and the possibility of complaining about abuse and/or canceling the agreement at any time. In the same way, the duties imposed on support persons (refrain from undue influence) are safeguards, and their duty to guarantee the right to legal capacity and prevent abuses.

It is necessary to emphasize that safeguards cannot substitute the will of the person in any case, and that support cannot be imposed against the will of a person nor decide what support is required by the person without giving them the opportunity and the right to modify or reject any support offered.

C. AUTONOMY, SELF-DETERMINATION AND INDEPENDENT LIVING

Sexual and reproductive rights:

According to the definition of the United Nations Committee on Economic, Social and Cultural Rights, sexual and reproductive rights entail a “set of rights and freedoms, among which are, free and responsible decisions regarding matters related to one’s own body and one’s own sexual and reproductive health and access to goods and services related to the enjoyment of the right to sexual and reproductive health.”¹⁸

Social Protection:

Social protection encompasses a variety of policies and actions in various fields that should promote the exercise of economic, social and cultural rights (ESCR) in the labor market, food, health, pensions and care; The achievement of decent levels of income must also be sought (ECLAC).¹⁹

Independent living:

Independent living and inclusive life in the community are ideas that historically stemmed from persons with disabilities asserting control over the way they want to live, by creating empowering forms of support, such as personal assistance, and requesting that community facilities be in line with universal design principles.²⁰

17 The Notarial Guide to Good Practices for Persons with disabilities. The Notary as institutional support and public authority, from Rosalía Mejía, Peruvian Notary, it is an excellent initiative that develops the duties of notaries in the service of persons with disabilities in their right to exercise legal capacity under conditions of equality with others. The Guide was published by the International Union of Notaries, and can be found here: https://www.uinl.org/documents/20181/339555/ANM_CGK-10-6-CDH+Guia-ESP/283f8ae1-da62-4e72-ab3e-b96fec0caaec

18 Cf. General comment no. 22 (2016), on the right to sexual and reproductive health (article 12 of the International Covenant on Economic, Social and Cultural Rights), United Nations, Economic and Social Council, paragraph 5, p. 1. Available at: <http://docstore.ohchr.org/SelfServices/FilesHandler.ashx?enc=4slQ6QSmIBEDzFEovLCuW1a0Szab0oXTdlmnsJZZ-VQfQejF41Tob4CvIjeTiAP6sU9x9eXO0nzmOMJyzdy4BaN42PNWX1A0Szab0oXTdlmnsJZZVQfQejF41Tob4CvIjeTiAP6sU9x9eXO0nzmOMJyzdytOOLN42PNWX1A0Szab0oXTdlmns>

19 <https://www.cepal.org/es/temas/proteccion-social>

20 See: General Comment#5, United Nations Committee on the Rights of Persons with Disabilities, paragraph 4, 2017. Available at: https://conf-dts1.unog.ch/1%20SPA/Tradutek/Derechos_hum_Base/CRPD/00_Observaciones%20generales%20CRPD.htm#GC6



Deaf person:

It is one that, based on its significantly reduced or non-existent auditory functionality, acquired from birth or in pre-locution stages, has developed as an eminently visual person, and, therefore, has as a priority - and, in many cases the only way - of communication and social identity the use of Sign Language.³⁸

Deafblind person:

The person with reduced or non-existent double sensory functionality (vision and hearing) due to various causes, and who, when interacting with a standard environment, encounters barriers to communicate without assistance, and to move freely and independently, which isolates these people from society and to maintain an interaction with other people on equal terms. Few countries offer appropriate services to include people with deaf-blindness in society today. An example is the service of guide-interpreters covered with public funding. The sense of touch becomes very important to receive information from the environment.³⁹

38 Cf.: Law 21.303 of the Republic of Chile, which modifies Law 20.422, which establishes Norms on Equal Opportunities and Social Inclusion of Persons with disabilities, to promote the use of Sign Language. Library of the National Congress of Chile, BNC, January 22, 2021. Available here: <https://www.bcn.cl/leychile/navegar?idNorma=1154963&idParte=10194827&idVersion=2021-01-22> amending Law 20.404 on the Social Inclusion of Persons with disabilities. The Republic of Chile

39 Definition adapted from the World Federation of Deafblind, available here: <https://www.wfdb.eu/es/about-us/>



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1. Background

A. HARMONIZATION OF THE REGIONAL AND INTERNATIONAL LEGAL FRAMEWORKS

When the United Nations Convention on the Rights of Persons with Disabilities (hereinafter CRPD) entered into force, there was a paradigm shift with respect to the right to exercise the legal capacity of persons with disabilities. According to article 12 of the CRPD “persons with disabilities have legal capacity on equal terms with others in all aspects of life”. This article affirms that the subrogation of the exercise and fulfillment of the rights of persons with disabilities before the law and in all aspects of decision-making about their lives, should be replaced by a new system based on unrestricted respect for the decision-making of the person with disability. The current model of most Latin American Civil Laws is characterized by protection under legal instruments such as declarations of interdiction and subsequent establishment of conservatorship. The new system includes support to make such decisions, when required and requested and also has safeguards to ensure that there is no abuse or undue interference in the implementation of mechanisms for supported decision-making.

On the other hand, Article 1.2, paragraph b) of the Inter-American Convention for the Elimination of All Forms of Discrimination against Persons with Disabilities (CIADDIS) establishes that “In cases where domestic legislation provides for the figure of the declaration of interdiction, when necessary and appropriate for their well-being, it will not constitute discrimination”. This criteria was adopted at a time when another understanding of the concept of disability prevailed, as a synonym for medical diagnosis or individual “deficiency” (the so-called medical-assistance approach), which later turned out to be incompatible with the change introduced by Article 12 of the CRPD. Consequently, the Committee for the Elimination of All Forms of Discrimination against Persons with Disabilities (CEDDIS), which is the body in charge of monitoring the implementation of CIADDIS, decided to adopt a general observation in 2011 to set an interpretation standard that is in line with the recognition of the right to exercise full legal capacity. These general observations include support in the cases in which the person requests it and considering exceptional safeguards, such as evaluation and monitoring mechanisms that guarantee that supported decision-making works. For this, the CEDDIS has described the legal and social arguments that justify a paradigm shift, moving from a model of substitution of the will to a model of full exercise of decision-making, with support if required, based on respect to dignity and personal autonomy, which by no means suppresses or restricts the will of the person with disability or the exercise of their rights and decisions by themselves.

The adoption of this general comment, which serves as a criteria for the interpretation of Article 1.2.b) of CIADDIS, constitutes a great achievement for the CEDDIS, since it sets forth the first efforts to harmonize CIADDIS with the CRPD, reflecting the need to establish synergies between these conventions so that there are no conflicting mandates for the countries of the region that have ratified both instruments.

B. REGIONAL DIAGNOSIS ON THE EXERCISE OF THE LEGAL CAPACITY OF PERSONS WITH DISABILITIES

During the First Extraordinary Meeting of the CEDDIS held in May 2011 in San Salvador, El Salvador, the Committee agreed to create a Guide to facilitate the implementation of Article 12 of the United Nations Convention on the Rights of Persons with Disabilities, as well as the recommendations contained in the CEDDIS general observation described in the previous section. Prior to this guide, it was considered the necessity to carry out a preliminary diagnosis, which would allow us to visualize the main difficulties found by the countries of the American continent that have ratified the CRPD to apply Article 12 of the Convention, determining whether such obstacles are of a natural, legislative, institutional, cultural or financial nature.

A questionnaire was presented to the OAS Member States on February 1, 2012, in order to collect the necessary information to achieve this diagnosis. It was addressed to government officials belonging to the branches of the Judicial, Legislative and Ministries, Councils or Secretaries of Social Inclusion, Social Development, Infrastructure, or national offices whose mission is related to disability policies, exclusively or as an advisory body of the State (CONADIS/SENADIS or related). The questionnaire contained questions related to access to the justice for persons with disabilities in terms of existing legal frameworks; training and awareness of judicial officials; architectural accessibility of court facilities; availability of tools to facilitate communication; existence of adequate procedures when one of the parties or witnesses in the trial is a person with disability; applicability and monitoring of the guardianships imposed for the exercise of the legal capacity of the banned persons, among other issues.

In November 2011, the CEDDIS appointed Mr. Pablo Rosales, Argentina's principal expert before the Committee as Special Rapporteur, to process all the information received from the national questionnaires in order to carry out the preliminary diagnosis.

A total of 14 countries sent their questionnaires: Argentina, Bolivia, Brazil, Costa Rica, Chile, Ecuador, El Salvador, Guyana, Mexico, Panama, Paraguay, Peru, Uruguay and the Bahamas.

The questionnaires results were processed and became the first regional diagnosis on the exercise of legal capacity, presented by the Rapporteur during the Third Extraordinary Meeting of the CEDDIS held in San José, Costa Rica in November 2013.

Specifically, the main conclusions of the diagnosis were the following:

- Most states have regulations that protect persons with disabilities, even before the CIADDIS or the CRPD came into force.
- The majority of the States use different ways to determine disability situations showing heterogeneity between them, although a common ground is that the medical classifications of disability still predominate, with the the International Classification of Functioning, Disability and Health (ICF) used by half of the States: Five States report determining the disability situation with the ICF classification, two of them with the CIDDIM*, another two use the ICD-10 and the remaining ones determine the disability situation by other means.
- None of the States has reported having in their internal regulations a definition that clearly distinguishes the concepts of mental disability and that of intellectual disability, and none has determined the concept of psychosocial disability (real or perceived). However, different definitions of disability are reported, most of them based on a model similar to the ways previously mentioned of determining disability and, in general, comparing it with parameters of "normality". Some states have specific mental health laws or incorporate the concept of mental health into other general regulations. In summary: a) The concept of "disability" is defined in all States, b) the definition is related to the modality of determination of the disability situation, within the framework of the medical model and in relation to "normality" as a parameter and in most cases, there is no distinction between mental (or psychosocial disability) or neurodiversity, or other) and intellectual disability and c) the concept of mental health is growing and developing in the region.

- The States report on the recognition of a varied class of stereotypes, circulating images or negative perceptions that affect persons with disabilities in different areas, including the judicial system. The main stereotypes identified by the informants are: a) entrenched presence of the rehabilitative medical model, b) inadequate recognition of the ability to exercise rights, c) lack of awareness of value and respect for human diversity; d) the invisibility of persons with disabilities and e) standardized judicial procedures and the lack of official studies on these negative practices.
- The region actively promotes the training of legal professionals through activities carried out within the Judicial Power or jointly with programs or agencies of the Executive Branch (mainly CONADIS or similar). It presents the form of programs in collaboration with CONADIS, cross-sectional incorporation of the subject in judicial schools, specific workshops, training within the judiciary, accessibility focused courses and in other cases it is addressed within other courses in a generic way. Most states plan on having new training options in the future.
- The States reported knowledge of the UN-OAS Conventions on disability as a priority content of the training. Specifically, they also refer to: a) awareness and recognition of the autonomy and will of persons with disabilities and the social model of disability; b) fight against negative stereotypes that Persons with disabilities have in the public and private spheres to allow the assessment and inclusion of diversity and the identification of discriminatory actions, c) accessibility of persons with disabilities and d) training based on workshops techniques.
- The educational offer of higher education in the region, although the degree of inclusion is not reported in terms of article 24 of the CRPD, is growing and is expressed through local educational offer, through regional networks of universities or through international collaboration.⁴⁰
- The architectural accessibility of judicial buildings constitutes a debt in the region since most of the States report that there are accessibility barriers for persons with disabilities. In some cases, the lack of accessibility is fully, in others a difference is established between judiciary buildings prior to the UN Convention and the new spaces that are built, which are accessible. Accessibility in the Judicial Branch facilities has been gradually promoted, and currently the States that are in these processes report that the new buildings include universal accessibility standards. Several States report that they are in the process of making all kinds of public facilities accessible to persons with disabilities, although, in general, the State does not have detailed inventories or reports on accessibility of these facilities.
- For the most part, the State's web pages are not yet accessible, but it is positive that the majority have regulations that regulate their obligatory nature. It is reported that some official government pages and those related to disabilities do have accessibility, although the others are still in the process of doing so. At least 20% of the States do not yet have web accessibility, but they say they are working on it.
- Some States have sign language experts or permanently accessible reading tools (in these cases they are generally regulated through laws or regulations) and others provide these accessibility tools when they are required in each particular case, counting on State financing. Other States are still in the process of legal framework or organization of these tools, establishing some areas of the State for the defense of Persons with Disabilities. No State, as of now, reports having both tools throughout the judiciary, but they recognize the need to develop them.
- Regarding legal proceedings, in principle, in all States, the rule is that when a person with disability intervenes in a legal proceeding, he or she is represented by a third party, in some cases called a conservator, in others a guardian, or it may be a person nearby or a body of the judiciary. In all the States surveyed there is some form of legal advice or sponsorship of persons with disabilities within the scope of the State that is free of charge, but that work with different modalities.
- Regarding the accessibility of legal procedures in which persons with disabilities take part,, such as defendants, witnesses or juries, none of the States report having specific adjustments to the procedural procedures in these cases. The procedural codes are applicable to the entire population in general, although

40 Note - Translation Note - CIDDDIM is the International Classification of Functioning and Deficiency, developed by WHO prior to the launching of the CRPD.

some specific tools are established in each case when Persons with disabilities intervene. In summary, the comprehensive adaptation of the rules of legal procedures in this regard is pending, although all States have tools to support Persons with Disabilities in these processes.

- In legal proceedings, if the judge or administrative personnel notice that one of the parties to the process or a witness has some kind of disability, the States take various measures. In the first place, the measures to be taken by the Judiciary have a direct relationship with greater or lesser visibility of the disability situation. The most common of the measures is the determination whether the person requires representation or not, suspending the process until the decision is taken.
- In none of the States national legislation provides mechanisms or systems for supported decision-making by persons with disabilities in the terms of art. 12 of the CRPD. In some cases, the “support” requested is that of an expert or a doctor. In other cases, the Brasilia Rules also apply.
- Regarding persons with disabilities in confinement situations, the lack of measures towards facilitating the autonomy and dignity of Persons with disabilities in this scenario constitutes the reality of all States, which is worse in the case of persons with disabilities mental or psychosocial disability (real or perceived), people on the autism spectrum, and people with sensory disabilities (blind or deaf), or with multiple challenges, and particularly the lack of architectural accessibility for people with motor disabilities. The difficulties mentioned are varied: a) the detention centers are not suitable for the permanence of persons with disabilities, b) the Correctional Facilities do not have measures or structures adapted for people with physical disabilities, c) federalism regulates exclusive powers of the provincial states that hinders the homogeneity of the proposals, d) ignorance of the conditions in which persons with disabilities are held, e) environments in overcrowded conditions, with small infrastructure and in most of them the number of inmates exceeds their capacity, and f) disadvantages of deaf people who cannot communicate with other inmates and staff who guard them because, in general, the sign language for communicating with deaf people is unknown in these enclosures,.
- Regarding the training mentioned in article 13, paragraph 2 of the CRPD, most of the States offer training, originated in a normative mandate or incorporated into the curricula of judicial schools, specifically regarding support and reasonable accommodations. The training also aims at preparing for work against stereotypes that generate discriminatory behaviors against persons with disabilities.
- Regarding the capacity to act of Persons with Disabilities, the majority of the States is in favor of the positive agreement to the change that the validity of Article 12 implies, expressing the need to gradually apply it in order to overcome the negative stereotypes that subsist with respect to the ability to exercise the rights of Persons with Disabilities. There is consensus in the States on the specific application of Article 12, although it is also concluded that it is necessary to make modifications to the domestic law for its better application. The modification mostly proposed by the States is that of the Civil Code. However, the States express the need to gradually apply some measures that facilitate the effective application of the model of art. 12, expressed in the form of priorities indicated in points 5. b.1, 5.b.2. and 5.b.3 of the rapporteur.
- Regarding the scope of the compatibility between interdiction or conservatorship and article 12 of the CRPD, a majority of States express the incompatibility of both models with different arguments, but the positions are shared with those who consider that the representation model should also be maintained. Other States find some practical compatibility in the two models, but conditioned to the need to make specific changes. Another position points out that the interdiction or conservatorship is only valid when it is issued by a court for the protection of persons with disabilities or because in practice it has shown positive results, and other States understand that the CRPD itself allows this interpretation. Some States propose not to eliminate the figure of interdiction or conservatorship, but to keep it for very specific cases. To conclude, we observe that between the acceptance of the article 12 model and the perception of its concrete application, there still remains an important margin of space for the gradualness and the overcoming the decades of validity and consolidation of the model based on representation through representation. interdiction or conservatorship, a legal figure that is accepted in several cases as a “successful model of protection” for Persons with Disabilities.

- In the event that substantive and procedural reforms are necessary, the States would be asked how they would consider that the path of eliminating the figure of conservatorship, guardianship or insanity should be carried out, in order towards the model of broad capacity of the Article 12 of the CRPD determining who (key political and technical actors) should participate in the design of proposals for such purposes. Three groups of proposals are indicated: a) Substantive and procedural reforms, b) Maintenance of the interdiction or conservatorship (proposals contrary to article 12 of the CRPD) divided into two groups: a.1) Maintain the interdiction or conservatorship, but regulating a procedure that aims to determine the circumstances of each particular case; a.2) Maintain the interdiction or conservatorship, but reinforcing guidelines. In conclusion, the full application of Article 12 of the CRPD does not yet appear in the region as a fully consolidated alternative to the representation model, regarding which for now there is a certain consensus to keep it limited to specific cases.
- Several States consider that it is necessary to adopt transition measures between the representation model towards the broad capacity model with the support of Article 12 of the CRPD. These proposed measures meet the following groups: a) Proposal of transition prior to the application of the model of art. 12 with revision of the current legislation. The need for a gradual process of modification of domestic law is proposed as prior to the full application of the model of art. 12. Another State considers it necessary to initiate preliminary legislative studies. B) Some States propose the immediate application of Article 12, based on the normative hierarchy of the CRPD, which must be accompanied by adequate training along with a wide dissemination and promotion of rights. A transition to the social model was also considered unnecessary, but to understand what it means. However, particularly on this question in the questionnaire, several States did not express an opinion.
- Regarding procedures for “adequacy of legal capacity to act”, (or “provision of supported decision-making”), within the framework of Article 12 and 13 of the CRPD, in some cases, legislative modifications had a central influence in judicial decisions. The normative provision arises in other States in the same national constitution and also through base documents on which the trainings were worked. In other cases, no legislative provisions are made for the adjustments, although this does not mean that they are not carried out in accordance with the supra-legal status of the Convention. However, none of the reporting States has regulated supported decision-making for Persons with Disabilities that require it under the terms of article 12 of the CRPD.
- Regarding examples of good practices that make it possible to replace the representation model or to apply it, but limiting it to particular cases, the States propose as examples: a) Massive campaigns that work to modify the negative stereotypes that affect Persons with Disabilities and their rights, b) Disability mainstreaming in all State programs and policies, c) Promote the elimination of stereotypes and elimination of harmful practices by public officials, d) Disseminate and raise awareness among all judges on the need to strengthen in their criteria the presumption of legal capacity to act that operates in favor of all people with disabilities as a human right, as well as all the implications that such strengthening implies in the interpretation of the law, e) Listen to people (or groups) with disabilities, f) Work with people with disabilities and their family groups in order to accompany the paradigm shifts towards the concept of autonomy and independent living affected throughout the region by the practices mentioned above, g) Discourage and limit security measures, mainly prolonged hospitalizations, that affect people with disabilities and especially those with real or perceived psychosocial disabilities, h) Limit interdictions to extreme cases within the framework of state institutions (legal units) that actively participate in the defense of Persons with Disabilities. It is also proposed: “Identify the types of events in which greater attention should be given within a support system, so that the institutions involved with those events receive priority training and design appropriate care protocols”, i) Inclusion in the plans of I study the rights of people with disabilities and on diversity, raising awareness through the educational model, j) Training not only aimed at public officials, but also at the private sector and k) Promote mediation and listening between the judiciary and people with disabilities in judicial processes.

C. WORKING GROUP FOR THE DEVELOPMENT OF A GUIDE ON SUPPORT AND SAFEGUARDS

Once the preliminary diagnosis was completed, a CEDDIS working group was formed, made up of the delegations of Argentina, Brazil, Costa Rica, Chile, Panama and Peru to work in coordination with representatives of civil society and professionals from various areas (anthropologists, sociologists, lawyers, among others) to prepare a Guide aimed at judicial workers, legislators and other public officials of the States of the Region, which helps to clarify the “how to do it” in the constitution of support systems and implementation of monitoring and evaluation mechanisms, or safeguards, according to article 12 of the CRPD, attending to the needs detected in light of the conclusions of the diagnosis.

The Working Group began its work in 2014 with the definition of the Manual’s objectives, which would later be called “Guide”, the characterization of its main recipients and the development of a content scheme. In that year and in the following year began the preparation of a Conceptual Framework prepared by the Representation of Argentina with the support of the Secretariat of Human Rights of that country, and the preliminary version was presented at a special meeting held by the Group in Lima, Peru. in April 2015. On that occasion, the development and dispatch of two questionnaires were approved, addressed, respectively, to officials of the government sector and organizations of persons with disabilities as part of civil society. It had the purpose to complement the Regional Diagnosis on legal capacity already outlined, and to compile the information available as the basis for the Guide. It was considered that specific information could be required, especially since a debate and an incipient process of attempting to adapt and harmonize legislation had begun in some States, in accordance with Article 12 of the CRPD.

The questionnaires were distributed to the OAS Member States in September 2015, to compile information on the difficulties in fully recognizing the legal capacity of persons with disabilities, with questions designed to probe, among other issues, the knowledge of the international legal systems frameworks, the existence of local legislation, training received, factors that limit the exercise of legal capacity, opinions that are valued to determine the type of support, and accessibility guarantees offered by the surveyed body, among other issues.

By mid-2016, a total of 170 questionnaires were received (85 from the public sector and 85 from civil society) among the following 11 participating countries:

COUNTRY	PUBLIC SECTOR	CIVIL SOCIETY	TOTAL
ARGENTINA	11	11	22
BOLÍVIA	4	3	7
BRAZIL	3	6	9
CHILE	28	47	75
COLOMBIA	6	-	6
EQUADOR	1	1	2
EL SALVADOR	9	6	15
GUATEMALA	6	6	12
PANAMÁ	11	3	14
PERU	4	1	5
REP.DOMINICANA	2	1	3
TOTAL	85	85	170

E. DEFINITION OF THEMATIC AXES

During the Sixth Extraordinary Meeting of the CEDDIS held in Sao Jose, Costa Rica in November 2017, the working group outlined thematic axes to ensure the full exercise of the right to decision-making by Persons with disabilities, with information received from OAS member states as well as collaborating experts. The nine thematic axes were:

1. Autonomy and self-determination
2. Access to justice
3. Right to found a family
4. Sexual and reproductive rights
5. Independent living
6. Exercise of economic rights
7. Political and electoral participation
8. Access to social protection
9. Free and informed consent

During 2018, the Committee took a pause in developing the contents of the Guide due to the approximation of the request date for the Third National Report on compliance with CIADDIS and The Program of Action for the Decade of the Americas for the Rights and Dignity of Persons with Disabilities (PAD), which was requested from OAS Member States in mid-2019. For this reason, the two regular meetings of the CEDDIS convened in 2018 focused on the review and update of the indicators that would make up the format of the Third Report.

Between April and May 2019, the CEDDIS held its Eleventh Regular Meeting in the city of Asunción, Paraguay, in which four working groups were constituted made up of the CEDDIS members and other collaborating experts that resulted in the first draft of the Guide (Version 1) that was originally distributed as an Annex to the Final Report of that meeting. This version was later supplemented by the CEDDIS Authorities, experts from Argentina, and the OAS Department of Social Inclusion during the second semester of 2019, resulting in a second document (Version.2) which was submitted for consultation by civil society organizations registered with the OAS at the beginning of 2020 and which was also shared with a group of international experts who have also served as collaborators throughout the process of collecting information for the definition of contents of this instrument.

After circulating Version No.2 of the Guide in 2020 to receive feedback from civil society organizations and experts, a total of 10 contributions were received as indicated below:

Contributions from international experts

1. Alberto Vásquez, President of Society and Disability (SODIS).
2. María Graciela Iglesias, Expert in disability and Executive Secretary of the Mental Health Review Body of the Argentine Republic.
3. Monica Cortés, Executive Director of the Down Syndrome Association Colombia (Asdown); Coordinator of the Network of Families for Change and Representative of Inclusion International.
4. Silvia Quan, Guatemalan specialist in human rights of persons with disabilities. Independent expert of the United Nations Committee on the Rights of Persons with Disabilities for the period 2011-2016 of which she was its Vice-President.
5. Tina Minkowitz, President of the Center for the Human Rights of Users and Survivors of Psychiatry.


