Model Protocol for Motherhood in Women with Disabilities

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I. Introduction

The initiative of the Special Envoy of the Secretary-General of the United Nations on disability and accessibility arises as a response to the need to create a guiding model protocol of motherhood in women with disabilities which is developed through a legal survey and a field study by interviewing women with different types of disabilities who have been mothers, and which also has the validation from the civil society through representative organizations.[1]

The women with disabilities that were interviewed stated that their disabilities had not been an impediment for them to be mothers. Most received the news with joy, whether their pregnancy was planned or not.

It must be mentioned that to a greater or lesser extent, this joy always came with a sense of insecurity and fear about the obstacles they would have to overcome later in this long process, which is translated into concern for their health and the child they bear.

The main obstacles or barriers that they experienced during their pregnancy and childbirth were related to the healthcare system. On the one hand, there are obstacles related to infrastructure, information, communication, treatment, and protocols for adapted deliveries. This reveals that promoting autonomy in women with disabilities is not at the center of the definitions of the public health care system. The existence of negligent and even demeaning treatment from the medical staff to women with disabilities during this period is revealed. Due to this, many avoid this interaction where the staff provides incomplete information, only talks to their partners, does not empathize with their emotions in critical moments, and may even intercede to facilitate having their children taken away from them due to alleged "lack of skills" to raise their children and fulfilling their roles as mothers. The above is mostly due to cultural and behavioral barriers that question and fear sexuality and motherhood in women with disabilities. Often, their families or those who provide support have preconceptions much before the pregnancy, which can reflect in women with disabilities. They often tend to impose barriers on them and sometimes actively deprive them of motherhood and childrearing.

On the other hand, the mothers with disabilities that were interviewed talked about other areas of their lives where they find obstacles. Cities that are not friendly with people with reduced mobility are a barrier to accessing health care services for their children during their first years. Not having a dignified and adapted home when they lack economic resources is an obstacle that makes it difficult to parent as they wish. Similarly, the extreme bureaucratization in the offer of childcare services for women with severe physical disabilities is a barrier for the mothers that receive individualized support to raise their children.

[1] CONADIS: National Council for the Attention of Persons with Disabilities (Chile) and CIMUNIDIS: Emancipation Circle of Women and Girls with Disabilities of Chile.

An education system that does not consider the need for support of mothers with intellectual disabilities that wish to continue being present in the learning processes of their children and that does not consider adaptations to include deaf women and women with hearing or visual impairments is also an obstacle for these mothers and their children.

Women with disabilities who are both mothers and workers are confronted with a labor system that does not include support for returning from maternity leave in a conciliating way, raising barriers for those women that need to continue developing their life projects considering motherhood and work.

Finally, a judicial and social security system that considers women with intellectual and psychosocial disabilities as "less fit" to become mothers; these are not only barriers but are dangerous for their motherhood and the best interest of their children.

The mothers with disabilities interviewed in this survey claimed to turn to their families as their main source of support. They highlight the emotional support provided, help to provide care for newborns during their first months of life, and the support in the communication between mothers and the public system, the school system, and medical checkups. In some cases, families have supported them financially and with a place to live; however, this does not happen in all cases.

Given the need to obtain support in certain areas, most have not applied to State assistance and support for different reasons: Lack of trust, lack of knowledge, because sometimes the services that they need do not exist, or because they consider state entities as inefficient and too bureaucratic in assistance and support services. In those cases in which they have chosen to request state assistance, it has been motivated by the activism of mothers that mobilize to demand their rights.

This document addresses assisted motherhood, including conception, birth, and childrearing, which are processes women with disabilities can undertake, but some will require support or reasonable adjustments. The word "assisted" makes us return to assistentialist models focusing on persons with disabilities.

Women with disabilities are equal to other women and have rights that will be described later. We will detail the cross-cutting issues, assistance and support, and the accommodations for mothers with disabilities to exercise those rights.

II. Background Information

The purpose of the base protocol is to create awareness on the rights of women with disabilities, specifically regarding their sexual and reproductive rights, and facilitate for these rights to become effective in the different services involved in their motherhood process, considering the stages of education in sexuality and reproductive health, pregnancy, childbirth, and childrearing.

The rights of women with disabilities are interrelated and interconnected in their exercise and are therefore indivisible and interdependent. They stem from the Universal Declaration of Human Rights and international treaties such as the Convention on the Rights of Persons with Disabilities and the Convention on the Elimination of All Forms of Discrimination against Women. The rights of women with disabilities regarding their sexuality

and motherhood are constantly supported by the declaration of Treaty Bodies[2], by reports of the Human Rights Council[3] and its universal periodic review, and by the recommendations of independent experts[4].

