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MOMS

MOTHER MATTERS

The right of women with disabilities to motherhood

The Research book



MoMs

ERASMUS PLUS PROJECT
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INTRODUCTION and PROJECT'S AIMS

Before delving into the project's topic and aims, we have to understand what disability is.

Who are people with disabilities?

There is no EU-wide definition of disability. The United Nations *Convention on the Rights of Persons with Disabilities* (UNCRPD or UN Convention) uses an open definition which says that (Article 1) "Persons with disabilities include those who have long-term 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."

The Convention recognises that disability is an 'evolving concept' and one that "results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others."

In practice, the definition of disability depends on its intended use: for example, non-discrimination laws may be based on different criteria from those used to determine eligibility for state benefits. Moreover, definitions within the same policy area vary between Member States: the "Study on the situation of women with disabilities in light of the UNCRPD" provides a comparative analysis of differences in the emphasis that European countries place on the medical and social aspects of disability when adopting non-discrimination laws.¹



There are still many prejudices related to the world of disability, in particular when we talk about relationships, sexual needs or the issue of parenthood when it comes to people with disabilities. It is still a delicate issue in general, has been little explored, and the tendency, and people tend to hold many prejudices, while others make generalisations without being informed enough. There are many women with disabilities who are advised by their families and healthcare professionals against becoming mothers and who feel judged on a daily basis for their need to have a family.

According to the European Disability Forum,² women with disabilities constitute 16% of the total

population of women in the European Union and 60% of the overall population of 100 million persons with disabilities. This last percentage is equivalent to the population of a Nation, for example to that of Italy, which amounts to 60 million.

Even today, women and girls with disabilities face multiple forms of discrimination, which intersect in all areas of their lives: socio-economic disadvantages, isolation, physical and verbal violence, forced sterilisation and abortion, low-quality housing, institutionalisation, denial of the

¹ *European Disability Strategy 2010-2020: A Renewed Commitment to a Barrier-Free Europe*

² <https://www.edf-feph.org/women-and-gender-equality/>

opportunity to contribute and engage actively in society. It is thought that a woman with a disability is unable to build a career, lead a social and independent life, carry a pregnancy and raise children.

At the end of the 1960s, the USA and Europe experienced the outbreak of various cultural movements requesting civil rights protections. These cultural movements have brought about significant social changes, as well as notable law reforms. Nowadays, people with disabilities enjoy a greater degree of social participation in their communities than ever before. However, they still face multiple types of prejudice and often experience feelings of isolation. For example, people with disabilities are still asking for public recognition of their right to become parents. Still, in 2021, the national percentages of people who have been victims of psychological and physical violence were still high: for example, in Italy, almost 37% of women with disabilities claim to have been subjected to a form of violence.

The status of women and girls with disabilities is not only worse than that of women without disabilities but also worse than that of their male peers. This is especially so in rural areas with fewer services and opportunities for this group than in urban environments.

Raising awareness and sensibilisation of professionals, educators, families, and the general public about the misconceptions that exist regarding the skills of people with disabilities is the first step to improving these people's social life, promoting real inclusion and respecting all people.

The Erasmus plus project titled “Mother Matters (MoMs)” aims to spread awareness regarding the issue of motherhood for women with disabilities among related professionals and people with disabilities themselves. The “MoMs” project promotes the development of the two groups’ competences/skills, aiming to fill the existing communication and knowledge gaps at the national and European levels.

Other objectives are:

- identify the barriers that women with disabilities encounter in relationships with gynaecological-obstetric services,
- contribute to the empowerment and self-representation of people with disabilities,
- break down sexist stereotypes regarding the sphere of sexuality, affection and maternity and promote gender equality as well as improve dialogue between public and private institutions and people with disabilities.



The partnership aims to highlight the significance of the issue of accessibility when it comes to medical examinations related to women's reproductive health, with broader references to the person's relationship with their own body and with their femininity.

THE PARTNERSHIP

The idea of MoMs project was born during the last months of 2022 after reading several articles talking about mothers with disabilities and the challenges they had to daily face.