Contributions from civil society organizations

1. Latin American Network of Organizations of Persons with disabilities and their Families (RIADIS).
2. Latin American Union of the Blind (ULAC).
3. Andar y Rodar Foundation.
4. Civil society organizations in Argentina: Network for the Rights of Persons with Disabilities - REDI, the Observatory of Mental Health and Human Rights of the province of Córdoba, and the Working Group on Disability and Human Rights of the province of Córdoba.
5. Peruvian civil society organizations from Metropolitan Lima, Ancash, Pasco and Moquegua that were consolidated by CONADIS-Peru.

The CEDDIS, through a technical consultancy developed in 2021 by the expert Pamela Molina, has consolidated all the comments received from the aforementioned experts and civil society organizations, resulting in the final version of the Guide submitted to the approval of the CEDDIS at its Twelfth Regular Meeting held from October 25 to 27, 2021.



2. Conceptual Framework

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- A. The Human Rights perspective.**
 - B. Social model of disability.**
 - C. The meeting of both perspectives.**
 - D. The exercise of legal capacity and Human Rights.**
 - E. Legal capacity and its relationship with other rights.**
 - 1. General features
 - 2. Awareness
 - 3. Inclusive education
 - 4. Independent living and inclusion in the community
 - 5. Work and employment
 - 6. Participation of Persons with Disabilities (Article 29 CRPD)
 - 7. Access to justice
 - 8. Women and girls with disabilities
 - 9. Right to Liberty and Personal Security, Protection against Torture or Cruel, Inhuman and Degrading Punishment; Protection against Exploitation, Violence and Abuse; Protection of Personal Integrity and Right to Free and Informed Consent (Articles 14, 15, 16, 17 and 25 CRPD)
 - F. Human Rights Treaties on disability.**
 - 1. Inter-American Convention for the Elimination of All Forms of Discrimination against Persons with Disabilities (CIADDIS)
 - 2. International Convention on the Rights of Persons with Disabilities (CRPD)
 - 3. Final Observations of the Committee of the CRPD (UN) to the member countries.
 - G. Obligations to establish Support Systems for Persons with disabilities who require it.**
 - 1. General conceptualization
 - 2. Types of support
 - H. The Inter-American Court of Human Rights.**
 - I. Jurisprudence in Legal Capacity in the Region.**

A. THE HUMAN RIGHTS PERSPECTIVE

Human rights are inherent rights of all human beings, without any distinction of nationality, place of residence, gender, national or ethnic origin, color, religion, language, or any other condition, such as being in a situation of disability.

Human rights treaties seek to establish a system to protect human dignity.⁴³ In this framework, we all have the same human rights, without any discrimination, and these rights are universal, indivisible, interdependent and interrelated⁴⁴.

Both the International Human Rights System of the United Nations (UN) and the Inter-American Human Rights System of the Organization of American States (OAS) have approved declarations and treaties that are the basis of the systems.⁴⁵ However, they have progressively generated instruments for the protection of rights dedicated to specific groups of the population, in order to reinforce their guarantee.

These groups include persons with disabilities, who in the Americas have had the Inter-American Convention for the Elimination of All Forms of Discrimination against Persons with Disabilities in the Americas since 1999, approved by the OAS General Assembly; and throughout the world, since 2006 with the Convention on the Rights of Persons with Disabilities, approved by the United Nations General Assembly.

B. SOCIAL AND HUMAN RIGHTS MODEL ON DISABILITY

Historically, disability was considered a disorder, an “abnormality” that resided in people who -for various reasons- show different corporalities, ways of mobilizing, learning rhythms and intellectual understanding, non-traditional ways of expressing and experiencing emotions, or receiving the information of the environment. The “different” was considered “abnormal”, and the “normal” was considered homogeneous. Consequently, “being disabled” became an adjective of the identity of a person, who automatically acquires a lower value for that reason, and is categorized according to medical diagnoses. The difference, defined according to diagnosis, was seen as the “natural” cause of the alleged “inability” of these people to successfully participate in the regular educational system, the open labor market, or to be included in social and civic life under the same conditions as other people.

When disability is perceived in this way, societal responses are limited to one of two paths: “repair” the person through medicine or rehabilitation (medical approach), or provide care through charitable programs or social assistance (charitable approach). Following these views, the lives of persons with disabilities are handed over to professionals who control fundamental decisions such as the school they will attend, the type of support they will receive and the place where they will live.

During the last decades there has been an important change in the understanding of disability. The concept of disability is considered to be a socio-political construction that has no real relationship with the individual characteristics of the person. Instead, disability is seen as the consequence of a person’s interaction with an environment that does not accommodate their individual differences, is not designed for human diversity, and therefore creates barriers to social participation. autonomous and independent life of people thus considered “different”. This approach is known as the social model of disability.

The social model of disability has its origins in the late 1960s in England and the United States. It was then that some persons with disabilities took the initiative to push for political changes, calling attention towards “the impact of social and environmental barriers, such as inaccessible transportation and buildings, discriminatory attitudes and negative cultural stereotypes, which, they alleged, resulted in their disability. In this way, the political participation of persons with disabilities and their organizations opened a new front in the area of civil rights and anti-discrimination legislation”,⁴⁶ favoring the transition from a welfare perspective to one of rights.

The social model is based on the assumption that “the causes that originate disability are neither religious nor

43 Medina Quiroga, Cecilia; The American Convention: Theory and Jurisprudence; P. 8; Center for Human Rights, Faculty of Law, University of Chile; published in <http://www.corteidh.or.cr/tablas/23072.pdf>

44 Vienna Declaration and Program of Action, A / CONF.157 / 23, July 12, 1993

45 In the framework of the OAS, see the American Declaration of the Rights and Duties of Man (1948) and the American Convention on Human Rights (1969). In the framework of the United Nations, see the Universal Declaration of Human Rights (1948), the International Covenant on Civil and Political Rights and the International Covenant on Economic, Social and Cultural Rights (both, 1966).

46 PALACIOS, Agustina. The social model of disability: origins, characterization and expression in the International Convention on the Rights of Persons with Disabilities. Page 106. CINCA Editions. Madrid. 2008

scientific, but social or at least predominantly social”⁴⁷. Thus, the limitations are not personal, but are linked to the way in which society considers, or does not consider, the human diversity expressed by persons with disabilities. As a consequence, social responses must be aimed at removing barriers and stigmas that hinder the exercise of fundamental rights by these people.

C. THE MEETING OF BOTH PERSPECTIVES

The human rights perspective and the social model show similarities in terms of values: “dignity, understood as an inessential condition of humanity; freedom understood as autonomy—in the sense of development of the moral subject—that demands, among other things, that the person be the center of the decisions that affect him; and the inherent equality of every human being—respectful of difference—”⁴⁸.

In the same way, the guardianship approach and the medical or charitable model are articulated to intervene on persons with disabilities who are no longer considered as subjects of law.

Comparative table Guardianship approach vs. Human Rights Approach:

Conceptualizations	Guardianship approach/ medical model	Human rights-based approach
Subject name	Disabled, insane, handicapped, or the person named according to a medical diagnosis or impairment (paralytic, blind, schizophrenic, autistic, etc.)	Person with Disability
Treatment of Persons with Disabilities	Demand for "normalization". Disability Disparagement.	Acceptance of diversity. Dignification of the person with disabilities as a subject of rights and as part of human diversity.
Faced with body and functional diversity	Activities are limited and the right to autonomy is segregated, incapacity is assumed.	Personal assistance, support or reasonable accommodations for independent living and for decision-making are implemented as a right.
Decision-making	For others: professionals, conservators, judges, family members..	For the person with disability without exceptions.
Faced with difficulties in making decisions	Restriction or absolute denial of legal capacity, conservators, legal declaration of incapacity..	Full exercise of legal capacity, support system to make decisions
State intervention	On the Person with Disability to correct, cure or eliminate the “deficiency”..	On the environment to remove obstacles that create barriers..
Public policies	Special benefits	Measures of equalization of opportunities for the enjoyment of rights and mainstreaming of the issue in all public policies with an intersectional approach.
Social interaction with the community	Institutional segregation (special schools, sheltered workshops, therapeutic homes, neuropsychiatric, among others)	Family and community inclusion. (inclusive education, competitive employment with support, if needed, home assistance or community life support people when required).

47 PALACIOS, Agustina. Idem. Page 103

48 PALACIOS, Agustina. Idem. Page 155/6

D. EXERCISE OF LEGAL CAPACITY AND HUMAN RIGHTS

Legal capacity has traditionally been addressed by private law, and in particular civil law.

The Civil Laws of the region resorted from its original sanction to a differentiation between the capacity to enjoy the right and the capacity to exercise it. The first one is designed to all people and impossible to be denied without affecting the condition of the person subject to law; the second one, on the other hand, is subjected to total or partial restriction, and can be corrected in that case, through representation.

The objective of the restriction (total or partial) of the capacity to exercise has been the protection of the patrimony and the guardianship of the interdicted person.

However, it is important to note that, in fact, this restriction has operated as a barrier to the enjoyment of fundamental rights, and even generates significant human rights violations.⁴⁹

⁵⁰It is not possible to exercise the right of access to justice without being able to give testimony, sue or denounce in one's own name.⁵¹ It is not possible to exercise the right to health without being able to grant informed consent ⁵². It is not possible to exercise the right to work without being able to contractually commit. It is not possible to enjoy property rights without making decisions about one's belongings .

For all this, the restriction of legal capacity has been considered a form of social oppression, even capacity for enjoyment or rights, since it leaves the person at the mercy of third-party decisions for everything that is relevant to life projects.

Remembering that this mode of guardianship has affected women in our region until a few decades ago, and was questioned by the Convention for the Elimination of all forms of discrimination against Women, and that, with respect to girls and boys, it has also been questioned through the provisions of the Convention on the Rights of the Child.

In parallel to all this, International Human Rights Law for a long time limited itself to recognizing the legal personality of human beings,⁵³ reminding us all of the ownership of the human rights established in the treaties. However, the scope of legal personality expanded as the international community observed that it was necessary to guarantee it, in addition to ownership, the effective enjoyment and exercise of rights.

The International Covenant on Civil and Political Rights (ICCPR) and the American Convention on Human Rights (ACHR) are part of the group of the first international instruments that recognize the right to equal recognition as a person before the law (art. 16 ICCPR, art. 3 CADH). For its part, the Convention for the Elimination of All Forms of Discrimination against Women (CEDAW), the Convention on the Rights of the Child (CRC), the Convention on the Rights of Persons with Disabilities (CRPD), and the Convention Inter-American for the Protection of the Human Rights of Older Persons, much more recent, are already venturing into ways of guaranteeing the exercise of legal capacity (arts. 15 and 16 CEDAW, art. 5 and 12 CRC, art. 12 CRPD, art. 30 CIPDPM).

The need to guarantee the exercise of legal capacity is related to the universal, inalienable, independent, indivisible and interrelated nature of human rights, but also to the inherent dignity of the human being, "which is built mainly through the recognition of moral autonomy and the possibility of pursuing a personal life project".⁵⁴

We reiterate: it is not possible to access justice if the person cannot sue somebody, testify or defend oneself in a judicial case. It is not possible to enjoy the right to integrity if the person is the subject of the decisions that others can make about their own body. You cannot own property if you cannot decide how to use it. It is not possible to exercise civil and political rights if the person is not recognized with the minimum right to vote.

More examples can be presented. The purpose of this enumeration is to expose the fact that the legal incapacity or restrictions to the legal capacity (which are in force in the countries of the region) have repercussions

49 Medical treatment, forced surgical sterilizations and contraception, forced pregnancies or abortions, denial of civil and political rights, violation of due process, etc.

50 Committee on the Rights of Persons with Disabilities, General Comment No. 1, Article 12: Equal recognition before the law, CRPD / C / GC / 1, para. 23

51 Committee on the Rights of Persons with Disabilities, Medina Velo v. Mexico, CRPD / C / 22 / D / 32/2015

52 Committee on the Rights of Persons with Disabilities, General Comment No. 3, on Women and Girls with Disabilities, CRPD / C / GC / 3, para. 44

53 BARIFFI, Francisco: The international legal regime of the legal capacity of persons with disabilities and its relations with the current regulation of internal legal systems, page 318, can be consulted at: <http://e-archivo.uc3m.es/handle/10016/18991>

54 *ibid*, page 324

on the exercise of all other human rights, hindering their fulfilment and affecting the legal rights of citizenship of persons with disabilities.

Therefore, it is important that, given the difficulties that persons with disabilities may have in making their own decisions, the States intervene in a holistic and rights perspective, by offering support for the exercise of legal capacity instead of restricting or denying the right. This way, the fundamental rights will be recognized for all people, by achieving a comprehensive and simultaneous guarantee, which is typical of the human rights approach, including for persons with disabilities.

The provision of support is the act of providing help or assistance to a person who requires it to carry out daily activities, to develop decision-making processes, and to participate in society. Support is a practice, deeply ingrained in all cultures and communities, that forms the basis of all our social networks. All people need support from others at some point, or even throughout their lives, to participate in society, make decisions, and live with dignity.⁵⁵

However, while some forms of support have been naturally integrated into social design, others, such as those required by persons with disabilities, remain marginal.⁵⁶

E. LEGAL CAPACITY AND ITS RELATIONSHIP WITH OTHER RIGHTS

1. General Aspects

The adoption of the comprehensive approach to protection highlights how the realization of a right conditions the effectiveness of another. The possibility of exercising and enjoying the rights to an adequate living standard, to physical integrity, to education, to civil and political participation, or to personal self-determination, just to give a few examples, directly affects the participation of women. persons with disabilities in society, whether in the public or private sphere.

The text of Article 12 of the CRPD reaffirms the full recognition of the right of exercising the legal capacity of persons with disabilities without exception. In order to ensure this, a system of supported decision-making is adopted (Article 12.3), for people who require it, which replaces the model of substitution of will (conservatorship). The latter, by depriving the person with disability of the ability to exercise their rights, also deprives them of the possibility of being heard or deciding, plunging them into a situation of total impotence and thus excluding them from the possibility of active participation in society on an equal footing with other people in matters related to the exercise of their fundamental rights (access to justice, freedom and security, protection against torture, protection against violence, exploitation and abuse, protection of personal integrity, respect for home and family, right to health, work and employment, participation in political and public life, among others). This, in turn, places the person with disability in a situation of greater violation.

2. Awareness raising (Article 8, CRPD)

Following the statement above, it should be pointed out that many times it is the pre-established perceptions, culturally rooted in social habits, which are the basis for these rights restrictions, therefore both the CRPD and CIADDIS commit the States and society as a whole to fight against stereotypes and prejudices and promote awareness of the dignity and rights of human diversity in conditions of equal value and equity, and the principle of non-discrimination based on divergent corporalities. In effect, legislative measures are not sufficient to ensure effective equality for persons with disabilities in all areas of life, so they must be guaranteed by measures, at the judicial, administrative, educational, cultural, financial and social levels, among others.

Prejudices on disability have two main aspects. On the one hand, they are a series of social-political representations, thoughts, stereotypes and false ideas, socially constructed, that structure positions of inequality for people thus stigmatized based on their bodily or functional diversity. These social preconceptions about certain people are naturalized. People unconsciously and subjectively, culturally inherit these stereotypes

55 Document A / HRC / 34/58, December 20, 2016: Report of the Special Rapporteur on the Rights of Persons with Disabilities, UN. NY
56 Idem

and reproduce them in their daily lives. But, on the other hand, prejudices also include those negative attitudes, reactions, emotions and treatments that ordinary people manifest when faced with that “uncomfortable” diversity, easily perceptible, that people with disabilities display in their corporalities and ways to function. Ideas, prejudiced emotions and treatment go hand in hand. Prejudices respond to automatic, unconscious but learned mechanisms. In this way, those who have not had the frequency or habit of direct or close experience with persons with disabilities, draw incorrect conclusions from them on the basis of generalizations or stereotypes. But also, those who have a regular relationship with persons with disabilities, may have preconceptions about the way in which such people live or should live in broad terms, generalizing these ideas with respect to other persons with disabilities. Prejudices, culturally and socially rooted, expose the general ignorance that exists about the reality, abilities, feelings and values of the immense variety of people with disabilities and thus become the main source of negative attitudes, barriers and discriminatory treatment or differentiated that people without disabilities impose on people with disabilities, exacerbating disadvantages and preventing their full participation and social inclusion, on an equal basis with other people.

In the same way, there are harmful stereotypes about persons with disabilities, which constitute a set of beliefs about the attributes assigned to this particular social group. These are behavior models that become actions deeply ingrained in our collective ideology, to the point that we adopt them as part of human nature, though they are not.

The most frequent use of the term stereotype is associated with a simplification that is made with respect to communities or groups of people who share some characteristics.

They are built firstly from a categorization or classification and have among its main characteristics: generalization from a social tradition, which offers resistance to change, despite having more information in that society. One of the main functions of stereotypes or social categorizations is linked to the cognitive field: the systematization, simplification and ordering of our social environment - which facilitates its coherent understanding, adaptation and, even, its prediction, while it implies a saving of analytical effort and time (this is the brain’s function of “ordering” the “chaos” what we call reality).

Another function of stereotypes is motivational, linked to the representation and preservation of important social values. In other words, based on the stereotype, a negative characteristic is attributed to someone who is considered a threat to the homogeneity of the social order, and a positive characteristic of ours is highlighted. There are also group functions: the first one, the explanatory function, in which stereotypes contribute to the creation and maintenance of group beliefs that are used to explain certain facts and to maintain certain structures.

Among the main stereotypes identified that are related to the subject of this Manual, the CEDDIS Rapporteur on Legal Capacity and Access to Justice, points out:⁵⁷

1. The deep-rooted presence of the rehabilitative medical model, which transfers to the person with disabilities the incapacity for personal fulfillment and of making decisions that allow them to assert their own rights, appears as the most frequent.
2. Inadequate recognition of the ability to exercise rights: In addition to the previous concept, there is a lack of knowledge or partial recognition of the ability to exercise the rights of persons with disabilities by themselves.
3. In addition to these rules that establish the causes of legal incapacity, there are still some rules that are based on prejudices about the role of the person with disability in the family or society, which have an absolute welfare vision that denies the decision-making capacity of the person with disability.
4. The difficulty in recognizing persons with disabilities as part of human diversity, as the CRPD does (see Preamble and Article 3).
5. The Regional Diagnosis on the Exercise of the Legal Capacity of Persons with disabilities published by the CEDDIS in 2015 , based on the information collected, it identifies that the families of the person with disability, in fact, can become facilitators for the exercise of legal capacity, but also a factor that restricts their rights. Additionally, the analysis of a field survey that was carried out as an input to this Guide, allowed to confirm this data with figures, since in many occasions it is the families

57 Cf. Rosales, Pablo (Principal Delegate of Argentina to the CEDDIS): Regional Diagnosis on the exercise of legal capacity of persons with disabilities. Rapporteurship for the Monitoring Committee of the Inter-American Convention for the Elimination of all Forms of Discrimination against Persons with Disabilities, CEDDIS. CEDDIS Technical Secretariat. Department of Social Inclusion, OAS General Secretariat, Washington DC, 2015, pp. 22-25. Available here: <https://www.oas.org/es/sedi/ddse/paginas/documentos/discapacidad/destacados/relatoria-espanol.pdf>

The Regional Diagnosis on the Exercise of the Legal Capacity of Persons with disabilities published by the CED-DIS⁵⁸ in 2015, based on the information collected, it identifies that the families of the person with disability, in fact, can become facilitators for the exercise of legal capacity, but also a factor that restricts their rights. Additionally, the analysis of a field survey that was carried out as an input to this Guide, allowed to confirm this data with figures, since in many occasions it is the families at the request of their own stereotypes or by the advice of professionals who are linked to the same prejudices and with them, those that urge processes of restriction of legal capacity.

3. Educação Inclusiva (art. 24 CDPD)

Inclusive education is based on principles and methodologies that reinforce the ability of everyone to achieve their goals and considers diversity as an opportunity to learn. Through an inclusive education system, it is possible to avoid the segregation of students with disabilities in special schools and to influence the formation of everyone as people respectful of diversity and human rights, allowing us to learn skills for life and development. social through the link with otherness and its differences.

Inclusive education is important from a social perspective because it provides a solid foundation for combating stigma and discrimination. “A blended learning environment that includes persons with disabilities allows their contributions to be valued and prejudices and misconceptions to be addressed and progressively eliminated. Inclusive education also fosters quality education for all by fostering broader curricula and teaching strategies that contribute to overall capacity and skill development. This link between teaching and development, when it includes diverse participants with different potential, introduces new perspectives to achieve goals and self-esteem and empower people to create a society based on mutual respect and rights.”⁵⁹

In this way, inclusive education systems (which is a right without an age limit) reaffirm the status of persons with disabilities as subjects of rights, in addition, promote awareness (art. 8 CRPD) by the community, both issues being of special relevance to achieve full recognition of the legal capacity of persons with disabilities.

“The Committee draws the attention of States parties to its general comment No. 1 (2014) on equal recognition as a person before the law and highlights that inclusive education offers students with disabilities..., The opportunity to express your wishes and your preferences. States parties should ensure that inclusive education contributes to building the confidence of students with disabilities in the exercise of legal capacity, providing the necessary support at all levels of education, among other purposes to reduce future service needs support if they wish.”⁶⁰

4. Living independently and being included in the community (art. 19 CRPD)

The central component of this right is to decide where and with whom to live, as well as daily routines. For many persons with disabilities, these decisions are prohibited, either because they are institutionalized or because they are the subject of judicial decisions of legal incapacity, the consequence of which is to authorize other people to decide on behalf of the person with disability, without the need for consultation.

The recognition of the right of persons with disabilities to independent living and community inclusion requires the shift of government policies away from institutions towards in-home, residential and other community support services. The key element of any intervention aimed at giving effect to the right to independent living and community inclusion is the explicit legal recognition of the right of persons with disabilities to determine where and with whom to live....”⁶¹

The Committee on the Rights of Persons with Disabilities pointed out that among the barriers to independent living are the denial of legal capacity, either through official or de facto laws and practices, which allow substitution in the adoption of decisions regarding the systems of life.⁶²

Access to justice as enshrined in article 13 is fundamental to ensure full enjoyment of the right to live independently in the community. States parties must ensure that all persons with disabilities have legal capacity and standing in courts. States parties must furthermore ensure that all decisions concerning living independently in the community may be subject to appeal. Support to enable living independently in the community shall be enforceable as rights and entitlements. To ensure equal and effective access to justice substantial rights to legal aid, support

58 Ibid

59 OHCHR, Thematic Study on the Right of Persons with Disabilities to Education, A / HRC / 25/29, December 18, 2013.

60 CRPD / C / GC / 4, November 25, 2016, General Comment No. 4 (2016) on the right to inclusive education, UN, NY, Paragraph 50

61 OHCHR, Thematic study prepared by the Office of the United Nations High Commissioner for Human Rights to improve knowledge and understanding of the Convention on the Rights of Persons with Disabilities, para. 50, A / HRC / 10/48, January 26, 2009

62 Document CRPD / C / GC / 5, General Comment No. 5 (2017) on the right to live independently and to be included in the community, UN, NY.

and procedural and age-appropriate accommodations are essential.”⁶³

The Right to exercise independent living and in the community, according to article 19, includes people with physical, sensory, psychosocial and intellectual disabilities who may require various types of personal support or assistance. This right is not only regarding personal care and mobility, but also emotional support, the prevention of unwanted isolation, the performance of daily life tasks, among others. They refer, for example, to the figures of personal assistants, assistants for supported decision-making in matters of daily life, interpreters, interpreter guides, etc., which act as support for the exercise of the right to independent living and living in the community.

These support do not refer to or are linked to the interdiction or restriction of legal capacity. However, they are necessary to ensure the full exercise of the right to live independently and be included in the community.

5. Trabalho e emprego (art. 27 CDPD)

“The right to work is essential for the realization of other human rights and constitutes an inseparable and inherent part of human dignity. Work is usually a means of subsistence for the person and his family and also contributes, insofar as it is freely chosen or accepted, to its full realization and recognition within the community.”⁶⁴ Thus, the full recognition of this right is related to the exercise of legal capacity,⁶⁵ since the person not only chooses the task to be carried out and the conditions in which he agrees to carry it out, but also how they use the money earned.

In this sense, autonomy and self-determination unfolds through work, while its enjoyment is hampered when the person with disability cannot choose what task to perform, sign a work contract, or how to dispose of their income.