Sexual and reproductive rights consider the right to access to essential healthcare services and the right to make decisions free of coercion and violence.

Sexual rights constitute the application of human rights linked to sexuality and sexual health. They protect the rights of all people to satisfy and express their sexuality and enjoy sexual health, with due respect for the rights of others within a framework of protection against discrimination[5].

Sexual health is linked to respecting, protecting, and complying with human rights. Sexual rights comprise certain human rights recognized in relevant international and regional documents, other consensus documents, and national legislation[6].

The Convention on the Rights of Persons with Disabilities, adopted in 2006 by the General Assembly of the United Nations (hereinafter, CDPD or the Convention,) represents a historical milestone, recognizing the human rights model in persons with disabilities, in which this protocol is based. In this way, charity and medical-assistentialist models through which disabled persons were seen in the past are left behind. The CDPD addresses the concept of persons with disabilities, indicating that it includes those who have long-term

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[2] CDPD Committee: General Comment No. 3 (2016) - Women and girls with disabilities: https://www.ohchr.org/EN/HRBodies/CRPD/Pages/GC.aspx. Concluding Observations Examples: https://uhri.ohchr.org/es/documento/2e0a4dcc-ba5c-48e1-b497-12d68966b93c https://uhri.ohchr.org/es/documento/03d5bfdd-5709-42c1-b969-09be6de6b241 https://uhri.ohchr.org/es/documento/2a1c8828-155c-4a4a-9acc-01b622b43c51 https://uhri.ohchr.org/es/documento/6cedd70a-d380-4761-aeda-12f7cfebbcf8, https://uhri.ohchr.org/es/documento/c316165a-c5d6-4f97-801d-6c3bdc063fd2 https://uhri.ohchr.org/es/documento/c316165a-c5d6-4f97-801d-6c3bdc063fd2, https://uhri.ohchr.org/es/documento/80d56909-a037-4b9b-b706-a1e4e82d0b1d

CEDAW Committee Concluding Observations Examples:

https://uhri.ohchr.org/es/documento/3c08b240-d0b1-4aec-8401-98dff3767dcd, https://uhri.ohchr.org/es/documento/68c7f20b-2621-454c-89e2-d7e2a18e3e10 https://uhri.ohchr.org/es/documento/5ffd2008-cc78-419b-be07-19451910187a https://uhri.ohchr.org/es/documento/fe8572e6-e58f-4955-a991-1715b6d4a3ce https://uhri.ohchr.org/es/documento/6d7327a5-663e-4547-ae38-bc015f0a920c

Human Rights Committee (CCPR). Example:https://uhri.ohchr.org/es/documento/1aaec269-f897-4c63-b09c-727591ab437b

[3] EPU: A mechanism that addresses the situation of human rights in the member countries of the United Nations. Examples: https://uhri.ohchr.org/es/documento/1da3328a-d597-4fc8-b5ca-6be1f005864f https://uhri.ohchr.org/es/documento/7a207c5b-dc3e-4c7c-9ddf-f22e93df9377 https://uhri.ohchr.org/es/documento/fc8770d3-9605-4b9c-82f2-d57e3628f8e0

[4] Special Rapporteur on the rights of persons with disabilities Examples: https://uhri.ohchr.org/es/documento/03b8a39f-ea44-4d21-a6dc-73b00d4eecb7 https://uhri.ohchr.org/es/documento/8ec074c2-6041-45f3-aa66-688dc11ac3f3

[5] Sexual health and its linkages to reproductive health: an operational approach. Geneva: World Health Organization; 2018. License: CC BY-NC-SA 3.0 IGO. https://www.who.int/reproductivehealth/publications/sexual_health/sh-linkages-rh/es/. Page 3

[6] Ibid

physical, mental, intellectual, or sensory impairments which, in interaction with various barriers, may hinder their full and effective participation in society on an equal basis with others[7].

Consequently, the role of State Parties and society, as a whole, will be eliminating different types of barriers and creating conditions for women with disabilities to fully and effectively exercise their sexual and reproductive rights in society.

According to the Convention, States Parties recognize that women and girls with disabilities are subject to multiple forms of discrimination. In this regard, they shall take measures to ensure their full and equal enjoyment of all human rights and fundamental freedoms without discrimination. States Parties shall take all appropriate measures to ensure the full development, advancement, and empowerment of women with disabilities.

SDG 3 of the 2030 Agenda on Sustainable Development promotes guaranteeing a healthy life and well-being for everybody at all ages, including in its target 3.7 for 2030 to ensure universal access to sexual and reproductive healthcare services, including family planning, information and education, and the integration of reproductive health into national strategies.