The five partners involved in this project come from four different countries (Italy, Spain, Bulgaria and Cyprus). They are all involved in social, cultural and inclusive subjects for people with and without disabilities.

The coordinator is the Turin Institute for the Deaf (here in short IST), based in Italy, it is a non-profit foundation for the inclusion of Deaf people from kindergarten to senior age.

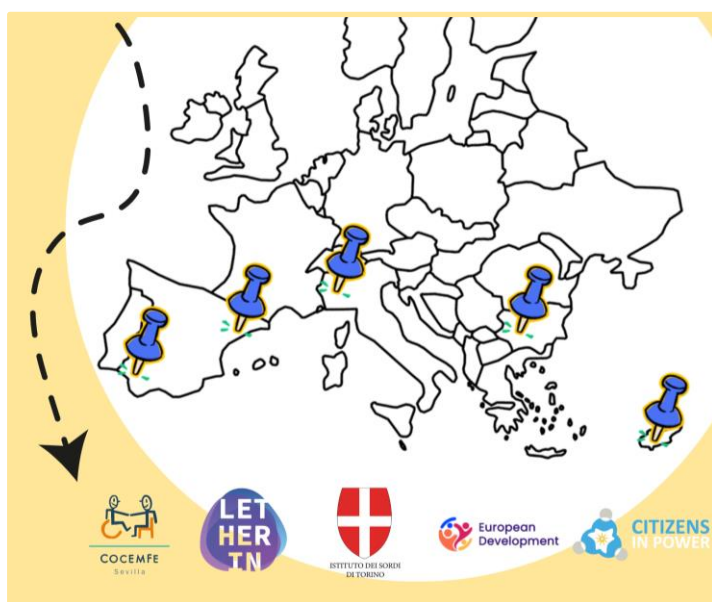
IST met the partners of this project on different occasions in the past, for instance Let Her In network (based in Spain) which is an international organisation born to support and enhance women, included IST from the beginning of its foundation since the two share common values. IST worked with COCEMFE Sevilla in former European projects about women with disabilities inclusion in the labour market (Ready Women Erasmus plus project) and about independent life for people with disabilities in rural areas (Rural in life - <https://www.ruralinlife.eu/>).

European Development Foundation (EDF) is an organisation born in 2011 in Bulgaria that works for the social integration of vulnerable members of society. It is managed by three women and from 2022 is part of Let Her In network, too.

Citizens In Power (CIP) is a non-profit, educational and research organisation. It worked with IST in former European projects about accessibility in different areas such as schools' materials (RecreaMaths), green and ecological topics (Green Gardens and CitSci4All), economy (Fingo), culture (Bibliodos and Periegesis).

The partnership complement each other in the skills and competences developed during the years. In particular, IST is expert in Deaf community needs and accessibility for people with disability; Let Her In is expert on gender issue topics and inclusion of women in all social and life areas; COCEMFE Sevilla is expert in accessibility and inclusion of people with physical and organic disabilities, as well as psychological support for people with disabilities; EDF developed great expertise on creation of inclusion environments for kids with disabilities, continuous education and cultural

exchange on the territory, EDF knows how to evaluate a situation and take the right steps to improve it; CIP is really connected with the society, CIP constitutes one of the leading organisations in Cyprus in the fields of global education, social innovation, entrepreneurship, STEM and sustainable growth, CIP knows how to talk with people and disseminate the material produced.



LEGAL AND CULTURAL FRAMEWORK IN EUROPE: *UN CONVENTION AND AGENDA 2030*

When talking about Europe and human rights, we can't fail to talk about two important documents: the *UN Convention on the rights of persons with disabilities* (UNCRPD)³ and the Agenda 2030.⁴

The first one is an international treaty aimed at combating discrimination and violations of human rights. Inspired by the *Universal Declaration of Human Rights* of 1948, the *UN Convention on the rights of persons with disabilities* confirms the fundamental principles in relation to the rights of equal opportunities and non-discrimination. Written in 2006 in New York, it is composed of 50 articles analysing the different life elements about which freedom in choice and respect as to be protected. From the UN Convention we will talk in particular about five articles (number 6, 8, 9, 19 and 23), fundamental for our topic, women with disabilities.