This occurs when decisions are made by other people, or when the person with disability is not guaranteed the support for making their decisions, and also when the law excludes persons with disabilities from working in certain jobs.

6. Participation of Persons with Disabilities (article 29 CRPD)

The right to participation of persons with disabilities has at least two dimensions. The first is linked to the possibility of participating as a citizen in relation to political and electoral rights, but there is also a second one linked to the possibility of forming organizations of Persons with disabilities that have to be consulted for the design, implementation and evaluation of programs, plans and actions related to all matters that concern the group of Persons with disabilities. In both cases, interdiction processes tend to directly affect the exercise of this inalienable right to participation.

Equal recognition before the law is a precondition for the exercise of the right to participation, as reported by the CRPD committee,⁶⁶ that especially affects people with intellectual, psychosocial and hearing disabilities.

7. Access to Justice (Article 13 CRPD)

Access to justice can be characterized as the right that allows the fulfillment, enjoyment and exercise of all other rights; However, for persons with disabilities there are legal, physical, communicational and sociocultural barriers that hinder the exercise of this right. That is why the Convention introduced, for the first time in a human rights instrument, the requirement to adapt procedures in order to enable access to justice for Persons with Disabilities, as well as to provide them with reasonable accommodations in all processes in which they were involved. Until the preparation of the Thematic Report of the Office of the United Nations High Commissioner for Human Rights, this right of access to justice was linked to the right of access to jurisdiction and the guarantees of due process.

The deprivation of legal capacity and the modalities of substitution for decision-making exclude persons with disabilities from legal proceedings, in addition to forcing them to be represented by a third party, for example, by a legal guardian, without even being consulted. The exercise of legal capacity is closely related to the right

63 Document CRPD / C / GC / 5, General Comment No. 5 (2017) on the right to live independently and to be included in the community, UN, NY

64 Ibid, par. 3

65 OHCHR, Thematic Study on the Work and Employment of Persons with Disabilities, para. 54, inc. c, A / HRC / 22/25, December 17, 2012

66 Cf. United Nations Committee-CRPD: General Comment No. 7, (2018).

of access to justice, since the latter cannot often be exercised without it. On the other hand, without access to justice, persons with disabilities cannot fight against the deprivation of their legal capacity, the denial or restriction of their rights that results from it.

The deprivation of legal capacity, whether by an official mandate or as a result of de facto practice, leads to exclusion from judicial processes and has devastating effects on the right of persons with disabilities to a fair trial with due process guarantees. For example, accused persons with psychosocial and intellectual disabilities are often deprived of the right to be heard in person, engage in adversarial proceedings, present evidence or challenge witnesses. These restrictions affect the principles of equality of procedural means and non-discrimination and prevent access to justice on equal terms with others.

Another manifestation of the denial of legal capacity in access to justice is the practice of declaring unimputability (“non-liability”; “non-imputabilité”) or claiming “mental alienation”, which implies attributing to the person a “psychic alteration” or a “mental disorder” at the time of the commission of the alleged crime, which gives rise to an exemption from criminal responsibility. As a result, the person is removed from the procedure and subjected to a series of security measures that imply deprivation of liberty and actions against their will, often for an indefinite period of time, so that they are denied the same access to procedural guarantees as other people in violation of the right to a fair trial. The CRPD Monitoring Committee has recommended that criminal procedures have to be reviewed to reconsider the concept of non-liability, as well as any version of the allegation of insanity. In addition, it has requested that the security measures involving forced medical or psychiatric treatment in institutions have to be eliminated and has expressed concern about the measures that imply a lack of periodic guarantees in the criminal justice system and an indefinite deprivation of liberty, the abolition of these practices should be taken into great consideration.

Decision support needs to be further developed in the context of access to justice. It is essential to have protocols and guidelines that support the work of judges, lawyers and other justice officials who intervene in judicial or administrative processes. Providing procedural adjustments in this context can also help create appropriate practices. Theoretical and applied research can serve to systematize practices and develop instruments that guarantee respect for the right to exercise legal capacity in all legal procedures.⁶⁷

8. Women and Girls with Disabilities (Article 6 CRPD)

In practice, the options and opinions of women with disabilities, especially women with psychosocial, hearing or intellectual disabilities, are often ignored and their decisions are often superseded by those of third parties, including legal representatives, service providers, guardians and family members, in violation of their rights under Article 12 of the Convention. All women with disabilities must be able to exercise their legal capacity by making their own decisions, with support when they so wish, about medical care or therapeutic treatment, including decisions related to preserving their fertility and reproductive autonomy, exercising their right to decide the number and spacing of the children, give your consent and accept a declaration of paternity and exercise their right to establish relationships and exercise motherhood and parenting with the support required if appropriate. The restriction or removal of legal capacity can facilitate forced interventions, such as sterilization, abortion, contraception, female genital mutilation, surgical interventions or treatments performed on intersex children without their informed consent and forced detention in institutions.

Contraception is a free choice for any woman, and should not be a justification for sexual abuse and violence. Similarly, forced sterilization can also lead to sexual violence without the consequence of pregnancy, especially in the case of women with psychosocial or intellectual disabilities, women admitted to psychiatric centers and other institutions, and women deprived of liberty. It is therefore especially important to reaffirm that the legal capacity of women with disabilities must be recognized on an equal basis with others, and that women with disabilities have the right to found a family and to receive adequate assistance in raising their children.

Harmful gender and/or disability stereotypes based on concepts such as disability or incapacity can lead to the situation where mothers with disabilities suffer legal discrimination, which is why these women are overrepresented in child protection procedures and lose in a way disproportionate contact and custody of their children, who are the subject of adoption proceedings and/or are placed in an institution. In addition, separation, divorce and full custody of children can be granted to the husband on the basis of his wife’s disability.

67 Document A / HRC / 37/25, December 27, 2017, Annual report of the United Nations High Commissioner for Human Rights and reports of the Office of the High Commissioner and the Secretary General Promotion and protection of all human and civil rights , political, economic, social and cultural, including the right to development, UN, NY, paragraphs 33, 34, 36 and 38.

Women with disabilities, more often than men with disabilities and women without disabilities, are denied the right to legal capacity. Their rights to maintain control of their reproductive health, in particular on the basis of free and informed consent, to found a family, to choose where and with whom to live, to physical and mental integrity, to own and inherit property, controlling their own economic affairs and having equal access to bank loans, mortgages and other forms of financial credit, are often violated through patriarchal systems of substitution in decision-making.

Women and girls are disproportionately affected, as in practice they are the main providers of support in their home. Thus reducing their freedom and choices regarding their own life projects.

The programs designed to end domestic violence should include appropriate forms of assistance and support that take into account age and gender for girls and women with disabilities. States should budget for and plan for such measures when designing policies and programs to ensure that support is available for women and girls with disabilities from the outset.

9. Right to Liberty and Personal Security, Protection against Torture or Cruel, Inhuman and Degrading Punishment; Protection against Exploitation, Violence and Abuse; Protection of Personal Integrity and Right to Free and Informed Consent (Articles 14, 15, 16, 17 and 25 CRPD)

It is essential to consider the right to liberty and personal security in relation to the right to exercise legal capacity. As stated in article 14 of the CRPD, no one should be deprived of liberty on grounds of disability. This provision leads to the abolition of all mental health laws whose primary, and often exclusive purpose is to regulate and authorize forced detention and treatment, based on reasons of “prevention”, “protection against oneself or third parties”, or to “provide care and treatment” linked to an apparent or diagnosed mental illness.⁶⁸ Psychiatric internments, from International Law, can no longer be justified, not even on the grounds of “emergency” or “crisis”. In its Guidelines on Article 14, the CRPD Committee indicates that: “The involuntary internment of persons with disabilities for reasons of medical care contradicts the absolute prohibition of deprivation of liberty for reasons of disability (art. 14, par. 1 b)) and the principle of free and informed consent of the person concerned to receive medical treatment (art. 25). The Committee has repeatedly stated that States parties must repeal the provisions that allow the involuntary placement of persons with disabilities in mental health institutions because of real or perceived mental health problems. Involuntary placement in mental health institutions implies the denial of the legal capacity of the person to decide about care, treatment and admission to a hospital or institution and, therefore, violates Article 12, read in conjunction with the article 14”.⁶⁹

Persons with disabilities - especially people with psychosocial and intellectual disabilities - who live in institutions or have been admitted against their will are in a more vulnerable situation to be victims of torture, cruelty, inhuman or degrading treatment.⁷⁰ The CRPD in its article 15 prohibits the application of medical or scientific experiments to persons with disabilities without their free and informed consent. Many States allow such experiments on people whom they consider incapable of consenting. Hence, there is a clear link between this article and Article 12. There is also a link between Articles 15, 16 and 17. “Acts of violence and abuses carried out by individuals or institutions may constitute torture if the government does not has exercised the due diligence to prevent such violence. Abuses in the field of medicine, such as forced medical interventions related to a disability, and forced abortion or sterilization, can also constitute torture or mistreatment.”⁷¹ Forced treatment constitutes a violation of the right to be free from torture and other cruel treatment, but also a violation of the right to exercise legal capacity.⁷² The United Nations Rapporteur on Torture says in his report on issues relating to psychological torture,⁷³ that “The supposedly benevolent aims cannot, per se, justify coercive or discriminatory measures. For example, practices such as miscarriage, sterilization or psychiatric intervention for reasons

68 See: International Disability Alliance (IDA): Guidance Document. Effective Application of the International Human Rights Monitoring Mechanisms for the Protection of the Rights of Persons with Disabilities. May 2010, p. 44. Available here: https://www.internationaldisabilityalliance.org/sites/default/files/documents/crpd_guidance_document_spanish-11.pdf

69 Cf.: Committee on the Rights of Persons with Disabilities: Guidelines on article 14 of the Convention on the Rights of Persons with Disabilities. The right to liberty and security of persons with disabilities. Adopted during the Committee's 14th session, held in September 2015. Para. 6 et seq., P. 2. The violation of rights that these hospitalizations and unwanted treatments involve, and that are justified by the legal figures of interdiction and conservatorship, has become evident with the famous current case of singer Britney Spears in the United States. Some analysis here: <https://www.bluradio.com/judicial/interdicion-la-polemica-american-legal-figure-which-visualized-the-case-de-britney-spears?fbclid=IwAR2gAz3pxFN-hOr548WXteQJsdF4QLXR3KTDNjfnrHrk2Q>; <https://discapadades.nexos.com.mx/la-interdicion-mas-alla-de-britney-spears/>

70 IDA, op.cit, p. 45.

71 Ibid.

72 This is also reiterated in the Guidelines on Art 14 (paragraph 12, p. 3) and in General Comment 1 of the CRPD Committee on Legal Capacity (paragraph 42, p. 12): “The segregation of persons with disabilities in institutions remains a pervasive and insidious problem that violates several of the rights guaranteed under the Convention. The problem is exacerbated by the generalized denial of legal capacity to persons with disabilities, which allows others to give their consent to intern them in institutional settings”.

73 Cf.: A / HRC / 43/49, paragraph 37, pp. 11 and 12

of “medical necessity” or the “best interests” of the patient (A/HRC/22/53, paras. 20 and 32-35; and A/63/175, para. 49), (...) often involve highly discriminatory and coercive attempts to control or “correct” the personality, behavior or decisions of the victim and almost always inflict severe pain or suffering. Therefore, in the opinion of the Special Rapporteur, if all the other defining elements are present, it is very possible that these practices amount to torture”.

Persons with disabilities who have been interdicted, who live in institutions or similar facilities, or receive services from them, are particularly exposed to situations of risk and domestic violence, exercised -among others- by caregivers, including neglect, concealment or abandonment, confinement at home and the use of drugs or invasive methods to control behavior, without the free and informed knowledge of the person with disability, which constitutes a violation of the right to exercise legal capacity, as well as the right to protection against violence and exploitation guaranteed by article 16 of the CRPD, especially in its section 3.⁷⁴

The protection of physical and mental integrity in article 17 of the CRPD is also linked to article 12, as it prohibits any medical intervention, carried out against the will of the person.

E. E. HUMAN RIGHTS TREATIES WITH SPECIFICITY ON DISABILITY. TREATMENT OF LEGAL CAPACITY

1. Inter-American Convention for the Elimination of All Forms of Discrimination against All Persons with Disabilities (CIADDIS)

In our region, the States are bound by two human rights treaties with specificity regarding disability.

On the one hand, the Inter-American Convention for the Elimination of All Forms of Discrimination against Persons with Disabilities (CIADDIS, OEA, 1999), establishes: “... In cases where domestic legislation provides for the figure of the declaration of interdiction, when necessary and appropriate for their well-being, it shall not constitute discrimination...”(Art. 1, inc. 2, in fine).

On the other hand, the Convention on the Rights of Persons with Disabilities (CRPD, UN, 2006), which in its article 12, provides “Equal recognition as a person before the law”:

“The States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.

States Parties recognize that persons with disabilities have legal capacity on an equal basis with others in all aspects of life.

The States Parties shall adopt the pertinent measures to provide persons with disabilities access to the support they may need in the exercise of their legal capacity.

States Parties shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law. Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person’s circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body. The safeguards shall be proportional to the degree to which such measures affect the person’s rights and interests. Subject to the provisions of this article, States Parties shall take all appropriate and effective measures to ensure the equal right of persons with disabilities to own or inherit property, to control their own financial affairs and to have equal access to bank loans, mortgages and other forms of financial credit, and shall ensure that persons with disabilities are not arbitrarily deprived of their property.”

From a comparative reading of both texts, it can be seen that CIADDIS legitimizes representation for decision-making (interdiction) as a form of protection for persons with disabilities, while the CRPD demands the implementation of supported decision-making, when the person so chooses and requires it, as a way of guaranteeing the fundamental right to exercise rights with self-determination (legal capacity).

Noting the aforementioned discrepancy, the Committee for the Elimination of all Forms of Discrimination against

⁷⁴ IDA, Op. Cit, p. 46.

Persons with Disabilities, in charge of following up on the commitments acquired through CIADDIS, issued a “General Observation on the need to interpret Article I.2, Subsection B) In fine of the Inter-American Convention for the Elimination of All Forms of Discrimination against Persons with Disabilities, within the framework of Article 12 of the United Nations Convention on the Rights of Persons with Disabilities”.

In this observation, dated April 28, 2011⁷⁵, the CEDDIS states that “Article I.2 paragraph b) in fine of the Inter-American Convention for the Elimination of All Forms of Discrimination against Persons with Disabilities of the OAS, needs to be reinterpreted in light of the new paradigm of Article 12 aforementioned.”⁷⁶

Additionally, the Inter-American Human Rights System approved in June 2015, the Inter-American Convention on the Protection of the Human Rights of Older Persons, which is in force, and which in its article 30 reproduces article 12 of the CRPD, of which reference is given in the following paragraph, reinforcing the validity of the standard of equality before the law, of right and exercise, in our continent in the case of people over 60 years of age.

2. Convention on the Rights of Persons with Disabilities (CRPD)

Paragraphs 70 to 74 of the Inter-American Convention for the Protection of the Rights of Older Persons reproduce Article 12 of the CRPD, referring to which, in 2014, its Committee of Experts generated an interpretive observation: “General Comment No.1- Article 12: Equal recognition as a person before the law”.

In this observation, which establishes the scope that the Committee, as the body in charge of supervising the CRPD at the international level, grants to Article 12 of the treaty for its practical implementation, it is recalled that “equality before the law is a principle basic general of the protection of human rights and is indispensable for the exercise of other human rights”⁷⁷. In this sense, it clarifies that “this article does not establish additional rights for persons with disabilities; it simply describes the specific elements that States parties must take into account in order to guarantee persons with disabilities the right to equality before the law, on equal terms with others”⁷⁸.

Although all of General Comment No. 1 are important for the purposes of interpreting Article 12 of the CRPD, it is necessary to highlight the following considerations:

Article 12 of the Convention affirms that all persons with disabilities have full legal capacity.⁷⁹

In relation to its paragraph 1: Every human being must be respected as a person before the law: that is, as the holder of legal personality, which is an indispensable requirement for the legal capacity of the person to be recognized.⁸⁰

Regarding article 12, paragraph 2: Legal capacity includes the capacity to be the holder of rights and to act in law.⁸¹(...)

Legal capacity means that all people, including persons with disabilities, have the legal capacity and standing to act simply by virtue of their human status. Therefore, for the right to legal capacity to be fulfilled, both aspects must be recognized; those two aspects cannot be separated.⁸²

Legal capacity, such as the ability to be the holder of rights and obligations (legal capacity) and to exercise those rights and obligations (legitimacy to act), is the key to accessing true citizenship, full participation in society. It has nothing to do with nor is related to the concept of mental capacity, so the latter should not be used as an argument to deny, restrict or question the legal capacity.⁸³

Regarding article 12, paragraph 3: States parties must not deny legal capacity to persons with disabilities, instead, they have the obligation to provide them with access to the support they need to make decisions that have legal effects.⁸⁴

75 The text of this General Comment can be consulted at the following link: http://www.sedi.oas.org/ddse/documentos/discapacidad/CEDDIS_text_observaciones_rev.doc

76 As of the Third Compliance Report of CIADDIS and the PAD, which covers the period 2016-2019, the protection and promotion of the exercise of the Legal Capacity of persons with disabilities was incorporated through specific indicators, in accordance with Resolution of the OAS General Assembly AG / RES. 2928 (XLVIII-O / 18) of June 5, 2018, which approved the update of the contents of the PAD, in harmony with the CRPD and the 2030 Agenda.

77 CRPD Committee: General Comment No. 1 Article 12: Equal recognition before the law, paragraph 1, p. 2, CRPD/C/GC/1

78 Ibid

79 Ibid, paragraph 8

80 Ibid, paragraph 11

81 Ibid, paragraph 12

82 Ibid, paragraph 14

83 Ibid, paragraph 13

84 Ibid, paragraph 16

Support in the exercise of legal capacity must respect the rights, will and preferences of persons with disabilities and must never consist of deciding for them. (...) Persons with disabilities who choose and require support can choose one or more support people whom they trust to help them exercise their legal capacity regarding certain types of decisions, or they can resort to other forms of support, such as peer support, defense of their interests (including support for the defense of their own interests) or assistance to communicate (...) Support for people with disabilities in exercise of their legal capacity may include measures related to universal design and accessibility (...) Support may also consist of the development and recognition of different and unconventional communication methods, especially for those who use non-verbal forms of communication to express their will and preferences⁸⁵.

The type and intensity of support to be provided will vary considerably from one person to another due to the diversity of persons with disabilities (...). Besides, not all persons with disabilities will require support to make decisions or will choose to request support. At all times, even in crisis situations, individual autonomy and the ability of persons with disabilities to make decisions must be respected.⁸⁶

Regarding article 12, paragraph 4: the main objective of safeguards must be to guarantee respect for the rights, will and preferences of the person. In order to achieve this, safeguards must provide protection against abuse, on an equal footing with other people.⁸⁷

When it is not possible to determine the will and preferences of a person, although all efforts for that have been made, the determination of the “best interests” should be replaced by the “best possible interpretation of the will and preferences”. This respects the rights, will and preferences of the person, in accordance with article 12, paragraph 4. The paradigm of “will and preferences” must replace that of the “best interest” for persons with disabilities to enjoy the right to legal capacity under conditions of equality with others.⁸⁸

Undue influence is characterized by the quality of the interaction between the person providing the support and the person receiving it shows signs of fear, aggression, threat, deception or manipulation. Safeguards for the exercise of legal capacity should include protection against undue influence; however, protection must respect the rights, will and preferences of the individual, including the right to take risks and make mistakes.⁸⁹

In relation to paragraph 5 of Article 12 CRPD: the denying of persons with disabilities legal capacity for financial matters should be replaced by support to exercise legal capacity, in accordance with Article 12, paragraph 5. The same way gender cannot be used as a basis for discrimination in the areas of finance and property, neither can disability⁹⁰.

Outras considerações

One of the objectives of support in exercising legal capacity is to build the confidence and skills of persons with disabilities so that they can exercise their legal capacity with less support in the future, if they so wish.⁹¹

The person should have the right to refuse support, to end the support relationship or change it at any time (...) The provision of support for the exercise of legal capacity should not depend on or require an assessment of mental capacity; This support in the exercise of legal capacity requires new and non-discriminatory indicators of support needs.⁹²

The rights established in article 12 are closely linked to the obligations of States regarding accessibility (art. 9), because the right to equal recognition as a person before the law is necessary so that persons with disabilities can live independently and participate fully in all aspects of life.⁹³

In order for persons with disabilities to be able to claim compliance with their rights and obligations on an equal basis with others, their legal personality must be recognized with the same capacity before the courts and tribunals.⁹⁴

85 Ibid, paragraph 17
 86 Ibid, paragraph 18
 87 Ibid, paragraph 20
 88 Ibid, paragraph 21
 89 Ibid, paragraph 22
 90 Ibid, paragraph 23
 91 Ibid, paragraph 24
 92 Ibid, paragraph 29
 93 Ibid, paragraph 37
 94 Ibid, paragraph 38

In order to make the rights established in article 12 fully effective, it is imperative that persons with disabilities have opportunities to formulate and express their will and preferences, in order to exercise their legal capacity on equal terms with others. This means that persons with disabilities must have the opportunity to live independently in the community, to make choices and have control over their daily lives, on equal terms with others, in accordance with the provisions of Article 19.⁹⁵

The interpretation of article 12, paragraph 3, in the light of the right to live in the community (art. 19) assumes that support in the exercise of legal capacity must be provided through a community-based approach.

States parties should recognize that social networks and the support for persons with disabilities that occur naturally in the community (such as that provided by friends, family and school) are essential elements for the support in the adoption of decision-making process⁹⁶.

3. Final Observations of the CRPD Committee (UN) to the member countries

Since ratifying the CRPD, several States in the region have submitted the reports required by Article 35 of the treaty.

To date, the Committee on the Rights of Persons with Disabilities, the body in charge of monitoring compliance with the Convention at the international level, has examined some presentations and issued the pertinent recommendations in accordance with article 36 of the CRPD regarding the Exercise of Legal Capacity.

The first thing that emerges from the final observations of the Committee to the LAC States that are part of the CRPD in relation to Article 12, is that they must review and repeal the domestic laws that include and legitimize a regime of substitution of the will for the decision-making due to disability, and replace those legislation with models “to supported decision-making process that is respectful of the autonomy, will and preferences of the person”.⁹⁷ The committee is gradually becoming more and more specific regarding this recommendation to the States. It recommends “the immediate review of all current legislation that, based on the substitution of decision-making, deprives the person with disability of their legal capacity. At the same time, it urges you to take steps to adopt laws and policies that replace the substitution regime in decision-making with supported decision-making that respects the autonomy, will and preferences of the person.”⁹⁸ For the adoption of these measures, the Committee emphasizes the need for them to be formulated “in consultation with organizations of persons with disabilities and other service providers.”⁹⁹ That the State ensure: “that the reform process has the effective and independent participation of persons with disabilities through the organizations that represent them”¹⁰⁰. It also mentions at this point that “it is concerned that procedures for supported decision-making require judicial approval and that the autonomy, will and preferences of persons with disabilities do not prevail.”¹⁰¹

Second, the Committee recommends directly to the States of the region that have not done so, the **reform of their Civil Code** to eliminate the measures that restrict the exercise of legal capacity of persons with disabilities, “in order to adequately guarantee all persons with disabilities to exercise their civil rights.”¹⁰²

Third, the Committee also recommends that the States implement “**an independent review mechanism** in order to fully restore the rights of persons who have been judicially declared incapacitated”.¹⁰³ It requests the annulment of the interdictions already applied and the freezing of any interdiction process that is pending. “Urges the State to review all legislation... to remove any restriction of rights related to the state of interdiction or due to the person’s disability”. The Committee is also concerned about “the lack of information about the number of persons who have been subject to guardianship and conservatorship, as well as the lack of resources and legal guarantees in force, such as the conduct of independent examinations and the right to appeal, to revoke

95 Ibid, paragraph 44

96 Ibid, paragraph 45

97 Bariffi, Francisco: The international legal regime of the legal capacity of persons with disabilities and its relations with the current regulation of internal legal systems. Doctoral Thesis. Bartolomé de las Casas Human Rights Institute, Carlos III University of Madrid, Getafe, March 2014, P. 574-578. Available here: https://e-archivo.uc3m.es/bitstream/handle/10016/18991/Francisco_%20Bariffi_tesis.pdf. Also, for this entire section, review the final observations of the United Nations Committee on the reports of Argentina, Brazil, Bolivia, Chile, Costa Rica, Cuba, Ecuador, El Salvador, Guatemala, Mexico, Panama, Peru, the Dominican Republic and Uruguay, available here: <http://www.riadis.org/observatorioregional/>

98 Ibid.

99 United Nations, Committee on the Rights of Persons with Disabilities: Final Observations of the Committee on the Final Report of Brazil. (Approved by the Committee at its 14th session, August 17 to September 4, 2015. United Nations, CRPD / C / BRA / CO / 1, September 29, 2015

100 United Nations, Committee on the Rights of Persons with Disabilities: Concluding observations of the Committee on the combined second and third periodic reports of Ecuador (approved by the Committee at its 22nd session, August 26 to September 20, 2019. Nations United States, CRPD/C/ECU/CO/2-3, October 21, 2019.