All women with disabilities have the right to the following to fully exercise their sexual and reproductive rights in equal conditions as others:

- ✓ Receiving good treatment and not being discriminated against in all matters relating to marriage, family, motherhood, and relationships.
- ✓ Accessing information and communication regarding their sexual and reproductive rights, exercising their motherhood, and raising their children in their language or the media, in augmentative or alternative means or formats.
- ✓ Making their own decisions, giving their free and informed consent, and not being subject to substitute decision-making.
- ✓ Enjoying a healthy sex life, the right to pregnancy, and having children.
- ✓ Deciding on the number and spacing of their children.
- ✓ Deciding if they want to form a family and its composition.
- ✓ Raising their children directly.
- ✓ Having a place to live.
- ✓ Having an adequate standard of living and social protection for them and their family.
- ✓ Determining how they will live, where and with whom.
- ✓ Having equal, timely, and quality access to various in-home or residential support services and other available community support services, including individualized support, considering their needs and requirements.
- ✓ Deciding which type of assistance and support they require and their frequency.
- ✓ Having universal access and reasonable accommodation.

Legal basis

[7] Article 1 inc 2 CDPD

United Nations Convention on the Rights of Persons with Disabilities

Equality and non-discrimination (art. 5)

Women with disabilities (art. 6)

Accessibility (art. 9)

Reasonable accommodation (art. 2)

Equal recognition before the law (legal capacity, free and full consent, support) (art. 12)

Freedom from violence (art. 16)

Freedom from torture or cruel, inhuman, or degrading treatment or punishment (art. 15)

Protecting the mental and physical integrity of the person (art. 17)

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

Forming a family (art. 23)

Sexual and reproductive rights (art. 23)

Education (art. 24)

Health (art. 25)

Habilitation and rehabilitation (art. 26)

Work and employment (art. 27)

Adequate standard of living and social protection (art. 28)

The **WHO** indicates that the fundamental rights for sexual (and reproductive) health are the following[8]:

The rights to life, freedom, autonomy, and safety of persons.

The right to equality and non-discrimination.

The right to freedom from torture or cruel, inhuman, or degrading treatment or punishment.

Privacy.

The right to the enjoyment of the highest attainable standard of health (including sexual and reproductive health) and the highest level of social security.

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[8] Sexual health and its linkages to reproductive health: an operational approach. Geneva: World Health Organization; 2018. License: CC BY-NC-SA 3.0 IGO. https://www.who.int/reproductivehealth/publications/sexual_health/sh-linkages-rh/es/. Page 3

The right to marry and to found a family on the basis of free and full consent of the intending spouses and equality within the marriage and at the time of its dissolution.

The right to decide on the number and spacing of their children.

The right to information.

The right to education.

The right to freedom of expression and opinion.

The right to effective remedy in the case of violation of fundamental rights.

III. THE PROTOCOL AND ITS RECOMMENDATIONS

1. General Recommendations: Cross-cutting issues to build a motherhood service model for women with disabilities based on a human rights, gender, and intersectional focus.

The cross-cutting issues for women with disabilities to exercise their rights regarding sexuality and motherhood are the following:

1.1 Awareness raising

State Parties, society, professionals, health care and education workers, and workers of all institutions and services, whether public or private, shall recognize the dignity, personal identity, and the rights of women with disabilities.

It is also necessary to combat stereotypes, prejudices, and harmful practices relating to persons with disabilities, including those based on sex and age, in all areas of life. The capacities, skills, and abilities of women with disabilities must not be underestimated. This fully applies to their role as mothers in making their own decisions and providing free and informed consent, with reasonable support and adjustments requested by them or required as necessary.

Awareness must be promoted regarding the capacities and contributions that persons with disabilities can make, focusing on women with intellectual or psychosocial disabilities because the tendency is to legally separate them from their role as mothers due to their disability, a condition related to incapacity. In courts, they are considered unfit for motherhood without even being evaluated. This denial of motherhood from third parties is recurrent in the case of institutionalized women with disabilities. This is considered as discrimination on the basis of disability[9], understanding it as any distinction, exclusion, or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment, or exercise on an equal basis with others, of all human rights and fundamental freedoms.

People judge women with disabilities not only on exercising their motherhood but also on their right to sexuality when persons with disabilities can live their sexual lives as any others.

[9] Article 2 CDPD

1.2 The right to respect for personal dignity and privacy

All services provided to women with disabilities must respect their personal dignity, understood as a "quality inherent to the human condition from which fundamental rights derive, together with the free development of their personality, and because of this foundation, they are inviolable and inalienable."[10]

Similarly, no person with disabilities shall be subjected to arbitrary or unlawful interference with his or her privacy. States Parties shall protect the privacy of personal, health, and rehabilitation information of persons with disabilities on an equal basis with others[11].