The *2030 Agenda for Sustainable Development* is a program of action for people, planet and prosperity. It takes into consideration not only persons, but also nature on earth and underwater, the climate, the labour market and how they interact and intertwine their energies. The Agenda 2030 was signed in 2015 by the States parties of the United Nations Organization, it consists of 17 objectives called Sustainable Development Goals (SDGs), each one composed by specific "little" objectives. The two main topics that are interesting for the project's topic are goal number 3 (good health and well-being) and number 5 (gender equality).

Let's get to know all the subjects mentioned before in detail!

The first and specific article dedicated to "women with disabilities" in the UN Convention is article number 6: "States Parties recognize that women and girls with disabilities are subject to multiple discrimination, and in this regard shall take measures to ensure the full and equal enjoyment by them of all human rights and fundamental freedoms." The recognition of an even more difficult situation in the disability condition, as well as the awareness of a higher risk of multiple discrimination is important to underline because it means that more attention is needed. Article number 8 enhances this aspect of awareness and cultural support in society of women with disabilities, in particular it says "to raise awareness throughout society, including at the family level, regarding persons with disabilities, and to foster respect for the rights and dignity of persons with disabilities."

The *UN Convention on the rights of persons with disabilities* dedicates a significant part to accessibility and independent life (articles 9 and 19) to highlight how autonomy in all aspects of life, from reading a book to going to museums to work, is fundamental. We are never really conscious of that importance till when we lose such freedoms. "To enable persons with disabilities to live independently and participate fully in all aspects of life, States Parties shall take appropriate measures to ensure to persons with disabilities access, on an equal basis with others, to the

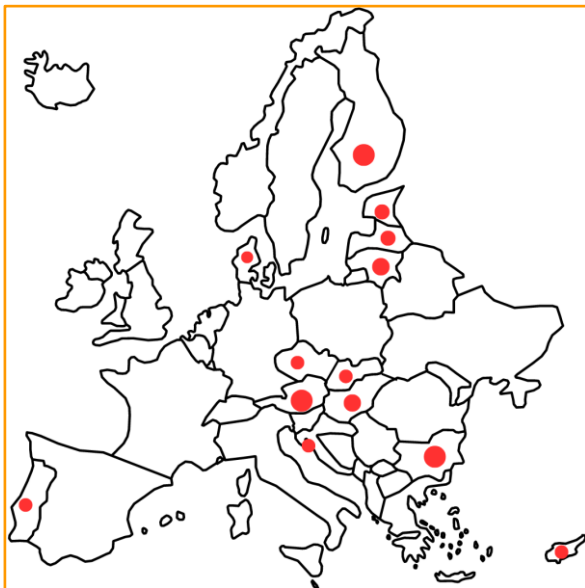
³ <https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-rights-persons-disabilities>

⁴ <https://sdgs.un.org/2030agenda>

physical environment, to transportation, to information and communications, including information and communications technologies and systems, and to other facilities and services open or provided to the public, both in urban and in rural areas.” And again, “persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement”.

Last but not least, from the UN *Convention on the rights of Persons with disabilities*, article number 23 about the “respect for home and the family:”

- a. The right of all persons with disabilities who are of marriageable age to marry and to found a family on the basis of free and full consent of the intending spouses is recognized;
- b. The rights of persons with disabilities to decide freely and responsibly on the number and spacing of their children and to have access to age-appropriate information, reproductive and family planning education are recognized, and the means necessary to enable them to exercise these rights are provided;
- c. Persons with disabilities, including children, retain their fertility on an equal basis with others.