101 Ibid.

102 Bariffi, Op.cit., Pp. 574-578.

103 United Nations, Committee on the Rights of Persons with Disabilities: Final observations on the initial report of Paraguay, approved by the Committee at its ninth session (April 15-19, 2013). United Nations, CRPD / C / PRY / CO / 1, May 15, 2013. Our underlining.

the imposition of these measures”¹⁰⁴, therefore, it recommends that the States also collect “data and information on persons with disabilities who have been judicially declared incapable, insofar as this declaration of incapacity represents an obstacle to the respect and full exercise of the legal capacity of the persons with disabilities in all areas of life, including, but not only, the heritage area”.¹⁰⁵

The Committee’s concluding observations related to Article 12 also refer to the application of **specific rights** such as: i) **liberty**, prohibiting forced internment due to manifest or diagnosed incapacity, and guaranteeing the right to choose the place of residence; ii) **Independent life and living in the community, and social protection**: the Committee recommends that “a plan for housing and support services be adopted for persons with disabilities that allows them to live independently and be included in the community”¹⁰⁶ iii) **physical and mental integrity**, demanding that laws and procedures respect “the right to free and informed consent to receive medical treatment”, prohibiting forced sterilization or medical treatment without the express, free and informed consent of the person with disability: “The Committee recommends that the State party review and repeal the provisions that restrict the free and informed consent of all persons with disabilities, including those declared interdicted and under guardianship, or those who are institutionalized, and adopt the necessary regulations for the full exercise of free and informed consent, to act in all kinds of medical or scientific interventions”;¹⁰⁷ iv. **The right Right to information**: “The committee recommends that all persons with disabilities who are in custody are duly informed about the new legal framework, and that it guarantee in all cases the exercise of the right to supported decision-making”¹⁰⁸ ; v) **family rights**, prohibiting the denial of the right to marry and to care for their children; vi) **right of access to justice**, “guaranteeing that persons declared incapable have procedural and real standing to claim before the judicial authorities”; vii) **Civil and political rights**, such as access to vote and identity as part of the right to exercise legal capacity, recommending that States implement “immediately programs to issue identity documents to people with disabilities, including those in rural areas and in long-term institutional settings, as it collects complete and accurate data on people with disabilities who are in institutions and who currently lack identity documents or do not have their right to have a name;”¹⁰⁹ viii) **property rights**, prohibiting people declared incapable from being deprived of the right to manage and dispose of their assets: “The Committee urges the State party to guarantee that all persons with disabilities have access on an equal basis with other persons to credits, mortgages and all the variety of financial services”.¹¹⁰

The Committee also indicates as part of its recommendations **the need for training** for legal professionals on the subject: “The Committee also recommends the launch of training workshops on the human rights model of disability aimed at judges with the purpose that they adopt the supported decision-making system instead of guardianship and conservatorship”.¹¹¹ But the Committee also goes further, recommending that training should also include government authorities and civil society: “train authorities and society on the right to legal capacity of persons with disabilities, based on the recommendations made by the Committee in its general comment No.1 (2014)”.¹¹²

As already mentioned in some parts above, we can see that a final guideline of interpretation that emerges from the concluding observations of the Committee is that States Parties to the CRPD must, by virtue of Article 12, **implement a system that serves as a support for the capacity to act or exercise legal capacity**,¹¹³ and that includes the following: a) Recognition of the capacity to act of all people and the right to exercise it; b) Adjustments and support mechanisms of access, if necessary, of the exercise of the capacity to act; c) Norms that guarantee that these supports for the exercise of legal capacity respect the autonomy, will and preferences of the person and include information mechanisms to ensure that it meets the needs of the person; d) Practical arrangements for the establishment of these capacity-to-act support systems. As Bariffi argues: “In short, the Committee’s doctrine supports an interpretation of the obligations contained in Article 12 that supposes: In the first place, the notion of “legal capacity” includes what is commonly understood as “capacity to act” or capacity to make decisions on one’s own behalf. Second, that the States Parties are obliged to review the laws and practices that deny the exercise of the capacity to act to persons with disabilities, whether they have the name guardianship, conservatorship,

104 United Nations, Committee on the Rights of Persons with Disabilities: Examination of the reports submitted by the States parties under article 35 of the Convention. Concluding observations of the Committee on the Rights of Persons with Disabilities. Peru. Seventh session, April 16-20, 2012. UNRPD / C / PER / CO / 1, May 16, 2012.

105 Ibid.

106 United Nations, Committee on the Rights of Persons with Disabilities: Final observations on the initial report of Colombia (approved by the Committee at its 16th session, August 15 to September 2, 2016. United Nations, CRPD / C / COL / CO / 1, September 30, 2016.

107 United Nations, Committee on the Rights of Persons with Disabilities: Final observations on the initial report of Chile (approved by the Committee at its 15th session, March 29 to April 21, 2016. United Nations, CRPD / C / CHL / CO / 1, April 13, 2016.

108 Ibid

109 United Nations, Committee on the Rights of Persons with Disabilities: Examination of the reports submitted by the States parties under article 35 of the Convention. Concluding observations of the Committee on the Rights of Persons with Disabilities. Peru. Seventh session, April 16-20, 2012. UN CRPD / C / PER / CO / 1, May 16, 2012

110 United Nations, Committee on the Rights of Persons with Disabilities: Concluding observations on the initial report of Costa Rica (adopted by the Committee at its 11th session, March 31 to April 11, 2014. United Nations, CRPD / C / CRI / CO / 1, May 12, 2014.

111 United Nations, Committee on the Rights of Persons with Disabilities: Final observations on the initial report of Argentina (approved by the Committee at its eighth session, September 17-28, 2012. United Nations, CRPD/C / ARG / CO / 1, October 19, 2012

112 United Nations, Committee on the Rights of Persons with Disabilities: Final observations on Mexico’s initial report (Adopted by the Committee at its 12th session, September 15 to October 3, 2014). United Nations, CRPD / C / MEX / CO / 1, October 27, 2014.

113 Cf. Bariffi, Francisco, Op.cit., Pp. 574-578.

incapacitation or disqualification. Third, that the right to exercise legal capacity extends to all aspects of life, especially regarding the right to liberty, physical and mental integrity, and other civil and political rights such as vote, access to justice or the right to marriage. Fourth, that the States Parties must implement a system of support for the exercise of legal capacity that guarantees the right to make decisions on their own behalf, but that at the same time guarantees an equal exercise of rights with safeguards”.¹¹⁴

F. OBLIGATION TO ESTABLISH SUPPORT SYSTEMS FOR PERSONS WITH DISABILITIES

1. General Conceptualization

In addition to what has already been outlined, regarding Article 12.3 of the CRPD, the Rapporteur on the Rights of Persons with Disabilities, Catalina Devandas, points out that “States must develop supportive arrangements of different types and intensities, formal and informal, for decision-making. These arrangements include, for example, support networks, support agreements, peer support and self-help groups, self-advocacy support, independent advocacy, and advance directives. Unlike in the case of surrogate decision-making regimes, in supported decision-making arrangements, legal capacity is never withdrawn or limited; Support persons cannot be appointed by a third party against the will of the person concerned, and support must be provided taking into account the will and preferences of the person. . The right to legal capacity is not subject to the acceptance of any type of support or adjustment, since people with disabilities have the right to reject them”.¹¹⁵

The same rapporteur indicates States must adopt a community-based approach to providing support. Support arrangements should be designed “from the cultural point of view in the communities where persons with disabilities live, taking advantage of existing social networks in such a way that” family, friends, neighbors, people in a similar situation and others play an important role in supporting people with disabilities.”¹¹⁶ This implies, among other things, that supported decision-making should not be thought of as solely assigned by the court, in the same way as it should not be limited to the families.

To claim for the intervention of a court every time a person requires supported decision-making, “creates a series of difficulties for persons with disabilities, since: a) in most jurisdictions these people find obstacles to access the justice, due to the lack of accessibility and procedural adjustments; b) it is a more expensive system, which makes access to support less affordable; c) delays in court may compromise access to support; and d) intensive training is needed to achieve a paradigm shift in the way judges approach the legal capacity of persons with disabilities”.¹¹⁷

Supported decision-making support must be freely chosen and accepted by the person with disability when required. Limiting supported decision-making only to the family circle, can reduce the possibilities of choice regarding the assistance they need to fulfill their life project. This could bring up problems related to overprotection, conflicts of interest and the increase of the control that families have over the Person with Disability.

Devandas highlights that States have the duty to guarantee the availability of support for persons with disabilities, and that these must be accessible, adequate and affordable, regardless of whether it is actually provided by public service providers, civil society, families, communities, or a combination of public and private actors. While support from family, friends and the wider community is extremely important and should be encouraged and enabled, it is not always a reliable solution when it comes to decision-making processes, or sustainable in the long term.

States must ensure that there is a sufficient number of programs and services in place to offer the widest possible range of support to the diverse population of persons with disabilities.¹¹⁸ All support arrangements and services must be culturally appropriate; take into account gender aspects, needs throughout the life cycle; and be designed in a way that respects the privacy of users. “States should ensure that support is available in a safe physical setting and at a reasonable distance to all people, including those in an institutional setting. Support must be affordable for all persons with disabilities” (free or at a nominal cost, taking into account gender dispa-

114 Bariffi, Francisco, op.cit., pp. 574-578. Available here: https://e-archivo.uc3m.es/bitstream/handle/10016/18991/Francisco_%20Bariffi_tesis.pdf.

115 Human Rights Council, 37th period of sessions, February 26 to March 23, 2018: Report of the Special Rapporteur on the rights of persons with disabilities. United Nations, A / HRC / 37/56, December 12, 2017, paragraph 27, p. 8.

116 Ibid, paragraph 28.

117 Devandas, op.cit, paragraph 42, p. 11.

118 Devandas, op.cit., paragraph 29, page 8. Also see report: A/HRC/34/58, pars. 48 a 56, 20 of December 2016.

rities and other intersectional identities in access to income and financial resources). “States must also apply accessibility measures and provide reasonable accommodation so that persons with disabilities can exercise their legal capacity. The obligation of States to guarantee access to support goes beyond the right to legal capacity, since some persons with disabilities may need support to make certain decisions that have no legal repercussions”.¹¹⁹

2. Types of Support

2.1 Support for Decision-making

It is encouraging to note that, since the approval of the Convention, many countries of the Inter-American Region, such as Argentina¹²⁰, Costa Rica¹²¹, Peru¹²², Brazil¹²³, Colombia¹²⁴, have revised their legal frameworks in order to recognize the right of persons with disabilities to the full exercise of their legal capacity on equal terms with other people, and to access support systems to exercise their legal capacity when required. In turn, many of them have repealed interdiction and conservatorship due to disability.¹²⁵

A first point in this regard is that according to the Committee on the Rights of Persons with Disabilities the request, acceptance and designation of supports correspond to the person with disabilities.¹²⁶ As noted by the CRPD Committee of Experts in its General Comment N1 on Legal Capacity and the Special Rapporteur for the Rights of Persons with Disabilities¹²⁷, the supports can be of several types: individual or group, through public or private services, for decisions that have legal effects or that do not, based on the community, support networks, support agreements, peer support and self-help groups, support for the defense of one’s own interests, independent defense and the figure of the advance directive, among others.

It is important to note that in extreme cases in a person’s life as a measure of last resort, where it is not possible for them to express their wishes and preferences in a way that is evident to other people, and after having made “real, considerable and pertinent efforts to obtain a manifestation of the will of the person, and having provided accessibility measures and reasonable accommodation, and when the designation of support is necessary for the exercise and protection of their rights.”¹²⁸ Another person may establish the need for such support and designate them. In these cases, it is necessary to take into account several factors:

The designation of support by a third person must be done through a judicial process that guarantees the application of international human rights standards.

Within these standards, the criteria of the “best interpretation of the will and preferences of the person” must be applied. The judge must consider the relationship of coexistence, trust, friendship, care or kinship that exists between the support person and the person who requires support and “carry out the pertinent procedures to obtain the best possible interpretation of the person’s will and preferences, and attend to his life trajectory.”¹²⁹

The “best interpretation” criteria is based on concrete evidence and is not speculative. In practice, it involves considering, among others, “The life trajectory of the person, the previous manifestations of will in similar contexts, the information that the trusted persons of the assisted person have, the consideration of their preferences and any other pertinent consideration for the specific case”,¹³⁰ including “the verbal or non-verbal forms of communication of the person concerned”.¹³¹

The criteria of the best interpretation of the will and preferences “It involves determining what the person would have wanted rather than making a decision based on their best interests”,¹³² and it applies to the designation

119 Ibid. Also see report A/HRC/34/58, parrs. 29 a 41, December 20, 2016.

120 Argentina: Law 26,994, of October 2014, approves the Civil and Commercial Code of the Nation (see arts. 31 to 43)

121 Costa Rica: Law No. 9379, August 18, 2016, for the Promotion of Personal Autonomy of PwD. Executive Decree 41087, Regulatory Law 9379.

122 Peru: Legislative Decree 1384, September 2018. Regulation of Transition to the Support System in observance of the Social Model of Disability, 2019.

123 Brazil: Law 13,146 of July 6, 2015, Brazilian Law of Inclusion. Articles 114-116.

124 Colombia: Law 1996 of 2019.

125 Colombia, *ibid*; Peru, Legislative Decree 1384; Costa Rica, Law N ° 9379, August 18, 2016.

126 Committee on the Rights of Persons with Disabilities, No. 1 Article 12: Equal recognition before the law, paragraph 1, CRPD / C / GC / 1, para. 17 and 19.

127 Human Rights Council, 37th period of sessions, February 26 to March 23, 2018: Report of the Special Rapporteur on the rights of persons with disabilities. United Nations, A / HRC / 37/56, December 12, 2017, paragraph 27, p. 8.

128 Legislative Decree 1384 of Peru, reform Article 659 – E.

129 *Ibid*. See also General Comment 1 of the CRPD Committee, cited above, paragraph 21: The “best interpretation” standard replaces a “best interest” determination, which does not apply to adults with disabilities.

130 Decree Law Peru 1384, paragraph 659-B

131 Devandas, *op.cit.*, Paragraph 31, p. 9

132 *Ibid*.

of one person or another as a support, to any other determination regarding support, and to the actions of the support person(s) appointed. The “best interpretation” standard requires the best approximation, in good faith, to the most probable current will of the person. Therefore, when the person is again in a position to express their will directly, “the best interpretation” ceases to apply.

Therefore, the supports designated by third parties must be reviewed periodically, and the person with disability can reject or stop them.

In the same way, if a person is in a situation of emotional crisis, or of intense stress instead of responding with the cancellation of the right to legal capacity of these people and their forced psychiatric hospitalization, as up to now, their inherent human dignity and autonomy, applying the decision support paradigm shall be respected. “The advocacy paradigm offers a rights-based approach to dealing with such cases. For example, through advance planning, persons with disabilities can give instructions on how to cope with future emotional crises and / or appoint a person to support them in those circumstances. In addition, there is increasing evidence of the effectiveness of non-coercive support practices, within and outside the health sector . There is also a need to “urgently address the structural issues that prevent people with disabilities from accessing support during an emotional crisis (for example, due to prejudice, low expectations, lack of flexibility, lack of resources, or strict rules on liability)”.¹³³

This in turn, prior to deciding the designation of support, the existence of barriers to the exercise of rights in the entire decision-making process must be verified, and if they exist, their removal should be promoted by means that intervene on the environment and not on the person with disability.

2.2 Support for Communication: from the reception of information to the formulation and expression of opinions and decisions.

Support in the exercise of legal capacity may be relevant to the process of considering and making decisions, as well as communication in two ways: receiving information and expressing the will and preferences. The standards of Article 12 of the CRPD apply to all types of support in the exercise of legal capacity, including support for communication.

Some persons with disabilities may require support to overcome barriers that limit their adequate and complete understanding of relevant information, as well as their ability to communicate and make themselves understood. Although the provision of accessible information and communications can reduce the need for support of persons with disabilities, many may still require support for the communication of their opinions, preferences, wishes and decisions. The situation of girls and boys with disabilities, who due to their characteristics do not express themselves orally or who can do so in a limited way is especially alarming, given that their communication needs are often neglected in the education system and in the community, despite the existence of human, financial and material resources.

This is more significant in light of the paradigm of the progressive autonomy of this group contemplated both in the Convention on the Rights of the Child (CRC) and in the CRPD.

This is also the case of adults with disabilities who, due to their particular characteristics, do not express themselves verbally or orally and neither can receive information through traditional channels.

In this regard, States must adopt all pertinent measures to ensure that persons with disabilities, regardless of their individual characteristics and needs for communication, can have access to the support they require through different forms of alternative communication, as defined in article 2 of the Convention. This includes professional and neutral sign language interpreters, text visualization, braille, tactile communication, large-print, and easily accessible multimedia devices, as well as written language, hearing systems, plain language, media, digitized voice and other augmentative or alternative modes, media and formats of communication, including accessible information and communication technology¹³⁴

133 Devandas, op.cit., Paragraph 32, p. 9.

134 A / HRC / 34/58 GE.16-22489 21 79. See also General Comment No. 1 of the Committee of Experts of the CRPD, paragraph 17: “Support for persons with disabilities in the exercise of their legal capacity may include measures related to universal design and accessibility - for example, requiring private and public entities, such as banks and financial institutions, to provide information in a format that is understandable or to offer professional interpretation in sign language, so that persons with disabilities can carry out the legal acts necessary to open a bank account, enter into contracts or carry out other social transactions. Support may also consist of the development and recognition of different and unconventional communication methods,

2.3. Support for understanding legal acts and their consequences

Persons with disabilities may need someone to explain their options to make a decision, legally binding or not. They may need someone to explain the consequences (good and bad) that may occur when they make a decision. They may need help understanding the information given to them by healthcare professionals, lawyers, bank operators, legal professionals, service providers, employers, and others. There are people prepared to act as assistants in these processes to explain the meaning and scope of decisions and their consequences, to facilitate the person with disabilities in making a decision. This assistance can be given for legally binding decisions or for other more informal decisions related to the project of life and independent living. Persons with disabilities can choose their assistants via support agreements, among other ways.

2.4. Formal and informal and circumstantial support

A differentiation must be made between formal support and informal support, depending on whether or not there is a legal document (which can be a notarial agreement, a contract, among others) that establishes an agreement or a process for the allocation of support.

Informal support, decided and adopted without a legal document involved, can include the consideration and adoption of decisions, as well as the receipt of information or the expression of will (supports for communication). For example, peer support. It is an informal support system that constitutes an important practice within the movement of people with psychosocial disabilities. Peer support guides both decision-making processes and their communication, the process of making themselves understood, and the defense and respect of said decisions in conflictive situations. Informal support related to the exercise of legal capacity, which include its exercise in different aspects of daily life, may coincide in part with support to live independently in the community.

2.5. Support for independent living (art 12 in combination with art 19)

In addition to the support that can be used in decisions of daily life and those that are legally binding -including accompaniment between peers to prevent unwanted isolation-; there are support in the exercise of legal capacity that have a mixed or more difficult to be classified character, such as the Networks or Systems of Judicial Facilitators for persons with disabilities,¹³⁵ which are not formal in the sense of having a legally binding agreement or designation, but which nevertheless have legal duties to function within the Justice System. All these types of support are relevant in relation to the exercise of legal capacity in its application to all aspects of life and to other particular rights and duties.

G. THE INTER-AMERICAN COURT OF HUMAN RIGHTS (IACHR) AND THE RIGHT TO EQUAL RECOGNITION AS A PERSON BEFORE THE LAW

The IACHR has addressed the rights of persons with disabilities more explicitly in three cases: Ximenes López v. Brazil,¹³⁶ Furlan and family vs. Argentina,¹³⁷ and the now recently failed case Guachalá Chimbó Vs. Ecuador.¹³⁸

In the last of these cases, it has developed considerations directly linked to the legal capacity of persons with disabilities. Luís Eduardo Guachalá Chimbo, 23, a person with psychosocial disability, was admitted on January 10, 2004 at the Julio Endara Hospital in the city of Quito, His admission authorization was signed by his mother. Mr. Guachalá Chimbo was hospitalized until January 17, 2004, the day on which, according to the medical history, he would have left the hospital and, from that moment, until today, his whereabouts are unknown. The Inter-American Court determined that the State is responsible for the violation of the following rights: recognition of legal capacity, free and informed consent to medical treatment, the right to life, personal integrity, personal liberty, dignity and private life; access to information, equality before the law and the right to health, in accordance with articles 3, 4, 5, 7, 11, 13, 24 and 26 of the American Convention on Human Rights. Obligation to respect and guarantee these rights are placed into focus without discrimination and the duty to adopt provisions of domestic law to make their exercise effective, as established in articles 1.1 and 2 of the same instrument. In its Judgment, the Court emphasized that the use of the victim's disability to justify that her/his informed consent for hospitalization and medication was

135 The OAS has an Inter-American System of Judicial Facilitators (JF) not focused on disability issues yet, but which could have the potential to become a tool for a support system. The NGO Documents, in Mexico, established a FJ system for persons with disabilities specifically, which is a good practice to consider for its replication

136 Judgment available here: https://www.corteidh.or.cr/docs/canec/articulos/Seriec_149_esp.pdf.

137 Judgment available here: https://www.corteidh.or.cr/docs/canec/articulos/Seriec_246_esp.pdf

138 All the information on this Judgment of the IACHR, as well as a complete copy of it, can be found here: https://www.corteidh.or.cr/docs/comunicados/cp_36_2021.pdf

unnecessary, constituted discrimination on the grounds of disability. Also, and in a comment directly related to Legal Capacity and with a supported decision-making model, the court pointed out that subjecting a person with disability to health treatment without their informed consent may constitute a denial of legal personality. Specifically, the ruling determines that the State of Ecuador did not take any measure to support the person to whom he could give her/his informed consent for the hospitalization and treatment to which he was subjected, which constituted a denial of her/his autonomy as a person, and of her/his ability to make decisions regarding her/his rights.

In the case of *Furlán and Family v/s Argentina*, the Inter-American Court touches on the issue of the rights of persons with disabilities vaguely, and does include in the ruling the recognition of the need to make a joint interpretation of the CRPD and the regional instruments, in the light of the human rights model, which constitutes an important precedent. In this case, it is the right to compensation and social benefits for disability acquired by accident, by a 14-year-old child. The ruling states that in this case the violations of rights enshrined in the American Convention are framed in the fact that Sebastián Furlan was a child at the time of the accident and that accident later, triggered him to be an adult with a disability. Taking into account these two facts, the Court considers that the violations should be analyzed in light of: i) the international corpus juris for the protection of children, and ii) international norms for the protection and guarantee of the rights of persons with disabilities. Furthermore, the ruling also included the provisions of the Protocol of San Salvador on Economic, Social and Cultural Rights.

In other jurisprudential precedents it has stated:

García and Relatives Vs. Guatemala. Merits, Reparations and Costs. Judgment of November 29, 2012, Series CN ° 258, paragraph 109: “In this sense, the Court has considered that the proper content of the right to recognition of legal personality is that, precisely, the person is recognized anywhere as a subject of rights and obligations, and that he or she can enjoy fundamental civil rights, which implies the ability to be the holder of rights (capacity and enjoyment) and duties; the violation of that recognition implies disregarding in absolute terms the possibility of being the holder of civil and fundamental rights and duties ... “

Case of the Sawhoyamaya Indigenous Community v. Paraguay. Merits, Reparations and Costs. Judgment of March 29, 2006, Series CN ° 146, paragraph 189. “It is the duty of the State to ensure the legal means and conditions in general, so that the right to recognition of legal personality can be exercised by its holders. In particular, the State is obliged to guarantee to those people in situations of vulnerability, marginalization and discrimination, the legal and administrative conditions that ensure the exercise of this right, in attention to the principle of equality before the law”.