Considering the respect for the dignity and privacy of women with disabilities, they have the right to obtain health services without an accompanying person. It cannot be required to provide services. The staff must be prepared to interact directly with women with disabilities, providing services with full accessibility and any corresponding reasonable accommodation.

1.3 Gender perspective or focus

Gender perspective is a strategy accepted worldwide to promote gender equality.[12] "It is a strategy to include the concerns and experiences of women and men in the creation, implementation, monitoring, and evaluation of policies and programs in all social, political, and economic spheres so that women and men can equally benefit from them, and to avoid perpetuating inequality. The ultimate objective is achieving gender equality[13].

Therefore, it is important to analyze disabilities from a gender perspective since women and girls with disabilities are usually invisible in gender and disability studies and research, thus being subject to double discrimination. The Convention on the Rights of Persons with Disabilities dedicates Article 5 to Equality and non-discrimination, which must always be considered.

1.4 Intersectionality [14]

Intersectionality is a tool for analysis to address the different components involved in the same case, multiplying disadvantages and discrimination. This approach allows observing problems from a holistic perspective, avoiding simplifying conclusions and, consequently, how such reality is addressed.

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[10] Pan-Hispanic Dictionary of Legal Spanish:
https://dpej.rae.es/lema/dignidad-de-la-persona

[11] Article 22 CDPD

[12] Resolution 47/2 Mainstreaming a gender perspective into all policies and programs in the United Nations system*
https://www.un.org/womenwatch/daw/csw/csw47/csw47Res472-s.pdf

[13] Sources: UNICEF, UNFPA, UNDP, UN Women. "Gender Equality, UN Coherence and you", ECOSOC agreed conclusions 1997/2.
https://trainingcentre.unwomen.org/mod/glossary/view.php?id=150&mode=search&hook=perspectiva+de+g%C3%A9nero&fullsearch=1

[14] This expression was used for the first time in the United Nations Conference against Racism, Racial Discrimination, Xenophobia and Related Intolerance held in South Africa in 2001.

From the point of view of intersectionality, for instance, any person can suffer discrimination for being older, a woman, coming from an indigenous community, having a disability, or living in poverty; and all the possibilities mentioned above for inequality can coexist in a single person, which places them at a greater risk of vulnerability. These circumstances or others may lead to multiple discrimination.

General Recommendation 25 of CEDAW recognizes that: "Certain groups of women, in addition to suffering from discrimination directed against them as women, may also suffer from multiple forms of discrimination based on additional grounds such as race, ethnic or religious identity, disability, age, class, caste or other factors. Such discrimination may primarily affect these groups of women, or to a different degree or in different ways than men."[15]

1.5 Accessibility

Accessibility is based on "universal design," which is the design of products, environments, programs, and services to be usable by all people, to the greatest extent possible, without needing adaptation or specialized design. To enable persons with disabilities to live independently and participate fully in all aspects of life, appropriate measures shall be taken to ensure to persons with disabilities access, on an equal basis with others[16]. For women with disabilities, accessibility must consider the following:

a. **Access to the physical environment**: buildings, roads, transportation, and other indoor or outdoor facilities, including schools, housing, medical facilities, and workplace. Access to other facilities and services open or provided to the public, both in urban and rural areas. Minimum rules and guidelines on the accessibility to these facilities must be applied to ensure that private entities that offer facilities and services open or provided to the public take into account all aspects of accessibility for persons with disabilities. Provide in buildings and other facilities open to the public signage in Braille and in easy-to-read and understandable forms. Provide forms of live assistance and intermediaries, including guides, readers, and professional sign language interpreters, to facilitate accessibility to buildings and other facilities open to the public.
b. **Access to transportation:** ensure that it is accessible for persons with disabilities when commuting to services near their homes and to services far from their homes as required by the situation of the child or the mother. This implies providing previous accessibility to information on commuting and timetables.
c. **Access to information and communication**: including systems and information and communication technologies (including the Internet) and processes and procedures. Promote other appropriate forms of assistance and support to persons with disabilities to ensure their access to information:

- Providing information intended for the general public to persons with disabilities in accessible formats and technologies appropriate to different kinds of disabilities.
- Accepting and facilitating the use of sign languages, Braille, augmentative and alternative communication, and all other accessible means, modes, and formats of communication of their choice by women with disabilities.
- It is vital for the mass media, including providers of information through the Internet, to make their services accessible to persons with disabilities.