This last article is linked with the third goal of Agenda 2030: “ensure universal access to sexual and reproductive health-care services, including for family planning, information and education.” Nowadays, it seems to be an obvious topic, but it’s not! At the end of 2023, the European Disability Forum faced an issue raised by the European Union countries, during Council meetings. The 6th of February 2024, the Parliament and the Council of the European Union met for agreeing on a Proposal for a Directive on combating violence against women and domestic violence⁵ throughout the European Union. The Proposal talks about the crime of forced sterilisation, it is included among

the acts of violence against women, but there is no dedicated article with related sanctions as has been structured for other types of violence. European Disability Forum highlighted this fact⁶ and also the European reality that there are still some countries that allow the forced sterilisation of women: Bulgaria, Cyprus, Croatia, Denmark, Estonia, Finland, Latvia, Lithuania and Slovakia. Furthermore, three EU countries still allow the sterilisation of women and minors with disabilities: Portugal, the Czech Republic and Hungary.

⁵ <https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=CELEX%3A52022PC0105>

⁶ <https://www.informareunh.it/edf-per-lunione-europea-la-sterilizzazione-forzata-non-e-reato-occasione-sprecata/>

The European Disability Forum has therefore stated that the anti-violence directive should represent a great improvement for the situation of girls and women with and without disabilities across Europe, but what remains in practice is the feeling of a missed opportunity to "to take a further step in civilization."

In any case, the document represents a fundamental support for objective number 5 of the 2030 Agenda on achieving "gender equality and the empowerment of all women and girls". In fact, among the specific sub-objectives we find the elimination of all cases of violence, sexual exploitation and genital mutilation.

In conclusion, in this short and concise European framework on the human rights of people with disabilities, the Mother Matters project aims to culturally improve awareness on the topic of motherhood for women with disabilities. Freedom to choose what to do with one's body, not only in reproductive matters, but also in healthcare, in daily autonomy and in every aspect of life.

LEGAL AND CULTURAL FRAMEWORK IN EACH PARTNER COUNTRY

ITALY

In Italy, as of 2019, 5.3%⁷ of the population has officially declared having a disability, approximately 60% of them are women. Of course, this percentage rises if we think that there are a lot of people that do not declare to have a disability or that are not helped to obtain a declaration and thus support from social services.

The main national law which protects the rights of people with disabilities is Law number 104 passed in 1992, more than 30 years ago, under the title "Framework law for assistance, social integration and the rights of disabled people."⁸ This law ensures the rights of people with disabilities and the support offered to them by the different governmental services (education, healthcare etc.), but doesn't make any special references to the support specifically women with disabilities. The focus is on the factor of disability in general and how to diagnose it in time to organise medical, social and educational interventions. Law number 104/92 promotes the inclusion and social integration of people with disabilities, providing the necessary means, tools and assistive services, as well as interventions in favour of both the people themselves and their caregivers (family members who take care of the needs of the relative with disability).

⁷ <https://www.istat.it/it/archivio/226919>

⁸ <https://www.gazzettaufficiale.it/eli/id/1992/02/17/092G0108/sg>

In 2009, the Parliament of the Italian Republic recognised the UN *Convention on the Rights of People with Disabilities* and integrated its provisions into the national legal framework, under the law passed on 3 March 2009, n. 18.

After consulting the data contained in a report issued by UILDM (Unione Italiana Lotta alla Distrofia Muscolare - Italian Union to Fight Muscular Dystrophy) in 2022, after interviewing a sample of women with disabilities, we can highlight some important facts and percentages:⁹

- more than 55% of the women interviewed regularly carry out obstetric-gynaecological and breast checks, of which only 34% are part of a regional or national campaign for the prevention of female cancers;
- during gynaecological visits, only 31.5% of women receive information on contraception; 55% stated they didn't receive any other contraceptive advice. This data is significant in highlighting the stereotype that exists, according to which people with disabilities are "asexual", so they don't have any sexual desires or any sexual relations, and thus they don't need to receive any information about their reproductive health and about how to protect it;
- for those healthcare visits that involve moving oneself to a special bed, only 56% of the medical staff asked the woman how she wanted to be helped with moving. However, the great majority of those asked (83%) noted that there is a lack of an available lift or trained staff able to help them. In the preparatory phase for the visit, only 28% of the women interviewed were able to use an accessible changing room. Finally, during these types of visits, a significant number of interviewees (62%) stated that assuming certain positions to carry out the visit or using certain machinery created difficulties for women with disabilities.