H. JURISPRUDENCE ON LEGAL CAPACITY IN THE REGION

Over the years, and especially after the entry into force of the CRPD, national jurisprudence has developed in favor of the recognition of the full legal capacity of persons with disabilities without exceptions, of supported decision-making, respect for the right to free and informed consent, and the repeal of interdictions, among others. In some cases, these judgments have been issued applying the Conventionality Control; that is: applying the International and Regional Conventions on human rights signed and ratified by the country, over a contradictory national or domestic law; and in other cases, appealing to national laws or principles protected by the national Constitution in each country.¹³⁹

In “*Almonacid Arellano vs. Chile*”¹⁴⁰ 2006, the IACHR indicated that the national judges should take into account, when ruling their cases, not only the provisions of the American Convention on Human Rights, but also the interpretation that the Court has made of it. For its part, in the sentence passed in the case “*Dismissed workers of the Congress of Peru*” the following year, it was also emphasized that the control of “conventionality” had to be accomplished “*ex officio*”.

139 For example, see in Mexico: Appeal of complaint. Performance of persons with disabilities in an amparo trial in their own right. SCJN, 2016 <https://www.scjn.gob.mx/sites/default/files/pagina-micrositios/documentos/2018-08/recurso-queja-572016.pdf>; Unconstitutionality of various norms of the Law of Notaries and the Civil Code. Amparo in Review. Easy reading. SCJN, 2019 https://www.scjn.gob.mx/sites/default/files/listas/documento_dos/2019-09/AR-702-2018-190912.pdf; Unconstitutionality of the state of interdiction. Amparo under review. Easy reading. SCJN, 2019, https://www.scjn.gob.mx/sites/default/files/listas/documento_dos/2019-02/AR-1368-2015-190212.pdf. In Chile, a recent ruling by the Court of Talca in favor of a deaf young man who was not allowed to sign a vehicle purchase-sale contract because he did not communicate orally, stated that The Notary is responsible for the deprivation, disturbance and threat of the legitimate exercise of the fundamental guarantees enshrined in article 19 No. 2 and 4 of the Constitution, as the young person was discriminated against for her/his hearing disability, arguing that, by not being able to communicate, he qualified as absolutely incapable, according to article 1447 of the Civil Code. The ruling indicates that the legal norm invoked refers to deaf people who cannot make themselves understood clearly, a situation that does not occur in their case, because they can communicate through Chilean sign language and in writing. For this reason, “in accordance with the international and domestic standards related in this ruling, it cannot be concluded that the Substitute Notary Public did not observe the corresponding standards, verifying an illegal and arbitrary discrimination with respect to the respondent”. Although in this case the ruling does not question article 1447 of the Civil Code, at least it presents an advance by recognizing that there are alternative means for persons with disabilities to express their will and preferences, without being considered absolutely incapable a priori. Watch: <https://www.diarioconstitucional.cl/2021/07/14/corte-de-talca-acogio-recurso-de-proteccion-en-contra-de-un-notario-publico-y-le-ordeno-pedir-Apologias-public-for-discriminating-the-recurrent-on-the-basis-of-his-hearing-disability/>

140 I / A Court HR. Case of *Almonacid Arellano et al. V. Chile*. Preliminary Objections, Merits, Reparations and Costs. Judgment of September 26, 2006. Series C No. 154.

In some States, judgments related to the establishment of support and legal capacity have been handed down, exercising conventionality control, even in those countries that had not yet carried out legislative reforms.

It is illustrative to mention due to their institutional relevance, the judgments issued by the Supreme Courts and the Courts or Constitutional Tribunals, such as the cases of Mexico, Argentina and Colombia.

In the case of Mexico, it is the well-known judgment of October 16, 2013, in the case of Ricardo Adair Coronel Robles, in which, for the first time in the Region, a highest court of justice made a direct application of Articles 12 and 13 of the CRPD. On the occasion, the Supreme Court of Mexico established criteria related to the evaluation for the provision of support and legal capacity, at the same time that it included sections in simple language directed especially to the actor. On November 24, 2016, a judgment was obtained protecting the rights of the young person to exercise his legal capacity.

On June 16, 2021, Mexico's Supreme Court of Justice's First Chamber decided to cease the state of interdiction and recognize the system of support and safeguards of a young person with a psychosocial disability. The Chamber determined, in general, as unconstitutional the rules that regulate the state of interdiction and its forms of termination, differentiated between legal capacity and mental capacity, deciding that the first is not subject to the second. In the same way, it recognized the role that persons with disabilities should have in the design and implementation of their support system. This ruling is extremely important because, according to the new rules for generating jurisprudence in the Mexican system, it could constitute the first mandatory precedent in the matter.¹⁴¹

For its part, the Supreme Court in Argentina has taken the conventionality control in various situations related to guarantees in mental health processes and treatments, legal capacity, the right to motherhood and the right to vote.

In the IJM/Special Protection Orders, the Supreme Court, following the opinion of the Prosecutor's Office, revoked the status of a child's adoption, ordering the bonding and reinstatement of his mother, a person with intellectual disability who, in addition, was in a situation of socioeconomic vulnerability.

The attorney included the arguments that founded its position, after reviewing the norm and standards of various Conventions, among which the so-called Pact of San José de Costa Rica, the United Nations Convention for the Rights of the Child (CDN), the CRPD, among other instruments, including the Final Observations made to Argentina by the Committee on the Rights of Persons with Disabilities, to conclude that the judicial resolution that provides for adaptability is not compatible with the aforementioned standards. On the contrary, it states that the mother's situation demands from the State the need to provide reasonable support and adjustments.¹⁴²

In the FHO Case (case No. 83563) decided on July 10, 2018, the Supreme Court of Justice of Argentina ruled in favor of recognizing the right to vote of the plaintiff, when assessing the incorporation of the Convention on Human Rights of Persons with Disabilities, there was a substantial change in the regime regarding the legal capacity of persons with mental disabilities. The system of substitution and subrogation of the will was abandoned, and it was replaced by a social model of disability with the aim of promoting the person and guaranteeing the fulfilment of their rights. The Court, after reviewing the normative modifications of the Civil Code, concludes that as a result of the aforementioned norms, the restriction of the right to vote provided for in article 3, paragraph a), of the National Electoral Code regarding persons judicially declared insane (the text on which the contested judgment was based), must be applied in accordance with the principles and guarantees that govern persons with disabilities and imposes a detailed and specific assessment of the ability to vote. In this evaluation, the designation of support is mentioned in the event that the person is in a position to autonomously exercise that right but has some difficulty in being able to do so, provided that their will and preferences are respected, and without conflict of interest or undue influence and without conflict of interest or undue influence (argument of Article 12, paragraph 4 of the Convention on the Rights of Persons with Disabilities).¹⁴³

Likewise, in Colombia the Constitutional Court on October 19, 2016 ruled Case T573 in which it addressed the sexual and reproductive rights of persons with disabilities. On the occasion, the Constitutional Court concluded

141 For more information on this recent Judgment, see: <https://www.internet2.scjn.gob.mx/red2/comunicados/noticia.asp?id=6480>

142 CSJN 339-795 rulings, of July 7, 2016.

143 CSJN 341-1625 rulings of July 10, 2018.

after analyzing the international standards on the matter, that “it is not sustainable, in light of the Constitution, to insist on a decision that, perpetuating the social stereotypes that persons with disabilities perceive as human being incapable of making autonomous decisions in sexual and reproductive matters, it exposes them to a practice that violates their right to human dignity, equality and personal integrity. (...) No circumstance enables the adoption of decisions that concern the people in a situation of disability by means of substitute consent, and that, in any case, their legal capacity to make decisions freely and autonomously must be presumed, through the supports, reasonable accommodations and safeguards that the State must provide them for this purpose. Consequently, in those cases in which the person is unable to express their will about the possibility of having a sterilization procedure performed, once all the supports and safeguards have been granted to do so, the procedure should not be practiced. Claiming in this sense the principle “Nothing about us without us” that inspired the incorporation of the social model.”¹⁴⁴

On the other hand, in some countries of the region, a very significant practice has been verified; consisting of the preparation of manuals, guides or action protocols that inform and promote the Judgment of the Constitutional Court of Colombia mentioned in the previous paragraph (T-573/16)¹⁴⁵, which reaffirms the right of persons with disabilities to decide, on equal terms with others, about all aspects of their lives. It also reaffirms the right to free and informed consent in everything related to the sexual and reproductive rights of persons with disabilities, particularly women, and refers to the establishment of support for the exercise and legal capacity, even in those countries where the substantive legislation has not been harmonized in accordance with the social model paradigm and the Convention. Such is the case of Ecuador¹⁴⁶, Mexico¹⁴⁷ and Panama.¹⁴⁸

These references do not exhaust the subject or imply detriment to other lower court rulings that have addressed the issue of legal capacity¹⁴⁹ the CEDDIS encourages academics in the region to develop more detailed studies and compendia of national and regional jurisprudence on the matter.

144 Sentence T.573 par. 67.

145 See the sentence here: <https://www.corteconstitucional.gov.co/relatoria/2016/t-573-16.htm>

146 Ecuador: Manual of Attention to the Rights of Persons with Disabilities in the Judicial Function, 201

147 Mexico: Action Protocol for those who administer justice in the event that they involve the rights of Persons with Disabilities. 2014

148 Panama, Law 15 of May 31, 2016, Article 1

149 For a more detailed analysis see Bariffi F. and Jiménez, E., “Disability Rights”, in Treaty on the Control of Constitutionality and Conventionality, Volume 4, (Amaya JA Dir.), Astrea, Buenos Aires, 2018, pp. 409-451.



3. **THEMATIC APPROACH**

THE RIGHT TO EXERCISE DECISION-MAKING

International Legal Framework of References

- International Convention on the Rights of Persons with Disabilities (CRPD). Articles 2, 3, 12, 13, 14, 15, 16, 17 and 19.
- Inter-American Convention for the Elimination of all Forms of Discrimination against Persons with Disabilities (CIADDIS). Article 3.
- 2030 Agenda. Sustainable Development Goals (SDGs) 5, 10 and 16.
- General Comment 1, 5 and 7 of the CRPD Committee.
- Program of Action of the Decade of the Americas for the Rights and Dignity of Persons with Disabilities, PAD (2016-2026), Objective 10, Concrete Actions numeral 9, a-e.

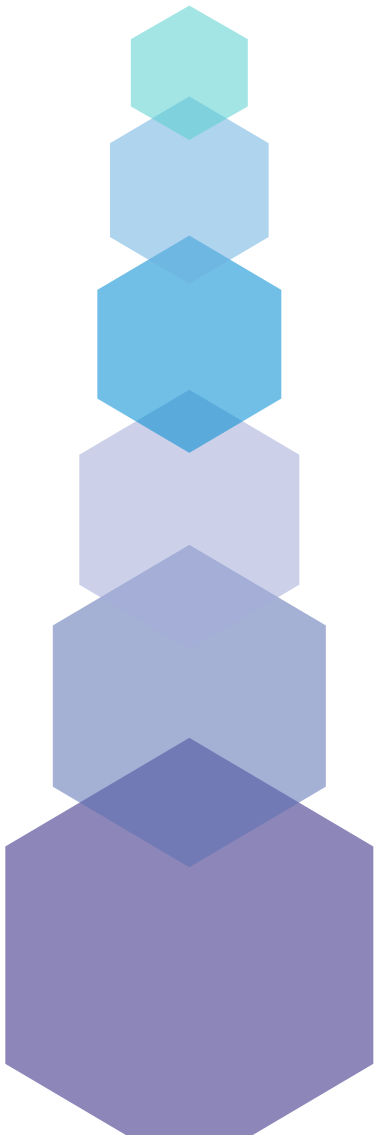
Barriers to remove

The limitation in the exercise of decision-making due to disability implies limiting the right of persons with disabilities to autonomy and self-determination, which prevents them from fully exercising their right to build their own life project, independently, controlling, facing, making and executing their own decisions in the public and private spheres.

Laws that authorize interdiction, conservatorship, forced institutionalization, and involuntary treatment in mental health services and of any kind; as well as any other regime of substitution of the will of the person constitute legal barriers that must be removed. Without directly facing the existence of these barriers and the obligation to remove them, autonomy and self-determination of the person cannot be achieved, within the framework of the CRPD. As the CRPD Committee observes in its General Comment # 1 (OG1), paragraph 7: “Historically, persons with disabilities have been deprived in many areas, in a discriminatory manner, of their right to legal capacity, due to regimes based on substitution in decision-making, such as guardianship, conservatorship and mental health laws that allow for forced treatment. These practices must be abolished, so that persons with disabilities regain full legal capacity on equal terms with others.¹⁵⁰ “

The prejudices or stereotypes that promote the idea that persons with disabilities - and in particular people with intellectual, psychosocial and hearing disabilities, as well as deaf-blind people, among others - do not have the capacity to act on the process of taking of decisions, to express their decisions “clearly”, or to measure the consequences of it. On the basis of this stigma, legal professionals and other actors justify the application of the objective superior interest standard, which is nothing more than the way to impose the will of a third party, over the will, desires and preferences of the person with disability.

150 Available here: https://conf-dts1.unog.ch/1%20SPA/Tradutek/Derechos_hum_Base/CRPD/00_Observaciones%20generales%20CRPD.htm#GC7



The application of the objective standard of “best interests” in the case of persons with disabilities who do not communicate their decisions in traditional ways (neuro diverse people, with psychosocial disabilities, people with cerebral palsy, deaf people, for instance); since it makes their preference and will invisible, considering that they cannot be determined “clearly”, and that they lack self-determination and autonomy

Practical guidance

To reaffirm as a State the obligation to guarantee the recognition and respect of the legal capacity of persons with disabilities on the basis of equality with others, including their exercise of said capacity and their decision-making in any area of life, be it formal and informal.

To do this, all legal bodies shall be reviewed, modified or cancelled, when appropriate, as well new legislation should be created, which clearly and expressly recognizes the right of all persons with disabilities to exercise their legal capacity under equal conditions. with the others and without restrictions due to disability. This implies reviewing the entire national legal body, from its Constitutions to the notarial and administrative rules and regulations, both civil and criminal codes, procedural norms and practices, to eliminate all laws and all practices that restrict the legal capacity of a person. .

In accordance with the above, it is recommended to revoke and annul the interdictions and conservatorships that have been declared up to this moment for persons with disabilities, annul also those that are in process, and those that are pending, and develop a system of supported decision-making based on in human rights; supports that can be formal and informal, circumstantial, always chosen, made up of people, networks, services or mechanisms; as well as to legislate safeguards that guarantee that this system of supported decision-making is always based on the principles of human rights and always subject to the choice and consent of the person with disability.

It is important to recognize the role of accessibility and reasonable accommodation in the exercise of legal capacity, including the need to be expressly recognized in the legislation. The State must guarantee both cross-sectional accessibility and the reasonable accommodations required to exercise autonomy in decision-making, such as: sign language interpretation services in all areas, the use of accessible and affordable assistive technologies for all persons with disabilities, and all those other reasonable accommodations, languages and communication methods specified in article 2 of the Convention on the Rights of Persons with Disabilities. Reasonable accommodation may also include informal and community-based support mechanisms, chosen by the person with disability.

When people are chosen to serve as supported decision-making it is essential that they are trained and prepared for the role they must play, the implications, ethics, and the obligation of full respect for the will and preferences of persons with disabilities. The role of the support person is to accompany a decision-making process by the person not to influence the result of said process.

Technologies can also be support mechanisms to express decisions, opinions, preferences and will, which allow people with sensory disabilities, neurodiverse, or all those who for some reason do not express themselves in oral language, to function with the greatest possible autonomy and make their decisions independently. There must be rules that safeguard the right of persons with disabilities to use these assistive technologies in all public and private spaces and services, formal and informal, where they require it, in order to facilitate their access to information and autonomous realization of procedures, exercising its legal capacity.

In relation to accessible communication mechanisms to express the will, it is also important to consider strategies to reaffirm what is understood, always returning to the person with disability to consult them and find out if the assumption about what was expressed through alternative means is correct or not. This should be incorporated into a standard for the conceptualization and operation of accessible communication mechanisms.

Establish the necessary support mechanisms to ensure respect for the wishes, preferences and will of persons with disabilities and the contextual and situational conditions that surround and affect them. The support developed must be adapted to the needs of persons with disabilities. It is not a universal standard that support decision-making and/or the performance of legal acts is different from an independent living support. As the Special Rapporteur observes on the Rights of Persons with Disabilities in her report on legal capacity, there are, for example, mutual support groups for persons with psychosocial disabilities that serve both functions¹⁵¹.

151 United Nations: Report of the Special Rapporteur on the Rights of Persons with Disabilities, A / hrc / 34/58, paragraph 64, p. 17. See: <https://undocs.org/es/A/HRC/34/58/>

The support arrangements or support mechanisms available are entirely voluntary: the person with disability may or may not require them if they so wish. The decision to require and use support, both formal and informal, for both decision-making and independent living, is voluntary. Decisions made by persons with disabilities in all aspects of life, including their expression of will in relation to particular legal acts, must be fully respected and that respect must be legalized and lawfully guaranteed, with or without a support system.¹⁵²

It is necessary to regulate and specify, in accordance with the principles of the CRPD, the obligations of public notaries to ensure respect for the expression of will of persons with disabilities in basic equality with other people. This, as part of the universal design of practices for the recognition of the legal capacity of all people, which are inclusive of people with any type of disability. In this sense, a good practice to consider and replicate is the Rosalía Mejía Notarial Guide, which serves as a starting point to develop these obligations.¹⁵³

To develop a support system, it is necessary to consider the opinion from the people who experience the diverse ranges of disabling situations and from their intersectional identities. The determination of the nature of support rests with the person requesting it. In the legal reforms of Peru and Colombia in Legal Capacity, the arrangement of formal support is established mainly on the initiative of the person with disability. Both the design of the support mechanisms and the choice of support persons always belongs to the person with disability.¹⁵⁴

Define the supports in a personalized way, even if common procedures exist. Support mechanisms cannot be standardized.

If the person with disability wants to receive advice on their support needs, this advice should be interactive, a process of discussing and considering their needs and the options that can be developed and put into practice. Recommendations are submitted for the person's consideration for their comments, with explanations in plain language until they are made sure they are understood, subject to their modification or denial.

The support, as well as the safeguards to guarantee the exercise of decision-making, must be defined considering the economic, educational, social, family and cultural contexts, among others, of the person who owns rights. Each of these contexts requires different approaches for granting support and safeguards. This becomes particularly important also in the case of people who face multiple challenges, or multiple disabling situations, and who embody different intersectional oppressions.

To form an interdisciplinary support team for legal professionals, created for this purpose within the judicial body, which is guided by a procedural regulation based on human rights, not on diagnoses, and that a. Help determine the reasonable accommodations that are required within a support system, so that the person requesting support receives them effectively. b. Support legal professionals in determining the criteria for each type of support and the time of support, which are not based on, or require as a prerequisite, a medical or psychiatric diagnosis. c. Support legal professionals in determining the necessary procedural adjustments, including communication support, for the full participation of persons with disabilities in the judicial system, as well as in the identification of the preferences and the will of the person with respect to the support. The determination of support must always start from the will and preferences of the person

Perform integrated procedures, such as family history and sociocultural context, including the future plan that the person has defined, to determine the preference and will of people who face communication barriers at any given time, which complements the role and functions of the technologies, communication facilitators, assistants or sign language interpreters.

Ensure that persons with disabilities have support that they consider to be mechanisms for access to complete information, so that they are able to formulate their decisions in a free and informed manner. All information must be produced in accessible and alternative formats, for all types of disabling situations. The decisions of persons with disabilities must always be respected, including the possibility of taking risks; on equal terms with others.

152 As noted in GL1 of the CRPD, paragraph 19: "Some persons with disabilities only seek to have their right to legal capacity recognized on an equal basis with others, in accordance with the provisions of Article 12, paragraph 2, of the Convention, and may not wish to exercise their right to receive the support provided for in article 12 paragraph 3. " Watch: <http://www.convenciondiscapacidad.es/wp-content/uploads/2019/01/Observaci%C3%B3n-1-Art%C3%ADculo-12-Capacidad-jur%C3%ADdica.pdf>

153 See: Mejía, Rosalía: The Implementation of the Convention of Persons with Disabilities in the Notarial Function. Notaries Association of Lima, Peru, 2019. Available here: http://www.onpi.org.ar/documentos/publicaciones/publicaciones-del-notariado-internacional/la_implementacion_de_la_convencion_de_las_personas_con_discapacidad_en_la_funcion_notarial.pdf

154 See Legislative Decree 1384, Peru: <https://busquedas.elperuano.pe/normaslegales/decreto-legislativo-que-reconoce-y-regula-la-capacidad-jurid-decreto-legislativo-n-1384-1687393-2/>

Establish teams of facilitators for the articulation of plans for supported decision-making of people with psychosocial and intellectual disabilities and with multiple challenges (such as deaf-blind people, among others), in conjunction with and according to the requirement of the right holders themselves, and in accordance with their preferences, so that they progressively achieve their full autonomy. For this, it is advisable to include, in national regulations, the figure of assistants to support decision-making. To these people, the State should offer continuous training in the social model and the human rights approach to persons with disabilities, as well as in supported decision-making models. This, without detriment to the fact that the final decision on the selection of people or support mechanisms rests with the person with disability who owns the rights. It is also important that the State and national legislation promote and recognize arrangements or mechanisms for supported decision-making based on the community, networks, or peer support.¹⁵⁵

It is important to note that the Decision-Making Assistant may or may not also be the same person or group of people that assists a person with disability in their daily life activities. It is also important to be clear that the assistance involves different roles from those assumed up to now by the guardians and conservators, because the person with disability is no longer replaced nor the decision is made for them. It is the person with disability who chooses to have or not have the support and the type of support that corresponds, and the time in which they are exercised, as well as the same safeguards that protect against undue interest. See the definitions section.

The person, group of people or entity, designated as support can take the following actions among others: a) Facilitate the communication of the decision of the person who has support; b) Facilitate the understanding of acts that produce legal effects and their consequences; c) Guide the person who has support, in making decisions and carrying out acts that produce legal effects; d) Facilitate the expression of the will of the person who has support. The person who owns the rights is the one who decides what functions to designate your support people. Correspondingly, support counseling can recommend the functions that are evaluated as required, for the approval and acceptance of the person who owns the rights. In the case in which the support is resolved by a judge, the functions are decided according to the best interpretation of the will and the preferences of the person with disability regarding the options recommended by the interdisciplinary counseling and consultation teams.

It can be designated as support to one or more natural persons, of legal age, with full exercise capacity. Supported decision-making can also be granted to one or more non-profit legal entities, whose mission is in accordance with the objectives and the functions that they will perform as support. In addition, there are informal supports (that is, they have not been formally designated), which may be available to persons with disabilities, even in situations of psychosocial crisis, to support them in decision-making in the immediate and longer term, as well as in the daily practical tasks and the daily accompaniment, always respecting the will and preferences of the person holding the rights, and subject to their acceptance or rejection at any time. These supports can be provided by mutual support networks, by personal assistant(s), by alternative mental health services, by other types of chosen services; or even services within the mental health or other system, which may function based on the needs expressed by the person. In no case is a crisis situation equivalent to an impediment to expressing the will and personal preferences.¹⁵⁶ The principles of autonomy and self-determination always come first, and these services mentioned above, in addition to being the alternative of advanced directive, must be present and accessible to all persons with disabilities when they require them, according to their will and preferences.

In a situation in which a person, for various reasons, cannot at any time express his will through any means or way, and there is no advance directive, an exceptional judicial process must be initiated to determine the supports and safeguards to be applied, based on the best possible interpretation of the will and preferences of the person. The judge must explore the person's will and preferences, including consideration of their history and context, to determine what type of support the person wants and/or requires. In no case should these supports be seen as "mandatory".¹⁵⁷

When an undue influence or conflict of interest is reported on the part of the person who provides support the person with disability, a judicial safeguard may be applied, as an exception, that points to the prevention of abuse and protection against any type of exploitation or violence, according to the provisions of Article 12, 14, 15 and 17 of the Convention on the Rights of Persons with Disabilities, in terms of respect for the integrity of the person and their autonomy.

155 see A / HRC / 37/56, para. 28

156 See: United Nations, UN-CRPD Committee of Experts: General Comment 1, paragraph 18: "In at all times, even in crisis situations, individual autonomy and the ability of persons with disabilities to make decisions must be respected".

157 See on this topic: Minkovitz, Tina: Positive Policy to Replace Forced Psychiatry, Based on CRPD. Available here: https://www.academia.edu/39229717/Positive_policy_to_replace_forced_psychiatry_based_on_CRPD. Too: Discernment as Process, Not Precondition: https://www.academia.edu/39267688/Discernment_as_process_not_precondition.

As the CRPD Committee mentions in General Comment 1: “All people risk being subject to “undue influence”, yet this may be exacerbated for those who rely on the support of others to make decisions. Undue influence is characterized as occurring, where the quality of the interaction between the support person and the person being supported includes signs of fear, aggression, threat, deception or manipulation. Safeguards for the exercise of legal capacity must include protection against undue influence; however, the protection must respect the rights, will and preferences of the person, including the right to take risks and make mistakes”¹⁵⁸.