General Recommendation 25, on paragraph 1, article 4 on the meaning and scope of temporary special measures in the Convention on the Elimination of All Forms of Discrimination against Women

[16] Article 9 inc 21 - CDPD

d. **Sign language interpretation services:** Interpreters represent autonomy for deaf and hearing-impaired mothers. Many times women do not want the company of a family member or close person who knows sign language or it may not be possible for them to accompany them or hire interpretation services.

Institutions must invest in accessibility and not depend on individual will. Cross-cutting interpretation alternatives are suggested to fulfill the right to accessibility, and in this sense:

- Every institution or public service that provides these services must have at least one employee with knowledge of sign language and be readily available to provide access to communication to deaf or hearing-impaired persons. If appropriate, an external person must be hired free of charge for persons with disabilities.
- Or, they should work with a government agency with a permanent staff of sign language professional interpreters to assign them to accompany deaf or hearing-impaired persons based on their needs and the location of the service. This free service must operate without bureaucracy, allowing to make online requests or send text messages via phone with short response times. For instance, this service can be installed in the Ministry of Health, the Ministry in charge of Gender Equality, or in a National Institution that addresses disabilities.

1.6. Reasonable accommodation

"Reasonable accommodation" means necessary and appropriate modification and adjustments, not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms[17]. The denial of reasonable accommodation is considered disability discrimination[18].

For example, when women with intellectual disabilities attend medical checkups, simple language must be used. It must be ensured that they understood indications, or in the case of women with visual disabilities, the procedures taking place must be described. The instruments used during the checkup must be shown beforehand, and a narration of the situation must be made during the checkup.

Similarly, to provide reasonable accommodation, intersections between the types of disabilities and other specific conditions of women must be considered. For instance, women with physical disabilities who use canes, have hearing impairments and belong to indigenous communities.

1.7 Assistance and support

Every person with disabilities has a right to enjoy legal capacity on an equal basis with others. Legal capacity is an attribute of personality, legitimate to all human beings to engage in activities and enter into contracts which has also been extended to expressing the will to free and informed consent for medical treatment, surgeries, or other procedures.

[17] Article 2 Definition of Reasonable accommodation - CDPD

[18] Article 2 Definition of disability discrimination - CDPD

States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity in all aspects of life with adequate and effective safeguards. The safeguards ensure that the measures relative to the exercise of legal capacity respect the rights, will, and preferences of women with disabilities[19].

Therefore, the above applies to exercising motherhood and raising children.

In this aspect, women with disabilities have the right to decide if they require support and choose who will provide it, how it will be provided, and for how long. People supporting women with disabilities (facilitators), if they decide to, may be a person whom they trust, an independent professional, or choose peer support, not necessarily from the health care area.

Persons with disabilities who receive support do not lose their protagonism, and therefore facilitators must provide all reasonable accommodations to allow a direct interrelation between mothers with disabilities and the technical or professional staff providing services.

2. Specific recommendations for services

Services must be adapted to the needs and development of women with disabilities in the different stages of their lives. Services must be provided to all women with disabilities, regardless of their individual or collective activism or empowerment to demand their rights.

2.1 Health services:

This is the most important service for women with disabilities regarding sexual and reproductive health education and support during pregnancy, childbirth, postpartum, and childrearing. It considers the services provided in health care centers, hospitals, clinics, and private hospitals.

a. Access to information and communication:

Women with disabilities must have access to complete, timely, and accessible information with the corresponding reasonable accommodation regarding health. Education and support to obtain information on sexual health and preventing violence, abuse, and mistreatment are required because these crimes are more frequent when women have disabilities.

Counseling is also needed to address reproduction, family planning, contraceptive methods, and fertilization and sterilization treatments, and for women to make their own decisions, they must provide free and full consent. It is also important to provide information on preventing HIV and other sexually transmitted diseases.

When providing accessible information and communication, it is essential to consider the cultural and linguistic diversities of women with disabilities, considering deaf or hearing-impaired women, women with intellectual disabilities, migrants, and members of indigenous communities, where communication requires cultural and language relevance.

[19] Article 12 CDPD

Comprehensive education and information on sexuality are vital to empowering all women, including those with disabilities, to get to know their bodies, sexual development, and their sexual and reproductive health rights, to protect them against sexually transmitted diseases and unwanted pregnancies, to establish healthy and pleasurable relations and to make informed decisions on their sexuality and reproduction, regardless of their age[20], marital status, sexual orientation, race, ethnicity, religion, socioeconomic status, among others, including intersections that may lead them to situations of vulnerability and discrimination.

Access to information must include the rights of persons with disabilities and, in particular, of women with disabilities and their sexual and reproductive rights, considering that sexuality can be diverse, and also provide information on the services, assistance and support available, and support networks for motherhood and disability.