Another percentage that we have to consider for further reasoning is related to physical or sexual violence topics: 31.5% of women noted that they have suffered from physical or sexual violence over their lifetime. What about women with disabilities? The percentage increases: 36%. This is a delicate point to be investigated and analysed. Considering that this data reflects only the situations which have been recorded, what about the women who don't have the chance or the means to communicate that they have been victims of violence, or who don't realise that what they experience is violent because of an inappropriate education?

On September 14, 2022, the Unified Conference of the Government, the Regions, the autonomous Provinces of Trento and Bolzano, and the Local Authorities led to the stipulation of an Agreement,¹⁰ which is related to the minimum requirements of Anti-Violence Centres (CAV). The Anti-Violence Centres are structures that "provide prevention and reception services, free of charge, in compliance with confidentiality and anonymity, to all women who are victims of male violence or who find themselves exposed to this risk, together with their minor daughters/sons,

⁹ https://uildm.org/sites/default/files/Report%20Donne%20Sessualit%C3%A0_UILDM.pdf

¹⁰ https://www.informareunh.it/wp-content/uploads/Presidenza-Consiglio-dei-Ministri-Conferenza_Unificata_Intesa_centri_antiviolenza_case_rifugio_14_9_22.pdf

regardless of their place of residence."¹¹ The agreement is made up of fifteen articles and regulates the defining aspects, the structural and organisational requirements, the activity and training of the operators, the minimum guaranteed services, the accompaniment path, networking, the information flow, and the obligations to which the aforementioned structures are subject. It's important to highlight that the agreement contains relevant elements for the reception of women with disabilities who are victims of violence, including, for example, the explicit prohibition of discrimination on the basis of ability, the attention given to the accessibility of anti-violence centres and the provision of various methods of contact, the fact that operators also receive training on the specific needs of women exposed to multiple discriminations.

People who need to contact Anti-Violence Centres have to check in their territory the nearest one, since those places are based and organised at a local level: they can be managed by associations operating in the sector of support and assistance to women victims of violence or by public bodies and local authorities, individually or in association.

In Italy, in social contexts, disability is still seen as linked to charity and pietism. Even if the law about inclusion (Law 104/1992) is one of the best in the world because it is focused on the individual and on the needs of each one, the common feeling is that people with disability are poor people to help. They are not seen as autonomous. Disability is still something medical to take care of, not a condition to improve by improving the environment and the culture of awareness.

BULGARIA

According to the data collected on the health status of the population from the last census conducted in September 2021, the percentage of people with disabilities in Bulgaria is close to 10%. As of September 7, 2021, 654,547 persons have been recognized as having permanently reduced working capacity or a degree of disability. Of these people, 22,248 are children, and 632,299 are persons aged 16 and over. Also, as of September 7 2021, for every 1,000 people aged 16 and over, 124 have disabilities. The value of the coefficient for women is higher (129 per 1,000 women) than for men (118 per 1,000 persons of the relevant population). Among boys under the age of 16, 31 out of 1,000 boys have a disability. For girls, the indicator is 22 per 1,000 of the corresponding population.¹²

In 2012, Bulgaria ratified the UN *Convention on the Rights of Persons with Disabilities* (CRPD) and is committed to applying the principles of respect for dignity and individual autonomy, equal opportunities, non-discrimination and effective inclusion in society, accessibility, respect, acceptance, etc. Despite the political commitment and the reform carried out, people with disabilities still face a number of challenges in exercising their rights. These problems affect all major areas of life, and existing policies are not yet sufficient to address the challenges.