The duty to respect the right to take risks and to make mistakes refers to the substantive standard and to the application of safeguards as a mechanism linked to support. For example, in DL 1384 of the Republic of Peru, the safeguards, like the support, are designated by the person who requests them; the only safeguard required is the review within 5 years. This model respects the autonomy of the person who requires support and enables the access and use of support by anyone who wants it, without having to face the disincentive (or barrier) that constitutes the need to undergo constant monitoring that may constitute an invasive control of privacy by the judiciary. Access to support should not be conditioned to the acceptance of a monitoring system or safeguards that results in limitation of personal autonomy and the right to take risks and make mistakes¹⁵⁹.

The legal system must determine what are the measures and channels to complain or demand abuse de facto or de jure when applying support situations where there is undue influence. These norms, applicable to the general population of the country, can also be adapted to the specific situations of persons with disabilities (for example, in aspects related to accessibility and reasonable accommodation, as well as the training of legal professionals regarding their obligations towards persons with disabilities).¹⁶⁰ Persons with disabilities have the right to access under equal conditions to the mechanisms available to the general population, related to the exercise of legal capacity, and to the enjoyment of the right to protection against any abuse, within the framework of respect for autonomy. and private life.¹⁶¹

The measures and mechanisms used to protect against abuse (safeguards) must be required by the person holding the rights and can be accepted or rejected by him. The safeguards are designed together with the person with disability and in the same way that the arrangements or particular support plans are made, as an option according to the will and preferences of the person holding the right. If the person has a counselor, this person should recommend the relevant safeguards for the approval and acceptance of the person with disability. In the case of designation of support by a judge, when the person is absolutely unable to express their will at a certain moment, the best interpretation of the will of the person on the safeguards must be applied, as already indicated before. These measures can include, among others, the following: a) Accountability of the support system, through dynamic and operational processes that do not imply undue control, and that include procedural adjustments to make them accessible to persons with disabilities; b) Performing audits; c) Unannounced periodic supervision; d) Unannounced home visits; e) Conducting interviews with the person designated as support, with the person with disability and people who are close to the person with disability; f) Request information from public or private institutions, when the case warrants it or any other diligence.

Considering the advance directive, or power to decide, by public or private instrument according to the existing normative provisions in national legislations, in advance manifestations of will, with respect to the support that they want to receive, as well as determine if it requires future safeguards and from what type, in anticipation of requiring them for being in a crisis situation, or being at some point absolutely unable to interact with their environment and express their will or preference by any way, medium or appropriate format in order to facilitate the performance of acts that produce legal effects. It is important to note that an instrument for defining expressions of will in advance, and future support systems, must always be subject to the manifestation of will expressed by the person at the time it needs to be expressed. That is, if the person contravenes the instrument or changes his decision, at any time, the current manifestation of the will must be respected, and not the advance directive. This is a corollary of the obligation to respect the person’s decision ‘at all times, even in crisis situations’.

158 See: United Nations Committee on the Rights of Persons with Disabilities, 11th session March 31 to April 11, 2014: General Comment # 1 on Legal Capacity, paragraph 22, p. 6. Available at: <http://www.convenciondiscapacidad.es/wp-content/uploads/2019/01/Observaci%C3%B3n-1-Art%C3%ADculo-12-Capacidad-jur%C3%ADdica.pdf>

159 Cf. Legislative Decree # 1384 that Recognizes and Regulates the Legal Capacity of Persons with Disabilities. Republic of Peru, Official Gazette of the Bicentennial, September 3, 2018. Available here: <https://busquedas.elperuano.pe/normaslegales/decreto-legislativo-que-reconoce-y-regula-la-capacidad-jurid-decreto-legislativo-n-1384-1687393-2/>

160 See as an example of this the Guide for Notaries, by Rosalía Mejía, previously cited.

161 In this sense, the provisions of Article 19 of the CRPD, letter c, apply: The States Parties to this Convention recognize the right, on equal terms, of all persons with disabilities to live in the community, with options equal to those of the others, and will adopt effective and pertinent measures to facilitate the full enjoyment of this right by persons with disabilities and their full inclusion and participation in the community, ensuring in particular that: (...) c) Community facilities and services for the general population are available, under equal conditions, to persons with disabilities and take their needs into account. See: United Nations: Convention on the Rights of Persons with Disabilities, pp. 15-16. Available here: <https://www.un.org/esa/socdev/enable/documents/tccconvs.pdf>

There are three types of situations in which future instruments are relevant: 1) anticipation of a situation in which the person could be unable to express their will, due to being in a coma or similar; 2) anticipation of a psychosocial crisis; and 3) any other situation where it is important to plan ahead to guide your own actions and the actions of support people. Only in the first situation listed is it necessary to act on the basis of what is expressed in the instrument directly, applying the criteria of the best interpretation of the will, of which said instrument constitutes the most probative evidence. In a crisis situation, or any other situation that does not imply the absolute impossibility of expressing the current will of a person, the instrument should be used as a reference, a starting point, for acceptance or rejection by the person at the present time. It is always necessary to keep in mind that “the best interpretation” is only an interpretation, not a substitution of the current will of a person.

The advance directive instrument may include the designation of one or more natural persons or non-profit legal entities as support for decision-making. The public deed or private instrument that meets the same requirements for designation of future support may contain, among others: a) The request to raise the minute of designation of support and establishment of future safeguards to a public deed; b) Name and identity document of the person with disability who wants the support; c) Name and identity document and address of the natural person or where appropriate, or name and identification of the non-profit legal person designated as future support; d) The determination of the capacity and/or powers of the person designated as future support; e) Determining the duration of the exercise of future support functions; f) The determination of the circumstance in which the future support will assume the exercise of its functions, linked to the situation of disability, crisis or coma of the person who designates the support; g) The acceptance of the person who is designated as support; h) Proportional safeguards and according to the circumstances of the person requesting the support; indicating the minimum deadlines for the review of the support. The applicant can indicate in the public deed, natural persons, non-profit legal persons or public institutions in which the designation of support cannot fall. f) The determination of the circumstance in which the future support will assume the exercise of its functions, linked to the situation of disability, crisis or in a state of deep unconsciousness of the person who designates the support; g) The acceptance of the person who is designated as support; h) Proportional safeguards according to the circumstances of the person requesting support; indicating the minimum deadlines for the review of the support. The applicant can indicate in the public deed the natural persons, the non-profit legal persons or the public institutions in which the designation of support cannot fall.¹⁶²

Establish periodic monitoring and evaluation mechanisms of the support and safeguards plan, as well as the interdisciplinary teams that are constituted and formed for that purpose, which must be approved and agreed by the person who owns the rights.

Generate training programs on human rights and awareness for State authorities, judges, legal professionals, officials, educators and psychologists, among others, in matters of autonomy and the right to exercise the legal capacity of persons with disabilities.

Promote training in human rights and awareness among persons with disabilities themselves to exercise the leading role in the exercise of all their human rights, including their legal capacity. This training must include the right to exercise legal capacity, the right to have accessible communication and reasonable accommodations in said exercise; the right to designate and use supports according to their will and preferences at each stage of the decision-making process, from the design and approval of a support plan, the appointment of support persons, the actions of support persons, until the modification or termination of the support; and the right to complain and to resort to justice in the event of any abuse, undue influence or non-compliance by the support person(s).

Promote training in human rights, autonomy, the right to independent living, and the right to exercise legal capacity in family members, which must be subject to the training of persons with disabilities themselves, emphasizing the role that that family plays in the exercise of said autonomy.

Generate mechanisms that enable a public policy of informal support and establish the inclusion of any knowledge or information that acts as a facilitator of support for a person with disability in interdisciplinary teams.

Ensure universal accessibility in communications, including information and communication technologies, essential for the exercise of autonomy for persons with disabilities. This implies the duty of the people that are

¹⁶² Regulation that regulates the granting of reasonable accommodations, designation of support and implementation of safeguards for the exercise of the legal capacity of persons with disabilities, of Legislative Decree No. 1384, of the Republic of Peru

usually in a position to interact with persons with disabilities in their exercise of legal capacity due to their role, such as notaries, health professionals, legal professionals, bank operators, among others, to make available to persons with disabilities who require it. Accessible instruments and means of communication, as well as guaranteeing the necessary reasonable accommodation, including procedural adjustments in the case of legal proceedings. It is the duty of the State to train all these public and private actors to understand and exercise these obligations.

Establish monitoring mechanisms, at national and regional levels, of processes to support the exercise of autonomy in decision-making, at all levels and throughout the life of the person with a disability. Monitoring mechanisms should include persons with disabilities representing their national organizations, whose rights are directly affected. Organizations of persons with disabilities should actively participate in the monitoring process and not just through consultations. It is also important that the States designate resources for the operation of these monitoring mechanisms and procedures, as well as for the work of interdisciplinary teams, also constituted, among others, by the organizations of people with disabilities themselves. As part of these mechanisms, it is also recommended to carry out pilot projects and demonstration experiences on support systems for decision-making.

38. Have interdisciplinary technical teams, based in the community, to evaluate both the reasonable accommodations and the modalities and levels of support required by the person with disabilities in specific relation to the legal or informal act in which they need support to make decisions, in such way that it ensures the promotion of their autonomy and self-determination, always consulting the person with disability in the first instance, respecting their preferences and decisions. These teams must be previously trained in the social model of disability and human rights, and it should be considered that persons with disabilities and their organizations also participate in their constitution.



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INDEPENDENT LIVING

International Legal Framework of Reference

- International Convention on the Rights of Persons with Disabilities (CRPD). Articles 2, 3, 9, 12 and 19.
- Inter-American Convention for the Elimination of all Forms of Discrimination against Persons with Disabilities (CIADDIS). Article 3.
- 2030 Agenda. Sustainable Development Goals (SDGs) 1, 5 and 10.
- Program of Action of the Decade of the Americas for the Rights and Dignity of Persons with Disabilities, PAD (2016-2026), Objective 11, Concrete Actions numeral 10, a-c

Barriers to remove

Historically, persons with disabilities have been denied the ability to make choices and exercise personal and individual control in all spheres of their lives. Many of them are prevented from choosing where to live, who to live with, how to spend their money, manage wealth, have children, choose a partner and even how to dress or what to eat, just because of their bodily, intellectual, sensory or cultural diversity, psychosocial, among others.

Persons with disabilities face barriers to moving, communicating and participating in social life in conditions of autonomy and independence, due to the obstacles of an environment that does not conform to universal design and that does not provide community-based support. As the Committee of Experts of the CRPD argues in its General Comment #5: “Resources are invested in institutions and not in developing the possibilities that persons with disabilities have to live independently in the community. This has led to abandonment, dependence on family members, institutionalization, isolation and segregation”.¹⁶³

The presumption of incapacity of the person by the families, the educational system, the authorities and/or the community, which prevent even basic decisions as where and with whom to live, with whom to interact, what to eat, what to wear, etc., has impacts also on decisions of daily life that do not necessarily have legal consequences. Many times this presumption leads to interdiction (to a large extent requested by family members for economic reasons -social benefits-) and/or institutionalization, undermining the fundamental rights of persons with disabilities.

The governments' technical aid policies based on medical diagnoses, with a medical assistance vision; against the social paradigm of disability, which do not include or consider as technical aids personal assistance services and technologies for autonomy and independent living, nor assistance for community-based decision-making, regardless of the contexts economic, educational, social, family and cultural of the person with disabilities, towards independent living

Practical guidancer

The right to independent living involves guaranteeing the right to make decisions in all areas of daily life.

Define and establish assistance and support mechanisms in decision-making for independent living through the development of support plans based on the needs of persons with disabilities who require it and choose it. When such support plans are required, they must be chosen, formulated and approved by the person with disability.

Provide personal assistance services for independent living as a permanent public policy, the cost of which will be assumed by the State, trained in the social paradigm of disability and the human rights approach. The support will be available to the person with disability who decides to request it, and will be applied in the way and according to the extent that the person chooses.

163 United Nations, UN-CRPD Committee of Experts: General Comment # 5 on the Right to living independently and being included in the community, 2017. Available here: https://confdts1.unog.ch/1%20SPA/Tradutek/Derechos_hum_Base/CRPD/00_Observaciones%20generales%20CRPD.htm#GC5

Any support plan for decision-making, as well as personal assistance functions for independent living, are auxiliary to the self-determination of the person. Although in some cases the support acquires a legal figure, in most cases this is not necessary and informal systems can be generated, following the guidelines of both Article 12 and Article 19 of the CRPD, as indicated in the previous section.

At the intersection of these two articles of the CRPD, decision support is not necessarily related to particular legal acts. Support must be broadly conceptualized in terms of guaranteeing autonomy and not just access to formal mechanisms to implement legal acts. In the latter case, the judicial system must recognize the decision-making support systems, which have been chosen and accepted by the person holding the right, which may be natural or legal persons; peer support, self-advocacy (including self-advocacy support) or assistance in communicating. All supports, both formal and informal, both for decision-making and for carrying out activities of daily living when a person requires it, have their reason for being in promoting independent living.¹⁶⁴

Daily life decision support, which does not necessarily have to be formal, can be conceptualized as a type of personal assistance, and it should be provided in the same way as any other personal assistance. That is, a person can count on assistance to carry out household tasks and to decide on these tasks; and all support for independent living must be implemented taking into account the preferences, wishes and decisions of the rights holder herself/himself, such as in terms of deciding how, where, with whom to live and with what type of assistance; to decide on home care services for personal hygiene and/or for mobility or transportation; or to make decisions in each of these areas of daily life. There is not necessarily a correspondence between a type of disabling situation and the aspects of life in which a person may need support, both for decision-making and for exercising independent living. A wide range of needs must be taken into account to ensure the development and availability of various options, and the person must always be guaranteed the right to design their own support which should be suitable for their situation.

Not all persons with disabilities need support from other people to assess the support systems or mechanisms they require to make decisions. But yes, in all cases in which such an assessment is made, the person who owns the rights must be the one who chooses and has the last word, according to their wishes and preferences.

The support assistance in decision-making (natural or legal person) must be able to support the referred process in the areas of life in which it is required, according to plans drawn up from the assessment of the needs of the person holding rights, ensuring all the time that the person's own preference and decision is executed, even if whoever assists in the decision-making does not agree with that decision. It is important to train the support assistant in decision-making under the Social Model of disability and a human rights approach. All areas of life will be considered, according to the needs and decisions of the person with disability.

Children must have access from an early age to the opportunity and the right to make their own decisions regarding their daily life, and identity construction such as how to dress, what to eat, how to name themselves, how to organize their spaces, what to do in time free, among other things, according to their interests, preferences and opinions. The person's family must be configured as a guide and support but must always respect the opinions and preferences of girls and boys.

The decision support assistant must know the different forms of expression, communication and understanding that the holder of the rights has, whose decision is to be protected .

The person with disability has the right to choose their assistants, considering their preferences, priorities and opinions, the inherent dignity of the person and their freedom of expression.

Provide the person with disability with assistive and communication technology, with universal accessibility criteria, as part of the policy of technical aids and reasonable accommodation provided by the State, to guarantee the independent life of persons with disabilities and exercise full of its legal capacity. Any means of assisted technology, communication or technical assistance necessary for the exercise and expression of personal decisions, autonomy and independent living, including service animals that support a wide variety of tasks on how to alert about

164 See paragraph 17 (on the types of support that can be given), and paragraph 52 of General Comment # 1 on Article 12: Equal Recognition as a Person before the Law, of the United Nations Committee on the Rights of Persons with Disabilities: "States parties are encouraged to develop effective mechanisms to combat both formal and informal surrogate decision-making. To this end, the Committee urges the States parties to ensure that persons with disabilities have the opportunity to make real choices in their lives and to develop their personality, to support the exercise of their legal capacity. This includes, among other things, opportunities to create social networks; opportunities to work and earn a living on an equal basis with others; the possibility of choosing between different places of residence in the community; and inclusion in education at all levels".CRPD/C/GC/1, 2014. Available here: https://conf-dts1.unog.ch/1%20SPA/Tradutek/Derechos_hum_Base/CRPD/00_Observaciones%20generales%20CRPD.htm#GC1

risks, to seek help if needed, and to accompany the person emotionally. This must be covered and provided for by States in both the public and private spheres.

Under no circumstances, or for any reason, the forced or unwanted admission of a person with a disability in hospitals or treatment facilities shall be allowed, regardless of the duration of the referred hospitalization, or the argument of “urgency” or “emergency” to execute it, since in all its forms, such a measure is contrary to the principles of the right to integrity, to independent and community life, is ensured by articles 14, 17 and 19 of the CRPD. Furthermore, such proceeding constitutes an arbitrary act of discrimination and, therefore, violation of rights.¹⁶⁵



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ACCESS TO JUSTICE

International Legal Framework of Reference

- International Convention on the Rights of Persons with Disabilities (CRPD). Articles 2, 9, 13, 14.2, 15, 16 and 17.
- Inter-American Convention for the Elimination of all Forms of Discrimination against Persons with Disabilities (CIADDIS). Article 3.
- 2030 Agenda. Sustainable Development Goals (SDGs) 1, 4, 5, 10, 16 and 17.
- Brasilia Rules on Access to Justice for People in a Condition of Vulnerability. Chapters 2, 3 and 4.
- Program of Action of the Decade of the Americas for the Rights and Dignity of Persons with Disabilities, PAD (2016-2026), Objective 12, Concrete Actions numeral 11, a-d

Barriers to remove

Restriction and lack of accessibility in the effective and direct participation of persons with disabilities, during administrative and judicial processes.

Barriers within the normative framework at the national level, which prevent access to justice for persons with disabilities in the event of violations of their human rights; including laws on access to the economy, heritage, and mental health that authorize practices that constitute arbitrary detention and cruel and degrading treatment, torture, and that confer impunity on the perpetrators of these violations. It is necessary to remove these barriers through legislative harmonization with international human rights obligations, which implies, among others, the repeal of forced interments and treatment.

Lack of universal accessibility in the media and information technologies for the effective participation of persons with disabilities during judicial or administrative processes.

Ignorance of legal professionals about accessible communication measures for persons with disabilities.

Lack of access to a universal support system.

Prevalence of interdiction and conservatorship, as well as the lack of regulatory measures for access to a system of universal exercise of legal capacity and support.

Redaction and notification of court decisions in formats that are neither accessible nor suitable for persons with disabilities.

General barriers of access to justice, which particularly affect people in different situations of disability. In relation to legal capacity, the following should be considered, for example:

1. Persons with disabilities who are under interdiction do not have the legal capacity to report or sue.
2. Persons with disabilities are not considered viable as witnesses in a process, at the judicial or administrative level, that is of act or of knowledge. Their testimony is relativized because of their disability and their testimony is sometimes even prohibited.
3. Access barriers in legal proceedings, which affect the equal participation of persons with disabilities. The declaration of non-imputability, which is often a source of violation of basic human rights.
4. The interdiction remains a great barrier. In some countries, the process to adjudicate the interdiction cancels from the beginning the possibility of defending the person with disability, their ability to make decisions in the process and to access the support they need, since, many times, it is still under interdiction. before the resolution is approved; appointing a representative even before the end of the process.
5. The declaration of the interdiction of a person with disability by trade, in many cases, without interaction of the judge with the person to assess their ability to make their own decisions.
6. Restrictions of access by persons with disabilities to be informed about the regulations, lacking effective support for information; either due to the linguistic, cultural and educational gap or the lack of accessibility in the information and communication systems.
7. Exclusion and indifference in the participation of women with disabilities in judicial processes and in cases of domestic and/or sexual violence, increasing the intersection of violation and structural discrimination. This intersectional discrimination is increased in the case of persons with disabilities from indigenous peoples, Afro-descendants or in migration situations, among others (multiple and intersectional discrimination that it is necessary to consider).
8. The use of methodologies such as the Gesell camera¹⁶⁶ without prepared and trained personnel in the social model of human rights of persons with disabilities, as well as the lack of accessible information and communication systems applicable with this method, do not guarantee the real and effective testimony of the person with disabilities, mainly in cases of sexual violence against women and girls with intellectual or psychosocial disabilities.
9. Interviewers without preparation and training in the social model of the human rights of persons with disabilities, as well as the lack of accessible formats for communication and information with which the testimonies of persons with disabilities are collected, mainly intellectual, psychosocial and sensory.
10. The lack of accessible formats for notifications, which does not allow that persons with disabilities are informed.
11. The lack of preparation and training in the social and human rights model of persons with disabilities, and the lack of periodic evaluation of interdisciplinary teams within the judicial system, as well as the lack of accessible information and communication systems to attend and promote personal autonomy and the manifestation of testimony, will and decisions of persons with disabilities.

166 It is a laboratory for experimentation and observation of human behavior that consists of two spaces, divided by a large unidirectional mirror, which allows us to see what happens in the other from one space, but not the other way around. It was designed by the American psychologist and pediatrician Arnold Gesell. Endowed with technology, it has audio and video equipment for recording. It is an instrument that allows the evaluation of one or more patients at the level of behavior, thoughts and emotions from a biological, psychological and social perspective, without the presence of the observer influencing the behavior of the observed.

Establish and regulate procedural adjustments for access to justice for Persons with Disabilities, in the terms set forth in Article 13 of the CRPD: “age-appropriate accommodations, in order to facilitate their effective role as direct and indirect participants, including as witnesses, in all legal proceedings, including at investigative and other preliminary stages.”¹⁶⁷ Access to justice requires enabling rights, which include the recognition of the right to exercise legal capacity and also accessibility as a cross-cutting principle in all areas and processes. However, procedural accommodations should not be confused with accessibility only, nor with reasonable accommodations, as the former are not subject to the same burden of “reasonableness”. In addition to accessibility, it is important to consider the review of legal figures such as non-imputability, the recognition of the right to legal defense in basic equality with others, the presumption of innocence, the recognition of full procedural capacity, access to effective remedies. Procedural adjustments serve to enforce the right to a fair trial, under equal conditions, and the right to participate in the administration of justice, for which they are an intrinsic element of the right of access to justice, and are directly linked with civil and political rights and with the principle of non-discrimination.¹⁶⁸

Some concrete examples of procedural adjustments are: the participation of support persons or facilitators (one of the most innovative and necessary procedural adjustments), which encompasses all means of communication and information, available voluntarily chosen and duly accredited by the law holder, who meet the person with disability and their interests, not the court; legal and judicial information in accessible formats such as easy-to-read or Braille versions of documents and video statements; that sign language interpreters or other assistants freely chosen and authorized by persons with disabilities participate in the deliberations as support personnel or facilitators; the extension or readjustment of deadlines, the entire chain of justice: police, public prosecutors, judges, notaries, jurists, among others.

Establish mechanisms to have legal figures of assistants for decision-making, natural or legal persons (with the name that corresponds to the country’s legislation) trained to provide the support that the person needs or requires for decision-making and exercise of its legal capacity, when the person requires it, freely chosen and accepted by the person assisting in her/his decision-making, as we have indicated in previous sections. The support mechanisms in decision-making must be based on the technical defense of the people according to their preference and the judiciary must provide access to justice through the guarantee and recognition of this support. These figures are different from reasonable accommodation, including personal assistance adjustment, facilitation or support for communication, among others, when required (as professional sign language interpreters and other necessary communication techniques, such as visual communication and gestural, tactile, simple language, augmentative or alternative language, among others. Ref. Article 2 CDPD).

Guarantee the use, and make available to the person with disabilities, specialized technology and technology with universal accessibility, when and as the person requires during the judicial or administrative process.

Guarantee professional interpretation services in sign languages, interpreter guide and easy-to-read formats, through professionals trained in the area, who act independently and impartially. The support for communication must be oriented to the defense of the interests of the person who owns the rights, and to the claim for their full exercise of rights. The judiciary has the obligation to make this support available and to recognize the support chosen by the person herself/himself for equal opportunities in access to justice.

Train the entire staff of legal professionals, as well as the people or entities that operate as support in the decision-making processes, in relation to the social and human rights model of persons with disabilities, so that they effectively exercise their function, respect their integrity and dignity, and thus guarantee full access to justice, from the beginning to the end, ensuring at all times that the preferences and will of the person with disability is executed, even if they do not agree with the referred decision. These training must be given by professionals with proven knowledge in the matter, including experts with disabilities.

Within the training of legal professionals, it should be included to show the importance of always addressing the person with disability directly, even if he or she is accompanied by a support person. The support person

¹⁶⁷ United Nations: International Convention for the Rights of Persons with Disabilities, article 13, paragraph 1, p. 12, available at: <https://www.un.org/esa/socdev/enable/documents/tccconvs.pdf>.