In some cases, and to safeguard the lives and personal integrity (physical and mental) of women with disabilities victims of violence, either pregnant or mothers, it is necessary to provide them information on access to justice, support during legal proceedings, and offer them temporary shelters.

Access to these services and assistance and support must be timely and free from bureaucracy. The necessary means for women with disabilities to exercise their rights must be offered.

It is recommended that health and related services share all this information through collective workshops and individualized communication. An effective means of training is by including women with disabilities as rapporteurs. Further, hiring persons with disabilities for professional, technical, and administrative teams in these services allows for continuous awareness-raising, asking, and relating to users' needs.

Before pregnancy, education must include the decision to have children, preparing for pregnancy and childbirth, recommendations for a healthy pregnancy, getting to know each trimester of the pregnancy (changes in the body), discomforts, and frequent health issues. Regarding childbirth, information on natural or cesarean childbirth, warning signs, and the care of mothers and newborns must be included. Also, regarding the care of children, provide education on breastfeeding or other means of feeding, containment, sleep, diaper changing, hygiene, dressing, protecting their health, and how to move with them.

b. Accessible services with reasonable accommodation:

Pregnancy

Most women with disabilities receive the news of becoming mothers with joy, yet some feel afraid when thinking about how hard it can be to fulfill this role. Some fears and insecurities appear due to the obstacles or barriers they will face or because their health or their children's health may be affected. Many women think that their children may have a disability or that they will not be allowed to raise them. Certainly, the support of their families and organizations of persons with disabilities is essential for mothers-to-be, but this is not always available.

[20] UNFPA, UNFPA Operational Guidance for Comprehensive Sexuality Education: A focus on human rights and gender 6-8 (2014), https://www.unfpa.org/sites/default/files/pub- pdf/UNFPA_OperationalGuidanceREV_ES_web.pdf.

Health services must be provided during pregnancy, accessible services with reasonable accommodation for pregnancy diagnoses, assisted fertilization programs, pregnancy checkups, ultrasounds, and tests in general. This means that the physical facilities must be adapted for persons with disabilities, including restrooms, stretchers (low and without wheels), accessible gynecology chairs, and rooms on the first floor if no elevators are available.

Some implementation guidelines include the following:

- Offering at-home healthcare services at least once a month as requested or needed.
- Providing accessible transportation for health care services.
- Scheduling all appointments in one day.
- Training the staff in sign language, guidance, and mobility, as well as in simple language and easy reading, using pictograms, infographics, and images.

The most important thing to ask women with disabilities is how they need to be attended to during the service and spend more time with them than in regular appointments. Similarly, encourage them to ask questions and resolve doubts in the context of confidentiality.

The staff must provide care to women with disabilities directly, not relegating or invisibilizing them. Mothers with disabilities must make their own decisions about motherhood without making any assumptions or having third parties; even family members make decisions for them.

It must not be forgotten that routine checkups are as important for women with disabilities as for any other woman.

Childbirth

Consider the need to provide adaptive deliveries and make the rules of hospitals on accompanying during labor and visits more flexible, especially if the mother with disabilities requires support. Prepare the trusted person that will be in the room during birth and the mother in their support roles, breathing techniques, and communication. Assess the possibility of providing a single room at the hospital for mothers with disabilities before and after the delivery in case they require continuous support or different routines than those usually conducted in shared hospital rooms.

Become aware that delivery is not the appropriate time to offer last-minute sterilizations. This violates rights because it requires previous information and conversation. Forced sterilizations are against the right of all women to make free and informed decisions.

Delivery adaptations will depend on the disabilities and the decisions made by women with disabilities in terms of the best way to work during labor, the proper position to give birth, any supplies that are useful to facilitate the process (stretcher, birthing chairs, birth tubs) or if it is better to do it squatting or standing. Assess the most recommendable means of delivery (vaginal or cesarean) and if home birth is suggested.

During birth, companions must make reasonable accommodations to communicate with the woman giving birth. Women with disabilities need security and peace of mind, as in any other delivery.

Health institutions and State parties must also prevent any form of obstetric violence against women with disabilities. The WHO defines it as violence suffered by women during pregnancy and delivery by receiving physical mistreatment, humiliation, verbal abuse, or coercive or non-consented medical procedures.

Postpartum

Health services must maintain health care standards after delivery to protect the health of the mother and the newborn, not only in terms of their physical health but also through parental training programs adapted to teach the new parents how to care for their newborns. Consider mental health services that mothers with disabilities may require promptly after birth, on an equal basis with other women.