¹¹ https://www.informareunh.it/wp-content/uploads/Presidenza-Consiglio-dei-Ministri-Conferenza_Unificata_Intesa_centri_antiviolenza_case_rifugio_14_9_22.pdf (article 1)

¹² <https://nsi.bg/sites/default/files/files/pressreleases/Census2021-hd.pdf>

Additionally, as of 2018, more than 7,000 people have been placed under full or partial unemployment detention so that they cannot make decisions about their own lives. The law for individuals and the family, which regulates the institution of interdiction, has been in force since 1949, and its principles are outdated. It allows guardians or trustees to govern over or approve decisions made by disabled people about their personal lives and property. People placed under total interdiction cannot marry.¹³

There are programs related to employment and requalification, programs for people with disabilities who want to start their own businesses, but there is no specific program that supports women with disabilities who want to have children and start a family. The main law enforced in these cases is the general law on people with disabilities, which regulates public relations related to the exercise of the rights of people with disabilities. Although one of the areas addressed under this law relates to people's personal lives, there is no established practice followed in Bulgaria regarding these cases, such as a provision following the recommendation of the European Parliament related to women with disabilities and pregnancy.

The recommendations of the UN Committee on the rights of people with disabilities towards Bulgaria are related to the observance of the rights of people with disabilities in various areas, including any stereotypes and discriminatory practices, the issue of disadvantaged women and girls with disabilities, the legal framework for equality, the complaint mechanisms that are in place, the issue of marriage and family relations, the institution of guardianship, etc. Changes related to the *National strategy for people with disabilities for the period 2021-2030* are also underway in Bulgaria.

SPAIN

In 2020, in Spain, 9.26% of the population has declared disability. Of this percentage, approximately 58.64% are women.¹⁴

In Spain, the legal and cultural framework for the rights and needs of women with disabilities is characterised by both international agreements and national legislation. At the international level, the *Convention on the Elimination of All Forms of Discrimination Against Women* (CEDAW) (UN, 1979) is undoubtedly the reference framework for women's rights. Specifically and in relation to maternity, its Optional Protocol of 1999, in Article 12, states that States must guarantee women the appropriate services in relation to pregnancy, childbirth and the postnatal period, providing services free of charge when necessary and shall ensure adequate nutrition during pregnancy and lactation.

¹³ https://www.noveleea.bg/wp-content/uploads/2022/09/Tematikhen_doklad_hora_s_uvrejdania_bg.pdf/

¹⁴ Instituto Nacional de Estadística (INE). (2020). *Encuesta de Discapacidad, Autonomía personal y situaciones de Dependencia 2020*. <https://www.ine.es/>

The *Convention on the Rights of Persons with Disabilities* (UN, 2006)¹⁵ makes no explicit reference to the reproductive rights of women and men with disabilities, but rather the issues related are declared in Article 23, on Respect for the home and the family, and Article 25 on Health.

In addition, *The European Strategy for the Rights of Persons with Disabilities (2021-2030)*¹⁶ commits, in point 5.2., to equal access to social protection, health, education, goods and services. Furthermore, in point 5.4., dedicated exclusively to the right to health, accessibility issues are addressed. In the same point, Member States are urged to improve access to health care for persons with disabilities, including sexual and reproductive health.

Among the most important laws is *Ley Orgánica 3/2007 para la Igualdad Efectiva de Mujeres y Hombres* (BOE, 2007)¹⁷ [*Organic Law 3/2007 for Effective Gender Equality*]. This law establishes in Article 27 the commitment to integrate the principle of equal opportunities in health policies, and recognises in its Explanatory Memorandum the need to pay special attention to cases of double discrimination and the unique difficulties faced by women who are particularly vulnerable, such as women belonging to minorities, migrant women and women with disabilities.

Another important law is *Ley 27/2003, de 31 de julio, reguladora de la Orden de Protección de las víctimas de la violencia de género*¹⁸ (*Law 27/2003, of 31 July, regulating the order of protection for victims of gender-based violence*). These laws focus on the protection and promotion of the sexual and reproductive rights of women with disabilities, including specific measures to prevent and combat gender-based violence within this group.