¹⁶⁸ For more information on this point, see: Office of the United Nations High Commissioner for Human Rights: Right of access to justice under article 13 of the Convention on the Rights of Persons with Disabilities. A / HRC / 37/25, 2017, p. 6.

only provides punctual assistance, but does not impersonate the person with disability. Therefore, all questions, information or announcements must be communicated / or asked directly to the person with disability.

The person or entity that supports the decision-making process must have a deep knowledge of the different forms of communication and understanding of the extent and effects of the process that the rights holder has.

The person entitled to the right must always be the one who chooses those who support the decision-making process when required, considering first the principle of autonomy and dignity of the person with disability.

Ensure that interpretation services meet the worldview of the people or community to which the person belongs, when appropriate, including the deaf community.

Guarantee the procedural principles of intermediation, amplitude for evidence, communication and participation in all processes in which the person is a party, with the support required for that purpose, prior to hearings with counselors and legal professionals, in order to ensure full information and the communication of the person in the process.

Establish procedural guarantees for persons with disabilities who are deprived of their liberty in the penitentiary system. Guarantee the support (communicational and/or with assistants for daily life and for decision-making) that ensure their access to the services of the penitentiary system during the process (awaiting for sentence) or with a firm conviction.

It is necessary to review the national regulatory framework regarding protection against economic and sexual abuse, in the areas of justice and health; and ensure that these norms are inclusive on the situations and barriers faced by persons with disabilities.

The video and audio recording of hearings, debates, testimonies, etc., in order to guarantee the right to due process and to monitor/review the performance of support, interpretation and other services.

Evaluation-Assessment to determine support: a valid evaluation must take into account cultural and linguistic diversity, as well as differences in communication and in sensory, motor and behavioral aspects. That is, in order for the assessment to make sense, it must consider the diversity and uniqueness of the person who has to respond. Culture and ethnic origin (including home language), non-verbal communication, and customs that may influence evaluation results must be taken into account for the evaluation to be valid. Furthermore, any evaluation must conform to the will of the person, and cannot proceed against her/him. The person with disabilities knows their needs better than anyone. Therefore, an assessment for the purpose of offering support is subsidiary to the request of the person and their acceptance, modification or denial of the options offered.

Train all staff providing the different types of support, as well as sign language interpreters, in disability paradigms, accessible communication systems and the corresponding codes of ethics and conduct, to eliminate prejudices throughout the process of access to justice.

Writing of resolutions, sentences and notifications in accessible communication systems, according to the communicational characteristics of the person to whom they are addressed, in order to guarantee communication and access to due process, effectively.

Allowing that, in addition to any of these measures, the person with disability who so wishes, can have the support of a personal assistant, or an assistant for communication, or for decision-making, chosen by the person.

A communication barrier can never be considered a valid reason to deny access to justice.

The establishment of support systems for the access to justice is implemented if required by the person, to allow the direct participation of persons with disabilities in judicial or administrative processes, not to prevent, restrict or replace them.

Creation of interdisciplinary teams trained to assess all situations faced by a person with disability throughout a judicial or administrative process, away from prejudice and stigmatization, in order to propose concrete ways to eliminate barriers within the judicial system. As stated above, it is the person with disability herself/himself who best knows the support they need, in such a way that any assessment of support must be requested, proposed, reviewed and approved by the person herself/himself at all levels of the System. In the same way, the construction of a support plan for decision-making must start from what is proposed by the person who owns the rights, if the person so chooses. These plans are personalized, not standardized.

As long as national legal systems are adapted in accordance with International Human Rights Law, conventionality control must be applied to guarantee access to justice without further delay.

Validate decision-making mechanisms, which are respected. Establish records of advance decisions that guarantee the obligation to know if there was an advance decision by the person in any given process, as has been stated above in this document, the instruments to define manifestations of will in advance, and future support, must be subsidiary to the manifestation of will expressed by the person at the time it should be carried out, in a given process. If the will of the person at that time and given process contravenes the instrument or changes its decision, the current manifestation of the will must be respected and not the previous manifestation. This is a corollary of the obligation to respect the person's decision at all times.

The use of the Gesell camera, and/or filming of hearings or debates, must be carried out with suitable and trained personnel in the social model of disability and on the rights of persons with disabilities. Likewise, they may be used to assess, review and evaluate the performance of supported decision-making, communication intermediaries and sign language interpreters, as well as other professional intermediaries in the testimony of the person with disability.



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SEXUAL AND REPRODUCTIVE RIGHTS

International Legal Framework of Reference

- International Convention on the Rights of Persons with Disabilities (CRPD). Articles 6, 23.1 b and 23.1 c.
- Inter-American Convention for the Elimination of all Forms of Discrimination against Persons with Disabilities (CIADDIS). Article 3.
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- United Nations, Report of the Special Rapporteur for the Rights of Persons with Disabilities: The sexual and reproductive health and rights of girls and young women with disabilities. A / 72/133, July 14, 2017.

Barriers to remove

Stereotypes and prejudices that greatly contribute to limiting equitable access to health and the exercise of sexual and reproductive rights for girls and young women with disabilities. “The sexuality of persons with disabilities is usually considered a taboo topic. Relatives, teachers and health-care providers are generally anxious, untrained, and unconfident about discussing sexuality with them. Moreover, there is a prevalent assumption that persons with disabilities, particularly girls and young women with disabilities, are either asexual or hypersexual.”¹⁶⁹

Structural discrimination of women with disabilities, grounded on stereotypes based on gender and disability, particularly in the area of sexual and reproductive health and rights, which can have a profound negative effect throughout their life cycle and lead to their disempowerment and infantilization. Stigmatization is even higher in cases of women with multiple challenges, deaf, deafblind, with intellectual and psychosocial disabilities, especially if their diversity is congenital. They are more prone to the violation of rights, mostly because of prejudice, myths and stigma, they are deprived of the full exercise of their autonomy and privacy and are repressed the right to affirm and express their gender identities and sexual desires, whether intentional or not. Consequently, many girls and young women with disabilities lack the basic knowledge and support required to protect themselves from sexual abuse, unwanted pregnancy and sexually transmitted infections, forced sterilization and are not equipped to make informed decisions about their own bodies, health and lives.

Dominant patriarchal assumptions of a woman’s role as primarily that of a wife and mother. As it is considered, due to prejudice and stigma, that girls and young women with disabilities are unlikely to exercise these roles — or that they do not have the capacity to do so —, they are denied their sexual and reproductive rights, while they, out of resistance, desire more strongly reproduce social gender roles, which contributes to deepening inequalities. This is also compounded by the canonical prototypes of female beauty, which exclude women and girls with disabilities.¹⁷⁰

Girls and women with disabilities belonging to groups that have been historically discriminated, such as indigenous peoples, religious and ethnic minorities, poor or rural populations, migrants and refugees, and the LGT-BIQ community, experience forms of multiple and intersectional discrimination in their sexual and reproductive rights, including early marriage, sexual violence and unwanted pregnancy, and in all these cases, the denial of appropriate health care services.¹⁷¹

Obstacles to access information on services related to sexual and reproductive rights, and sexual education in general. There are great barriers to access to the regular education system, which also does not make sex

169 United Nations, Report of the Special Rapporteur on the Rights of Persons with Disabilities: Health and sexual and reproductive rights of girls and young women with disabilities. A / 72/133, July 14, 2017, p. 8

170 Ibid, p. 9

171 Ibid.

education accessible to persons with disabilities. There are also linguistic and communication barriers to access information on the subject through traditional channels, which leaves women and girls with disabilities and persons with disabilities in general more vulnerable.

Harmful and forced practices with respect to persons with disabilities - and in particular, at the intersection of gender and disability: women, girls, people from the LGBTBIQ community - for reasons of their disability, gender identity or expression, sexual orientation/preference, age, religion, pregnancy, marital status, among others. “The forced sterilization of girls and young women with disabilities represents a widespread human rights violation across the globe.”¹⁷², up to three times higher than in the case of women and girls without disabilities. The reasons for this violation of rights are, among others, eugenic, menstrual hygiene or prevention of pregnancy. While the United Nations has recognized that forced sterilization of persons with disabilities constitutes discrimination and a form of violence, torture and other cruel and degrading treatment, it remains a legalized practice around the world on the basis of disability. Other harmful practices include forced contraception, forced abortion, hormonal and surgical treatments to inhibit the growth of girls and young women with disabilities. Health professionals, family members and institutions give priority to the interests of those “in charge” of girls and women with disabilities, to the detriment and denial of the dignity and integrity of the person. “As the Committee on the Rights of the Child has emphasized, the interpretation of a child’s best interests cannot be used to justify practices that conflict with the child’s human dignity and right to physical integrity.”¹⁷³

Obstetric violence experienced to a greater extent by women and girls with disabilities due to the stigma of health personnel who do not consider it viable for women with disabilities to exercise their sexual and reproductive rights.

Lack of family and social recognition of the sexual and reproductive rights of persons with disabilities, and in particular girls and women with disabilities.

Lack of accessibility and support to exercise sexual and reproductive rights (information in accessible formats, medical equipment, intermediaries for communication and for the exercise of decision-making, etc.).

Practical guidance

Eliminate attitudinal, cultural, physical, legal, linguistic and communication barriers that are imposed on persons with disabilities, and that interfere with the exercise of their rights, particularly sexual and reproductive rights.

Review the legal and public policy frameworks, in order to adopt concrete measures in the areas of education and information, access to justice, accessibility, non-discrimination and the participation of women and girls with disabilities and persons with disabilities. disability in general in the exercise of their sexual and reproductive rights, assigning specific budgets for the implementation of these measures.

The laws and general regulations in force that limit the free access of girls and women with disabilities to sexual and reproductive health services should be reviewed and modified, in particular those that require conjugal or parental consent or establish a minimum age in order to promote equitable universal access to sexual and reproductive health information and services. The restrictive definitions of sexual violence, including those of sexual assault and rape, should be revised to take into account all forms of violence faced by girls and women with disabilities and by persons with disabilities in general.

The laws that legitimize and naturalize forced sterilization, the forced application of contraceptive and hormonal treatments, forced abortions and other surgical or medical procedures without the free and informed consent of the person with disability, or by authorization and decision of third parties, must be repealed.

States must establish protocols to guarantee full access to sexual and reproductive health services by persons with disabilities, and especially women and girls with disabilities, including the provision of reasonable accommodation and for supported decision-making and mediation for communication, among others.

Include persons with disabilities in national and local strategies for the prevention and promotion of sexual and

172 Ibid, pp. 12-13.

173 Ibid, p. 14.

reproductive rights and prevention of sexually transmitted diseases, ensuring their right to receive accessible information on the different contraceptive methods, free access to the method chosen and to sexual and reproductive health care.

Guarantee that persons with disabilities have access to complete, timely, accessible and culturally relevant information, so that they can decide on their sexual and reproductive rights, on equal terms with others and respecting their right to privacy.

Guarantee the universal accessibility of all services and all information related to sexual and reproductive rights. All public or private services and facilities open to the public or for public use, including gynecological and obstetric services, must take into account all aspects of their accessibility for women and persons with disabilities, including the accessibility of infrastructure, equipment, information, communication, and transportation. Otherwise, persons with disabilities will continue to be unable to exercise their sexual and reproductive health rights.

All information and communication regarding sexual and reproductive rights must be available in sign language, Braille, accessible electronic formats, alternative writing, easy-to-read formats, and augmentative and alternative modes, media and formats of communication.

Provide girls, women and persons with disabilities with comprehensive and non-discriminatory sexual education, both in school and outside of it.

Instruct health and educational personnel, community workers, and other public officials about the sexual and reproductive rights of girls, women, and persons with disabilities. All people who work within the primary health services on the issue of sexual and reproductive health, especially in rural and remote areas, must receive training to address the issue with persons with disabilities.

Sterilization of persons with disabilities can only be exercised at the request of the person with disability herself/himself, of legal age, guaranteeing that they have been given full information beforehand in accessible formats about the conditions and implications of it, under the same conditions as other people. This practice should be prohibited against the decisions of the person who owns the right or authorized by a third person.

Interventions to place intrauterine devices, or to give contraceptive or hormonal treatments, transdermal implants, tubal ligations or vasectomies, can only be implemented with the request and free and informed consent of the person with disability.

Guarantee the full consent and the right of persons with disabilities to freely and responsibly decide the number of children they wish to have; as well as ensuring their access to an accessible prenatal control program and the right to receive the necessary information to choose the type of delivery they want, as well as the support that mothers with disabilities require to exercise their motherhood with autonomy, under equal conditions with the others.

Review gender stereotypes and health-disease models that are applied to women with disabilities and in particular pregnant women with disabilities, in order to make visible the structural inequalities that affect them, and their influence on mental health. It is necessary to modify discriminatory practices in their care and in the exercise of their sexual and reproductive rights.

Guarantee the inclusion of children and adolescents with disabilities in sexual and reproductive health programs, including HIV/AIDS programs; as well as education on sexual and reproductive health. Ensure access of adolescents with disabilities to pregnancy prevention and human care programs.

Guarantee access to information and education on reproduction and family planning, in accessible formats respecting cultural matters.

Include in the corresponding regulatory frameworks, the sexual and reproductive rights of persons with disabilities, indicating their right to enjoy sexuality, to decide on their body autonomously, preserve their fertility, the right to exercise parental control, as well as to stay together with their children and take charge of their

upbringing, considering support services provided by the State for the autonomous exercise of these tasks.

Promote the implementation of the figure of the sexual assistant, which has been contemplated in the regulation of the Swiss health system.

Provide clear information in accessible formats, considering cultural relevance, as well as access and dignified, timely and equal health care on the early diagnosis / prevention and treatment of genital cancer or in the mammary glands, prostate or any other.

Ensure that women with disabilities are not victims of obstetric violence during childbirth, ensuring that they have the support they may require for decision-making and communication at all times of this process.

Ensure effective access to justice for girls and young women with disabilities who are victims of sexual, obstetric, forced sterilization and other forms of violence. Mechanisms for redress and reparation need to be instituted for girls and women with disabilities and persons with disabilities in general who have been subjected to harmful practices, such as forced sterilization and forced abortion, particularly within residential institutions¹⁷⁴.

Prevent, investigate and prosecute all acts of violence, including sexual violence, and protect the rights and interests of victims.¹⁷⁵

Consult children with disabilities, including girls and adolescents, women, and persons with disabilities in general in relation to sexual and reproductive health and rights, in line with articles 4, paragraph 3, and 6 and 7 of the Convention on the Rights of Persons with Disabilities. Girls and women with disabilities, and persons with disabilities in general, with all their intersectional identities, from an early age, have the right to participate in the formulation of policies, therefore it is necessary to provide them with support for participation, consultation and opinion, appropriate to age and disability.

Collect adequate information, including statistical and research data, to formulate and implement inclusive programs and policies on sexual and reproductive rights and monitor and evaluate progress in promoting and protecting the rights of girls, women, and persons with disabilities in general, with an intersectional approach.

Include in national and annual budgets, including those from international cooperation, financial resources that allow generating public policies that guarantee that girls, women and persons with disabilities in general can fully exercise their sexual and reproductive rights and access services quality sexual and reproductive health, taking into account their specific needs for the enjoyment and exercise of these rights.

174 Cf. United Nations, CEDAW / C / JPN / CO / 7-8, paras. 24 and 25.

175 United Nations, Report of the Special Rapporteur on the Rights of Persons with Disabilities: Health and sexual and reproductive rights of girls and young women with disabilities. A / 72/133, July 14, 2017, p.21.



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RIGHT TO FOUND A FAMILY

International Legal Framework of Reference

- International Convention on the Rights of Persons with Disabilities (CRPD). Articles 13 and 23.
- Inter-American Convention for the Elimination of all Forms of Discrimination against Persons with Disabilities (CIADDIS). Article 3.
- Children's rights convention. Articles 8, 9 and 21

Barriers to remove

Lack of legal recognition of marriage of persons with disabilities and/or their right to be parents or adopters.

Lack of family and social recognition of the marriage of persons with disabilities and their right to motherhood and fatherhood and to be parents or adopters.

Society's indifference and discriminatory attitudes towards the exercise of the right to found a family owned by people with disabilities.

Lack of accessibility and support systems to exercise the right to found a family (information in accessible formats, personal assistants, medical equipment, accessible transportation, social security for mothers with disabilities, etc.).

Limitations regarding parental responsibility and/or the exercise of the right of fathers and mothers to parental authority.

Orientações práticas

Review and revoke the interdictions that have been declared up to now on persons with disabilities, suspend those that are in process, and develop a support system that is respectful of the social model of disability with a human rights approach.

Review the legal systems in a transversal manner in the institutions of family law, marriage, filiation, coexistence union, adoption, parental responsibility, without prejudice to revoking or having revoked the interdiction.

As it has been stated in other sections, establish support systems that ensure respect for the wishes, preferences and will of persons with disabilities and the contextual and situational conditions that surround and affect them. The support developed must be proposed from and adapted to the needs of the persons with disabilities who request them.

Define support systems considering the economic, educational, social, family and cultural contexts, among others, of the person holding rights. Each of these contexts supposes different approaches for the granting of support when the person requires them, and to determine the safeguards that ensure that these support work and that the right of the person and their decisions are protected.

Prepare formats with accessibility criteria that cover the removal of the different situations and existing barriers that refer to the requirements, rights and obligations of the legal act of marriage, parenting and adoption.

Set up a learning program and support systems for parents with disabilities and especially, for those who lack family ties, that is in a situation of social and economic vulnerability or poverty; guaranteeing their autonomy and independence, on parenthood activities, such as breastfeeding, child hygiene, medical and vaccination control, local transportation, etc.

Effective care of State bodies for the protection of girls, boys and adolescents, ex officio or at the request of families with a member with a disability, within the framework of public programs to address poverty, public health conferences, reviews in schools and services care and personal assistance.

The Support systems - both for independent living and for decision-making - developed for families that include children with disabilities are different from supports for adults with disabilities. In this case, depending on the level of support required, they must be provided directly to the person with disability to administer them in their exercise of legal capacity. The interdependence between members of a family must be taken into account, and the right of the adult to control their own assets and to decide on the services that are provided, such as choosing and hiring their assistants, must be taken into account.

Respect the right of girls, boys and adolescents to preserve their identity, including nationality, name and family relationships, in accordance with their best interests.

Promote the adoption of girls, boys and adolescents with disabilities, ensuring the enjoyment of the necessary support services with the adoptive family.



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PATRIMONIAL RIGHTS

International Legal Framework of Reference

- International Convention on the Rights of Persons with Disabilities (CRPD). Article 12.
- Inter-American Convention for the Elimination of all Forms of Discrimination against Persons with Disabilities (CIADDIS). Article 3.
- 2030 Agenda. Sustainable Development Goal (SDG) 10.

Barriers to remove

The limitation in the exercise of the rights of persons with disabilities in their autonomy and self-determination. Particularly, this limitation results in restrictions on their right to own property, inherit assets, control their own financial affairs, open bank accounts, have access to bank loans, mortgages and any other form of financial credit, including the use of credit cards, debit cards and the collection and handling of cash sums.

Existing prejudices or stereotypes that promote the idea that persons with disabilities, particularly people with intellectual, psychosocial, neurodivergent or autism spectrum disabilities and people with hearing disabilities, as well as deafblind people, among others, do not have the capacity to take part on the decision-making process or measure the scope or effects of patrimonial legal acts of administration or disposal of assets. For this reason, the application of the standard of “objective superior interest” is justified, which is nothing more than the way of imposing the will of a third party, over the will, wishes and preferences of the person with disability.

The attitudinal or sociocultural barriers of family members, professionals (from the social and health areas), bank officials, notaries, legal professionals and people connected to persons with disabilities in general, which are based on diagnoses rooted in the medical model- rehabilitation and in their ideology “ableism”, and do not consider persons with disabilities to be “capable” of making their own decisions or understand the consequences and effect of concrete and daily legal acts, such as those that include the administration of patrimonial assets, among others .

Regulatory, legal and other barriers, as well as the content in laws, attitudes and practices, among others, that limit or impede the exercise of the economic rights of persons with disabilities, favoring “trafficking or legal business”.

The interdiction, which deprives persons with disabilities, in their entirety, of the exercise of their economic rights. It is worth mentioning that, sometimes, the interdictions are partial and affect only some rights, such as disposition or administration, allowing the handling, exclusively of small sums of money. This “restricted legal capacity” is also contrary to the CRPD and a barrier to be removed, since it is based on stereotypes and stigmas and constitutes a violation of rights.

The lack of support mechanisms recognized in national regulations, linked to administrative areas.

The generalized practice of evaluations focused on the medical-rehabilitative model, which attempts to measure in a standardized way, through various techniques, the aptitude of a person with disability to make their own decisions. For these purposes, conceptualizations about the measurement of “functional capacity and mental capacity or age” are used as elements that justify the interdictions to legal capacity. As we have said in other sections of this document, legal capacity and functional or mental capacity have no relationship with each other, therefore the latter should not be subject to evaluation or consideration as a prerequisite to guarantee the unrestricted right to exercise legal rights. This right is not subject to any diagnostic evaluation.

Practical guidance

Review and revoke the interdictions that have been declared against persons with disabilities, suspend those that are in process, and develop a support system and safeguards that is respectful of the social model of disability, with a human rights approach.

Define support mechanisms considering the economic, educational, social, family and cultural contexts, among others, of the person holding the rights, and according to their request.

Recognize the legal equality of persons with disabilities, which leads to respect for economic rights and implies the state guarantee that they will not be arbitrarily deprived of their property due to their disability.

Guarantee that persons with disabilities have support mechanisms for access to complete information, so that they are able to formulate their decisions in a free and informed manner. All information must be produced in universally accessible and alternative formats, according to the different needs and ways of communicating.

When the person wishes and requires it, they must have the possibility of having support for decision-making, and that such support is accepted. The support mechanisms for decision-making in legal and administrative acts are based on the social and human rights model with an interdisciplinary perspective. They are chosen and requested by the person who owns the rights, who may or may not formalize this function and relationship through administrative, judicial or notarial channels. In such cases, the procedure must be agile, and the person or entity may be a support for acts in general or for a specific act, for a specified time or with a more continuous nature. The support may be registered in the corresponding instance in accordance with the legislation of each State.

Ensure that the person or support entity assists, advises and provides the information in accessible formats that the person requires and considers the communication repertoire used by the person with disabilities for decision-making, guaranteeing and respecting the rights, desires, the will and preferences of the person with disabilities. This should be done without exerting any type of pressure, coercion, violence or undue influence in the decision-making process.

When there is a divergence between the person with disability and the support person, the will and preferences of the person with disability prevail. The support person, for merely declarative purposes, may register that her/his obligation to guide and advise on the required issue that has been fulfilled, as well as such divergence, when the matter is about recordable assets and acts, or in general when the decision taken could generate significant effects on the assets of the person with disability or their family. The final decision of the person with disability cannot and should not be questioned.

There are a variety of normative figures and support alternatives for the management and protection of assets that do not restrict the autonomy and full exercise of the legal capacity by persons with disabilities, such as trust assets or commercial trust, usufruct, family assets, among others.¹⁷⁶

Offer the person with disabilities support for the exercise of legal capacity, if they require it. The person has the right to request support, and also to refuse it. Likewise, a person who has formally registered support may decide to exercise their legal capacity without making use of such support. The role of the notarial staff trained in the social and human rights model is fundamental, both to recognize the right to exercise the legal capacity of persons with disabilities without restrictions, as well as in legal advice and confirmation of the will of the parties-. Notary staff must make assessment of the will of a person with disability regarding a particular legal act, under equal conditions with others. That is, they should focus exclusively on determining whether or not there is an expression of willingness to perform a particular act, rather than subjecting the person to additional and undue scrutiny of abilities just because the person chose to decline support or solely on the basis of their disability status.

176 An interesting and useful document at this point is the one prepared in Colombia by ASDOWN, PAIS and Community Mental Health Node: The exercise of legal capacity: A Practical Guide for its application. Bogotá, Colombia, June 2019, pp. 33-59. Available here: http://asdown.org/wp-content/uploads/2019/09/Guia-para-Implementacion-Cap_Juridica.pdf

If at any time or specific situation the will of the person cannot be determined, as indicated in the specific section on the exercise of legal capacity above, after having made a significant effort, including support and reasonable accommodation, it must consider the standard of “best interpretation of the will”, in the terms set forth by General Comment #1 of the CRPD Committee. If it is not possible to obtain an expression of will, after having made a significant effort, a useful resource is, among others, the early decision, which can also be raised in patrimonial and administrative matters, in the same terms indicated in the section on the exercise of legal capacity.