Women with disabilities have the right to raise their children, and the State parties, healthcare staff, and society must facilitate the exercise of this right on an equal basis with others, in all cases and without exception. Accessible information and training regarding childrearing and the assistance and support required must be provided.

c. Service staff

Healthcare professionals, assistants, and executives must provide persons with disabilities dignified and equal services with the same quality and options as any other person during the entire process. Respect free and full consent by raising awareness on the human rights, dignity, autonomy, and the needs of persons with disabilities through training and establishing ethical rules for public and private healthcare services.

This means respecting the dignity and personal identity of women with disabilities that request those services. Provide them with the good treatment that they deserve and with empathy. Women often try to hide their disabilities out of fear of discrimination and mistreatment. The staff must be continuously trained on the human rights model of persons with disabilities, with special consideration for mothers with disabilities, providing reasonable accommodation and guidelines.

Recommendations to provide services to women with different disabilities[21]

Women with visual disabilities

- Before interacting, tell them who you are.
- Use guiding words and not gestures.
- Ask them if they are blind or visually impaired.
- Help them move in the area, asking how they would like to be helped without invading them.
- Do not shout or overmodulate.
- If they use a cane, do not take it from them or raise the arm that carries it.
- Ask questions and comment on what you are doing, providing references to the place where you are.
- Say goodbye before moving away.

[21] Recommendations based on "A Health Handbook for Women with Disabilities," Hesperian Foundation 2007 https://es.hesperian.org/hhg/Un_manual_de_salud_para_mujeres_con_discapacidad. Chapter 2 To the health worker

Deaf or hearing impaired women:

- Make sure that they are paying attention before speaking. If they are not looking at you, you may touch their shoulder to turn around or start interacting.
- Do not shout or overmodulate.
- Look at them directly and do not cover your mouth so they can look at your facial expression.
- Ask what is the best way to communicate with them.
- If they do not communicate in sign language, use gestural language and simple written language as well as infographics prepared in advance (this is also useful for migrant and indigenous women and those who speak other languages.)

Women with physical disabilities

- Respect their pace of movement.
- If they use a wheelchair, sit facing them and do not touch the wheelchair or lean on it without asking for their permission.
- Do not move the crutches, cane, or any other support elements without asking for their permission, and make sure that these elements are returned to them if they have been taken.

Women with speech impairments

- If you cannot understand, do not pretend to do so.
- Ask them about how they would like to communicate.
- Ask questions that can be answered with a "yes" or "no."
- Give them all the time that they need to explain what is happening to them or what they need.

Women with intellectual disabilities

- If they are adults, do not treat them as children.
- Use simple words, brief sentences, and offer breaks.
- Open questions that are not inductive must be asked.
- Do not use acronyms or technical names in your explanations.
- Use pictograms, easy reading, and infographics; be flexible with protocols.

Women with psychosocial disabilities

- It is important to validate what they are saying, their requests, questions, and comments.
- Do not question them or minimize what they are expressing.

2.2 Support service for child-rearing at home

Women with disabilities can have different childrearing support needs. States Parties shall render appropriate assistance to mothers with disabilities in performing their childrearing responsibilities[22]. In no case shall a child be separated from their parents on the basis of a disability of either the child or one or both of the parents[23].

Assistance for child-rearing at home can consist of a person providing daily care for children. This type of assistance does not replace the mother or the father. Mothers and/or fathers make the decisions to satisfy the needs of their children, even when a third party is executing this task.

The mother's will is relevant to determine this assistance, how much they need for themselves, and the needs of the children. The assistance provided by State Parties must be provided promptly and consider the time between the birth of the child and their entry into the school system. It must include house adaptations and accessible transportation for the medical services provided to children if needed. In some cases, mothers with disabilities and their children with disabilities must have equal access to health services and individualized services, and even financial support. For the latter, the corresponding state entities must promptly address the request for these benefits, and a time limit must be set to evaluate the case, response, and effective availability of resources for mothers with disabilities.

2.3 Services referrals per interdisciplinary team

Considering the requests from women with disabilities during their pregnancy and or motherhood, it is proposed to have an interdisciplinary professional team as the focal point in the Ministry of Women and Gender Equity (or an equivalent Ministry) to coordinate the provision of the different public services to provide to mothers with disabilities, with the option of rendering these services at home. It must be considered that women with disabilities are always the ones making decisions, and the teams must suggest and explain their different options.

Services referrals must be made promptly, individually, and without bureaucracy. This interdisciplinary team must identify or look for support networks and refer mothers with disabilities according to their specific requests and needs. Brief response times must be considered to provide timely assistance and services. To cover the dynamic needs of mothers with disabilities, at least every year, it is vital to assess with them any amendments to these services.

Mothers with disabilities must receive accessible information and decide on which service or assistance they need, even with support, to make the decision.

Some areas in which women with disabilities may require services apart from child-bearing support services are the following:

[22] Article 23 No. 2 - CDPD
[23] Article 23 No. 4 - CDPD

a. **Psychological support**: Women with disabilities must have access to psychology professionals to receive timely, accessible, and affordable therapy support to exercise their sexual and reproductive rights, including support during pregnancy and motherhood.

   Regarding mental health, it is necessary to do psycho-affective preparation for motherhood, especially for those women with intellectual or psychosocial disabilities, and have mental health professionals trained in sign language for therapies.

b. **Pedagogical support:** It is important to support mothers in their role as parents of children in daycare centers, nursery schools, and schools as required. This role cannot be undertaken by another person only because the mother has a disability. Many times, mothers with disabilities feel threatened to lose their children's care. It is also necessary to consider any additional support needs for their children: speech therapists, psychologists, educational psychologists, etc. The education system must be prepared to embrace the diversity of mothers with disabilities.

c. **Job placement and reintegration services:** Offer specialized support for mothers with disabilities who wish to get a job or reintegrate into the labor market, as appropriate, balancing their work and family life, for instance, providing daycare centers near their workplaces, providing accessible transportation, and being flexible with working hours.

d. **Right to participate in adoption processes:** Women with disabilities can be part of adoption processes or go to similar institutions when they are supported through national law, protecting the child's best interests in all cases.

   Services referrals must be made promptly, individually, and without bureaucracy. This interdisciplinary team must identify or look for support networks and refer mothers with disabilities according to their specific requests and needs. Brief response times must be considered to provide timely assistance and services.

   Mothers with disabilities must receive accessible information and decide on which service or assistance they need, even with support, to make the decision. To cover the dynamic needs of mothers with disabilities, it is vital to assess with them and the interdisciplinary team, at least every year, any amendments to these services.

e. **Promoting peer support and community support networks**: All persons can develop better with support networks. This means being able to listen to or belong to peer groups or organizations of women with disabilities so they can relate and sympathize. These groups share experiences and actual forms of support and provide the emotional containment needed many times. Women with disabilities have the right to live an interdependent life and to be included in the community with their children.

f. **Legal representation:** Women with disabilities must be able to obtain legal representation to exercise their rights to motherhood, filiation, and childrearing, as required. For instance, if no reasonable accommodation is provided in services or they suffer discrimination. Regarding childrearing, it is important for them to have

legal representation in cases of alimony, direct and regular relation (known as visitation), recovering personal care, and filiation (paternity), as appropriate.

g. **Other specific and focused services:** In some cases, mothers with disabilities can be alone and in charge of their children and unemployed, due to which they require financial support for basic needs such as buying diapers, food, or paying their utility bills.

2.4 Institutional services

Women with disabilities must receive intersectoral and multidisciplinary services, and the institutions that provide them must do so in a timely, accessible, and[24] kind manner. This means that the Ministry of Women and Gender Equity, Social Development and Family, Education, Health, and Justice, among others, must be responsible for coordinating the execution of these policies.

Women with disabilities have the right to develop their public lives by going to banks, social security offices, municipalities, public services, community services, police stations, etc. These institutions must ensure accessible services not only in terms of space but also in terms of information, communication, and reasonable accommodation for those that need or require them.

Continuous training to raise awareness on the rights of persons with disabilities and especially women with disabilities, is vital in institutions or services.

IV. Suggested legal amendments

After analyzing the topics included in this model protocol, the following recommendations are made to be adapted as soon as possible:

- Compatibility between the remuneration or pension of mothers with disabilities and other subsidies or financial support provided by the State Parties.
- Benefits for mothers with disabilities must be part of State Policies on motherhood and must not change as administrations change.
- The response time for the different services requested by mothers with disabilities must be established in their internal regulations and not exceed 10 days. If the Service does not respond to the requestor in the mentioned term, they will have the right to file a complaint directly at the Directorate of the corresponding Service, notwithstanding any legal actions before the Courts of Justice with an expedited proceeding.
- Individualized support services for mothers with disabilities must be subject to continuous supervision to avoid situations that affect their dignity and rights.
- Mothers with disabilities may request a pension for their children if they have disabilities.

[24] When this model protocol refers to timely responses from services as requested by mothers with disabilities, this term shall not exceed 10 days.

Note:
The model protocol considers mothers with disabilities at all times, notwithstanding the fact that they are accompanied by or supported by the parent of their children or their families if they are alone.

Special Envoy of the Secretary-General on Disability and Accessibility, Prof. María Soledad Cisternas Reyes.