Implement legally and normatively the figure of the advance provision regarding economic rights, always subject to the current will of the person at the time of the legal act. Also guarantee a system of reasonable accommodations and supported decision-making that does not imply restriction to the autonomy of persons with disabilities neither control nor additional scrutiny in financial practices (administration of accounts and deposits, etc.).

Guarantee the procedural adjustments and reasonable accommodations that are required to exercise autonomy in decision-making, such as: sign language interpretation services in all areas, the use of assistive technologies, accessible and affordable for all people with disability, and all those other reasonable accommodations, languages and communication methods specified in article 2 of the International Convention on the Rights of Persons with Disabilities.



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Examples

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<https://dapre.presidencia.gov.co/normativa/normativa/LEY%201996%20DEL%2026%20DE%20AGOSTO%20DE%202019.pdf>

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Law for the Promotion of Personal Autonomy of Persons with Disabilities. Costa Rica Republic.
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http://www.leyes.congreso.gob.pe/Documentos/2016_2021/Proyectos_de_Ley_y_de_Resoluciones_Legislativas/PL0337020180913.PDF

The figure of the Swedish Personal Ombudsman.
<https://europe.ohchr.org/EN/Stories/Documents/MathsJesperson.pdf>

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FREE AND INFORMED CONSENT

International Legal Framework of Reference

- International Convention on the Rights of Persons with Disabilities (CRPD). Articles 12, 14, 15 and 25.d.
- Inter-American Convention for the Elimination of all Forms of Discrimination against Persons with Disabilities (CIADDIS). Article 3.

Barriers to remove

The limitation in the exercise of the rights of persons with disabilities in their autonomy and self-determination which prevents them from fully exercising their right to decide about their life and their body.

Prejudices or stereotypes that promote the idea that persons with disabilities, and in particular people with intellectual, psychosocial and hearing disabilities, as well as deafblind people, among others, do not have the capacity to carry out the decision-making process or measure the extent and effects of the decisions they make. For this reason, an attempt is made to justify the application of the standard of objective superior interest, which is nothing more than the way of imposing the will of a third party, over the will, desires and preferences of the person with disability.

Mental health laws and other legislative provisions related to the mental health system in particular, which authorize involuntary hospitalization and treatment practices. These practices amount to arbitrary detention and torture, cruel, inhuman and degrading treatment.

The application of the “best interests” standard in the case of persons with disabilities who do not communicate their decisions in traditional ways. Their preference and will are limited, considering a priori that they cannot self-determine.

Formal barriers and practical issues that prevent the exercise of the right of persons with disabilities to decide about their lives and their bodies.

Material and symbolic difficulties, prejudices and other aspects that prevent respect for the autonomy of persons with disabilities, by negatively interfering with their expectations and desires regarding health care and other areas of life.

Laws, Codes, norms, attitudes, practices, among others, that limit or prevent the processes of autonomy of persons with disabilities.

Representation systems that allow the subrogation of the will of persons with disabilities, granting guardians and conservators the power to consent in substitution of the person, even in very personal acts related to the right over the own body, medical investigations, etc.

Differentiated treatment, in cases of general medical emergencies, towards persons with disabilities, which violates the right to timely, informed and consented medical intervention.

The so-called “psychiatric emergencies or emergencies”, or “psychosocial crisis situations”, are often used as an argument to violate the right to freedom and free and informed consent of a person, and to justify another series of abuses and violation of rights, such as the right to physical and mental integrity, torture and cruel and degrading treatment.

The lack of recognition of legal capacity for persons with disabilities to consent to medical treatment or surgery, without exceptions.

The involuntary hospitalization and institutionalization of persons with disabilities.

The lack of accessible information at all levels, and of adequate and accessible medical equipment and infrastructure.

Practical guidance

Regarding the elimination of the interdiction and the implementation of support systems in decision-making based on the needs of the person requesting support, her/his will, preferences, economic, family, social, cultural situation, level of education, and so on, all those above should be reviewed as well as the procedures for informed consent, that imply an absolution or exemption from professional responsibility, and do not represent an effective and accessible process of information. The person's preference must always be privileged.

Remove the concept that informed consent is represented by a form and not through a dynamic and continuous process with the person with disability, aimed at full participation and the achievement of effective autonomy of the person for decision-making.

Guarantee the right of children with or without disabilities to give their informed consent in health interventions¹⁷⁷.

Review and remove all legislation or regulation that legitimizes forced hospitalizations and medical treatments, including electroshock, in order to generate a definitive change in the outlook and approach to the rights of people with psychosocial or intellectual real or perceived disabilities.

The so-called “psychiatric emergencies” or situations of psychosocial crisis must be treated in terms of respecting above all the decisions of the person with disability on the basis of equality with others.¹⁷⁸, using the criteria of best interpretation only if required and implementing the systems for supported decision-making, reasonable accommodations -including the communicative and emotional mediation chosen by the person- and advance directives if any, always putting and reviewing the current decision of the person. The term ‘psychiatric emergency’ should be replaced and the same standards of medical emergencies and emergencies should no longer apply in this particular situation. Psychosocial crises are not equivalent to urgency in the functioning of the body, the urgency is of a psychic and/or social nature and must be approached in an ideal way to meet the psychic and/or social needs of the person entitled to the right. There is no justification for interning a person for a psychosocial crisis by force. Regardless of the length of the internment, it constitutes an arbitrary detention.

The administration of psychiatric medications is never justified without the free, informed and express consent of the right holder, even in crisis situations, because it is an intervention related to the physical and mental integrity of the person¹⁷⁹.

Perform procedures that are integrated to family history and the sociocultural context, including the future plan that the person has defined, to determine the preference and will of people who face significant communication barriers, in addition to previously using reasonable adjustments, technological and human, as well as communication intermediaries that are required, chosen and accepted by the person with disabilities for the exercise of their right to express their will and decisions with autonomy.

The person with disability can include health-related decisions in their formal and/or informal support plan for the exercise of legal capacity, if they consider it to be necessary to develop such plans. It may also be that the person only wants to designate support for the health context. In any case, it is the person with disability who should have the opportunity and the right, if they so choose, to design and designate support and/or to have interactive advice on their needs. This interaction can be done in order to develop a plan that they can accept, modify or deny.

177 See in this regard: Committee on the Rights of the Child: General Comments No 14, 15 and 20, available here: https://conf-dts1.unog.ch/1%20spa/tradutek/derechos_hum_base/crc/00_6_obs_grales_crc.html

178 See in this regard General Comment # 1 of the United Nations Committee on the Rights of Persons with Disabilities on Legal Capacity, paragraph 18.

179 See in this regard General Comment # 1 of the United Nations Committee on the Rights of Persons with Disabilities on Legal Capacity, paragraph 42.

Guarantee that all information on medical treatments, surgical interventions and hospitalization is available in accessible and alternative formats, which cover the removal of all kinds of situations and barriers to the exercise of the rights of persons with disabilities, including dynamic communication processes and not only forms based on written word. The decisions of persons with disabilities must always be respected.

Offer mechanisms so that all people, including persons with disabilities, can make advance provisions to guarantee their decision-making, their preference and their will at some point in life when they are not in a position to express them. In any case, the current will of the person will always prevail over the advance directive.

Apply regular rules or protocols, on equal terms with other people, when any individual, including persons with disabilities, who are in a situation of compromised state of consciousness, due to an emergency and unforeseen situation such as an accident. A different procedure for reasons of disability is discriminatory and is a violation of rights.

Health professionals should apply inclusive protocols to communicate with their patients and request their free and informed consent for any procedure, scheduled medical intervention, treatment, etc., using accessible communication measures, granting reasonable accommodations and accepting the participation of support persons for said decision-making -acceptance or denial- or according to the will and preferences of the person. If the person - with or without disability - does not understand the scope of the treatment or practice, there can be no informed consent and therefore that practice cannot be done. The criteria of the best interpretation of the will can also be applied to determine consent or refusal. The decision must always be made by the rights holder, with or without support, and must be respected, even if the health professional does not agree with it.

It is important to bear in mind that the existence of a disability does not necessarily indicate the need for support, nor should a lack of understanding or the impossibility of communicating consent be presumed. Health personnel should not demand the use of support by the person with disability just because they are in a situation of disability. The use or not of support to give consent or not, is a decision of the person herself/himself.

In the event that a person cannot give their consent and a medical intervention is necessary to preserve their life (medical emergency situation), the intervention is to be made under the decision of the treating physician. In any other situation, consent must always be given only by the person herself/himself or the support person that the rights holder has chosen for these cases, always following the principle of the best possible interpretation of the will and preferences of the person in question, considering their history, preferences, tastes and social and family context. In these cases, the general standard for health emergencies is followed.

In case of conflict between the will and preference of persons with disabilities and medical criteria, the will and preferences of the person (with or without support) always prevail in all stages and all situations, observing the human right to decide about their life and their body. Health personnel have an obligation to offer accessible, alternative mechanisms and support systems to give free and informed consent or refusal., but the person's decision must always be respected, as it is their right and it is not a matter of "conflict resolution".

The participation of persons with disabilities in biomedical research - experimental or not - requires their prior, free and informed consent.



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<https://documents-dds-ny.un.org/doc/UNDOC/GEN/G14/031/23/PDF/G1403123.pdf?OpenElement>

Guidelines of the Committee of Experts of the Convention on the Rights of Persons with Disabilities.
<https://www.ohchr.org/EN/HRBodies/CRPD/Pages/Guidelines.aspx>



Example

Resolution 1904/2017 of May 31, 2017 issued by the Ministry of Health and Social Protection of the Republic of Colombia by means of which the “Regulation aimed at guaranteeing that persons with disabilities, based on a differential approach, have access to adequate and sufficient information on their sexual and reproductive rights and indicate the correlative obligations that arise for the members of the General System of Social Security in Health - SGSSS regarding the provision of support, reasonable accommodations and safeguards that allow them to make decisions informed in this matter for access to the respective services ”.

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POLITICAL AND ELECTORAL PARTICIPATION

International Legal Framework of Reference

- International Convention on the Rights of Persons with Disabilities (CRPD). Article 4, 29, 33b.
- Inter-American Convention for the Elimination of all Forms of Discrimination against Persons with Disabilities (CIADDIS). Article 3.
- 2030 Agenda. Sustainable Development Goal (SDG) 16.
- Program of Action of the Decade of the Americas for the Rights and Dignity of Persons with Disabilities, PAD (2016-2026), Objective 7, Concrete Actions 7, paragraphs a-h.

Barriers to remover

The limitation in the exercise of the rights of persons with disabilities and their right to elect or be elected to a position of popular election, and in the right to compete under equal conditions and opportunities for said positions, due to the structural inequality that affects them.

Prejudices or stereotypes that promote the idea that persons with disabilities, in particular people with intellectual, psychosocial, hearing and visual disabilities, as well as people who are deafblind and with multiple other challenges, among others, cannot exercise on their own or they do not understand or do not know how the electoral system works.

Prejudices or stereotypes that promote the idea that persons with disabilities, in particular people with intellectual, psychosocial and hearing disabilities, as well as people who are deafblind and with multiple other challenges, among others, do not identify legal and attitudinal barriers.

Constitutions, Laws, Codes, Norms, attitudes, practices, among others, that limit or impede the exercise of autonomy and legal capacity of persons with disabilities.

The interdiction, conservatorship or any disabling condition that deprives or limits the exercise of the political rights of persons with disabilities, such as their right to vote, be part of the election commission or be elected for public post.

The lack or insufficiency of support mechanisms and universal accessibility provided for by electoral regulations, as well as the scant relevance that electoral control bodies give to compliance with such regulations when they exist.

Practical guidance

Repeal the provisions, interdiction or any other substitute for the will, which prohibit citizen identification and voting for persons with disabilities.

Review and revoke the interdictions that have been declared up to now on persons with disabilities, suspend those that are in process, and develop a support system that is respectful of the social model of disability, with a human rights approach, as stated has emphasized in all the previous sections. It is also important to establish and regulate accessible and support mechanisms so that the person with disability, who manifests or requires it, can exercise their right to vote and/or be elected to a position of popular election, or, to perform on equal terms with others in their political or public functions.

Guarantee that persons with disabilities have mechanisms of access to complete communication and information, so that they are able to exercise their political rights in a free and informed manner. All information must be produced in accessible and alternative formats, covering all disabling situations.

Guarantee and promote that persons with disabilities can run before the electoral authority to compete for a popularly elected office, whether federal or local, on equal terms with other people, including affirmative measures to equalize opportunities.

Facilitate the right to vote for persons with disabilities, applying support mechanisms and reasonable accommodations throughout the electoral process, including the establishment of remote voting (differentiated electronic voting systems, mobile ballot box, postal voting, residential voting, among others), the semi-public vote, the presence of supporters and intermediaries for the exercise of the right to vote.

Offer persons with disabilities support for the exercise of their political rights, if they do not have them and if they require it.

Guarantee universal accessibility so that the person with disabilities can exercise their political rights, such as: sign language interpretation services in all areas, debates, political analysis, etc., the use of assistive technologies, accessible and affordable for all persons with disabilities; accessible materials for all disabling situations; clear iconographic signage; accessibility in polling stations, adapted voting room, among others.

Guarantee that the proposals and campaigns of the political parties are carried out in formats with universal accessibility criteria that cover all disability situations, including subtitles, sign language, audio description and easy reading.

To resort to conventionality control mechanisms by administrative or judicial means to remove the interdictions that affect the right to vote, in accordance with Article 29 of the CRPD.



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Examples

FRA (European Union Agency for Fundamental Rights). “The right to political participation of persons with disabilities”
https://fra.europa.eu/sites/default/files/fra-2014-political-participation-persons-disabilities-summary_es.pdf

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<file:///C:/Users/AliciaLozaGF/Downloads/Dialnet-LosDerechosDeParticipacionPoliticaDeLasPersonas-Con-5203528.pdf>

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ACCESS TO SOCIAL PROTECTION

International Legal Framework of Reference

- International Convention on the Rights of Persons with Disabilities (CRPD). Article 28.
- Inter-American Convention for the Elimination of all Forms of Discrimination against Persons with Disabilities (CIADDIS). Article 3.
- Children's rights convention. Article 3.
- 2030 Agenda. Sustainable Development Goals (SDGs) 1, 8, 10 and 11.
- Program of Action of the Decade of the Americas for the Rights and Dignity of Persons with Disabilities, PAD (2016-2026), Objective 9, Specific Actions 8, paragraphs a-f.

Barriers to remove

The obligation to have interdiction, conservatorship or some type of restriction of legal capacity for access to social protection mechanisms: subsidies, pensions, etc.

Social protection systems linked exclusively to formal work (pensions, medical and health benefits, insurance, etc.).

Practical guidance

Review and revoke the interdictions that have been declared up to now about persons with disabilities, suspend those that are in process, and develop a support system according to the social model of disability, with a human rights approach.

Apply conventionality control mechanisms to guarantee that the social protection of the rights system is not subject to interdiction processes that imply limitation of patrimonial or extra-patrimonial rights. Specifically, all norms and public policies that condition access to benefits and social protection services to the restriction of the legal capacity of the person must be revoked, including the declaration of interdiction.

Guarantee universal accessibility so that the person with disabilities can access social protection, such as: interpretation services in sign language in all areas, the use of assistive technologies, accessible and affordable for all persons with disabilities; accessible information that covers and responds to the needs of all disability situations; accessibility in public buildings and in banking entities for the collection of pensions, subsidies, patrimonial procedures, or any other benefit.

Articulate the social protection system focused on the person with disability (of legal age) and not for their family group. The socioeconomic conditions of their family environment should not determine the possibility of access to social protection, since what should be promoted is the right to autonomy and independent life. In this same sense the "personalization of support" should also be regulated and guaranteed with public policies of social protection, establishing budgets for personal assistance and assistance for decision-making, in such a way that persons with disabilities can choose and have control over benefits and support services they receive.¹⁸⁰

Move towards the universalization of benefits, in the field of social protection for persons with disabilities, while keeping in mind the principle of "same rights, same obligations".

In the administrative processes for granting social protection rights consider the intersectionality of persons with disabilities in terms of belonging to other groups in a greater situation of violation or who require special social protection, such as children and adolescents, the older adults, indigenous people, African-descendent population, migrants or refugees, people in a situation of social-economic exclusion, etc.

180 Cf. United Nations, Human Rights Council: Report of the Special Rapporteur on the Rights of Persons with Disabilities. 34 period of sessions, Civil, Political, Social, Economic and Cultural Rights, December 20, 2016, A / HRC / 34 / 58, para. 62. Available here: <https://undocs.org/pdf?symbol=es/A/HRC/34/58>



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Examples

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4.

General Recommendations To Expand The Mechanisms And Actions To Guarantee The Full Exercise Of The Legal Capacity Of Persons With Disabilities

1. Review and revoke the interdictions that have been declared up to now on persons with disabilities, suspend those that are in process, and develop a support system that is respectful of the social model of disability, with a human rights approach.

2. Establish a support system that ensures unrestricted respect for the preferences and wishes of persons with disabilities always and at all times, considering the contextual and situational conditions that surround and affect them. The support developed cannot be not standardized, it must be adapted to the needs of persons with disabilities and according to the situation or area in which they require and request support, and always apply to the decision and choice of the person considering their own expression and assessment of support needs.

3. Define the support systems considering the economic, educational, social, family and cultural contexts, among others, of the person with rights. Each of these contexts requires different approaches for granting support.

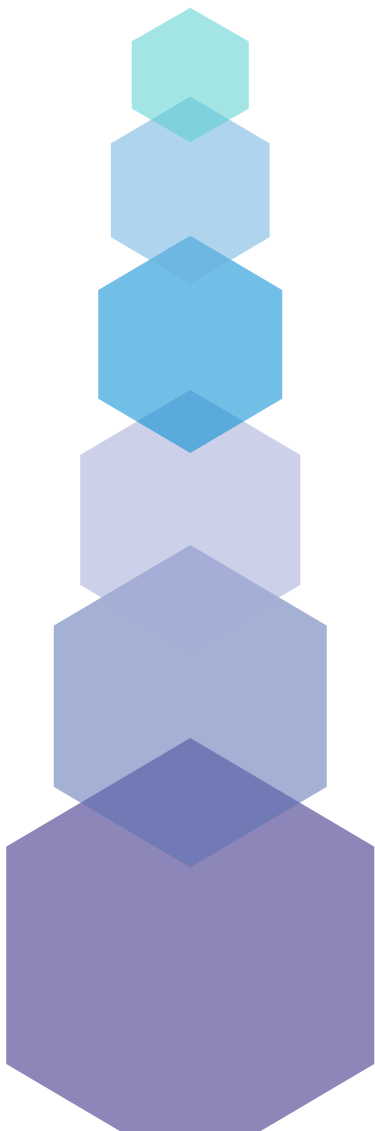
4. Guarantee that persons with disabilities have support that considers accessible and alternative mechanisms of communication and complete information, so that they are able to formulate their decisions in a free and informed manner. All information must be produced in accessible and alternative formats, which respond to the needs of all disability situations.

5. Develop support plans for decision-making for persons with disabilities that request it, interactively, giving them the opportunity to identify their specific support needs, design and designate formal and informal supports independently, and - if they require it and do not know it - have interactive assistance for the identification of needs and of the support alternatives and their operation, among others, under the same criteria of prioritizing the right and the opportunity of the person to design, implement and evaluate her/his own support plan. For this, it is advisable to include in national regulations the figure of assistants to support decision-making, who must be trained in the social model of disability, with a human rights approach, and may or may not be part of formal records of said function and role. The regulations must include the duty to recognize and accept as assistants for decision-making support in legal, administrative, health or other processes, the person (s) or entities that the person with disability has chosen for that purpose.

6. Invariably respect the decisions of persons with disabilities in all situations..

7. The design of a decision support plan is essentially a decision of the person with disability. The support a person requires and their support plan are **personal** and non-transferable, and respond to their own needs. The person with disability is the center of your support plan. In no case should it be intended to generate support models or standards. The decision and the role of the person with disabilities in the development of their support plan, as well as in its monitoring and evaluation, must be protected and in no case restricted..

8. At the regulatory and public policy level, generate recommendations so that support services in decision-making, personal assistance, intermediation for access to justice, legal advice, the notarial service and legal professionals, among others , are accessible, responding to the needs of accessibility and reasonable accommodations



that each disability situation requires. The function and role of the person or support entity in decision-making that the right holder chooses must be recognized and accepted, whether formal or informal, when appropriate, in order to guarantee the full exercise of the legal capacity of the holder of the right

9. When an undue, harmful, negative influence or with a conflict of interest is denounced by the assistant of the person with disability, a safeguard must be applied by exception, in accordance with the provisions of article 12 of the International Convention on the Rights of Persons with Disabilities. In the safeguard applied the decision and preference of the person with disability whose right is directly affected must always prevail.

10. In the same way, it is important to establish mechanisms for monitoring and evaluating the operation of the support system for decision-making -as well as the personal assistance systems for independent living-, which must have the essential role of the person with disability, and with the active participation of organizations of persons with disabilities.

11. Ensure that it is the person with disability who decides, designs, initiates and develops their support plan. This support plan must be updated, according to the changes in the situation of the person who has requested it, and also according to the decision of the person in relation to their need.

12. Generate training programs in human rights and awareness for State authorities, judges, legal professionals, notaries, officials, families, educators, social workers, health professionals, other professionals and the community in general about the social model of the disability, autonomy and right to exercise the legal capacity of persons with disabilities

13. Guarantee the reasonable accommodations that are required to exercise autonomy in decision-making, such as: sign language interpretation services in all areas, the use of assistive technologies, accessible and affordable for all persons with disabilities, and all those other reasonable accommodations, languages and communication methods specified in article 2 of the International Convention on the Rights of Persons with Disabilities.

14. Guarantee universal accessibility in communications and information and communication technologies, essential for the exercise of autonomy for persons with disabilities. In this sense, it is recommended that States generate accessible and plain-language versions of this Guide, to ensure that this information also reaches persons with disabilities themselves and their organizations, who should take the lead in the design, implementation and evaluation of the support systems, support plans, safeguards, intermediation services for access to justice, among others.

15. Although this work is aimed at exercising the legal capacity of persons with disabilities, the support services mechanism should not be limited only to persons with disabilities, as it should be available to anyone who needs support to access on equal terms conditions and opportunities for justice and the right to make free and informed decisions in all areas, such as those who did not have access to education, migrants whose native language is not English, people in extreme poverty, people elderly, people with diseases that restrict their development in the environment, people with learning difficulties, among others.¹⁸¹

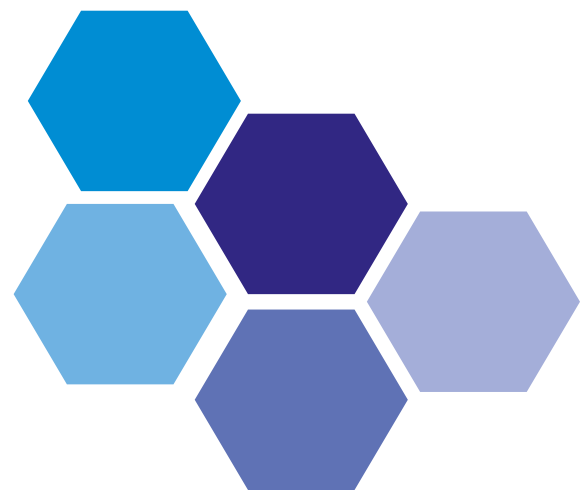
16. Recognizing that the application of the right to full exercise of legal capacity is not subject to the principles of progressivity and considering that implementing a national system of support requires budget availability, it is recommended to advance in the implementation of pilot support projects, based on gathered experiences and learnings, which serve as a basis for the full implementation of the system.

17. Although there are good practices in regulatory terms, such as the legislation of the Republics of Costa Rica, Colombia or Peru, as well as other experiences of support by legal professionals, such as those of the Argentine Republic and Mexico, it is necessary to take into account that this is not enough. The real exercise of legal capacity will be possible to the extent that the States advance in establishing support systems for decision-making, within a Comprehensive Support Policy Plan. Such initiative shall include and recognize support

181 For example, Spanish legislation indicates that "any person who has difficulties in exercising their legal capacity is entitled to request support."

for the development of independent living and in the community. A political will is necessary to adequately implement the required legislative changes, the training of all the actors involved in the system, and to allocate financial resources.

18. For this reason, it is proposed to the States that when harmonizing the legislation with Article 12 of the International Convention on the Rights of Persons with Disabilities (CRPD), this legal modification is also complemented by a regulation that regulates and clarify how to make the transition to a national system of support for decision-making, as well as to determine the monitoring and evaluation mechanisms (or safeguards) with the full participation of organizations of persons with disabilities complemented with a generalized training planning for all interested and involved actors.





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