Likewise, in *Ley Orgánica 1/2023, de 28 de febrero, por la que se modifica la Ley Orgánica 2/2010, de 3 de marzo, de salud sexual y reproductiva y de la interrupción voluntaria del embarazo* (BOE, 2023),¹⁹ [*Organic Law 1/2023, of 28 February, on sexual and reproductive health and the voluntary interruption of pregnancy*], it mentions among its objectives set out in article 5, public policies for sexual and reproductive health, the elimination of all forms of discrimination, with special attention to those persons with some type of disability, who will be guaranteed their right to sexual and reproductive health, establishing for them the necessary support according to their disability.

At the level of state public policies related to sexual and reproductive rights, the *Strategy for Normal Birth Care in the National Health System* (EAPN, 2007) represented an important change in terms of the approach and practices of humanisation in childbirth, as it has tried to improve the

¹⁵ United Nations. (2006). *UN Convention on the Rights of Persons with Disabilities*.

<https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/convention-on-the-rights-of-persons-with-disabilities-2.html>

¹⁶ European Commission. (2021). *The European Strategy for the Rights of Persons with Disabilities (2021-2030)*.

<https://ec.europa.eu/social/main.jsp?catId=738&langId=en&pubId=8376&furtherPubs=yes>

¹⁷ BOE. (2003). *Ley Orgánica 3/2007, de 22 de marzo, para la igualdad efectiva de mujeres y hombres*. Boletín Oficial del Estado, núm. 71, de 23 de marzo de 2007, 12611-12630. <https://www.boe.es/eli/es/lo/2007/03/22/3>

¹⁸ BOE. (2003). *Ley 27/2003, de 31 de julio, reguladora de la Orden de Protección de las víctimas de la violencia de género*. BOE núm. 185, de 5 de agosto de 2003, pp. 31387-31394. <https://www.boe.es/eli/es/l/2003/07/31/27>

¹⁹ BOE. (2023). *Ley Orgánica 1/2023, de 28 de febrero, por la que se modifica la Ley Orgánica 2/2010, de 3 de marzo, de salud sexual y reproductiva y de la interrupción voluntaria del embarazo*. BOE núm. 51, de 1 de marzo de 2023, pp. 30334-30375. <https://www.boe.es/buscar/doc.php?id=BOE-A-2023-5364>

information and participation of women, to offer humanised care, oriented to the needs of women. In addition, its principles include those related to care for women with disabilities: "women with disabilities must receive information adapted to their physical, intellectual or sensory capacities."

Of particular interest due to its direct thematic link with the research in question is the sociological study carried out in 2022 entitled *El discurso de las mujeres con discapacidad en torno al ejercicio de la maternidad y su derecho a formar una familia* ('The discourse of women with disabilities on motherhood and their right to start a family'), promoted by the 'Observatorio Estatal de la Discapacidad del Ministerio de Derechos Sociales y Agenda 2030 del Gobierno de España' (OED, 2022).²⁰ The general objective of this study was to provide knowledge on the situation of the reproductive rights of women with disabilities in Spain. To this end, it has highlighted the regulatory and policy framework in relation to the reproductive rights of women with disabilities. It has also made visible some of the knowledge generated about motherhood among women with disabilities, highlighting the existing gaps in the real and effective exercise of the reproductive rights of women with disabilities. For example, through the existing stereotypes in relation to the reproductive rights of women with disabilities.

'Plena inclusión España', a well-known organisation in Spain, has actively contributed to promoting the rights of women with disabilities. The *Guía informativa de apoyo a la maternidad y crianza en lectura fácil* ('Informative guide to support motherhood and parenthood') by 'Plena inclusión Madrid' provides valuable information and advice for mothers with intellectual or developmental disabilities. In addition, the book *Maternidad – Paternidad en personas con discapacidad intelectual* ('Start Publications Motherhood - Parenthood In People With Intellectual Disabilities') by Xabier Etxebarria explores the ethics of parenthood for people with intellectual disabilities, emphasising the importance of moral considerations, autonomy and ethical reflection.

'Plena inclusión España' has played a crucial role in advocating for the rights of women with disabilities. In September 2020, they celebrated the abolition of forced sterilisation in Spain, especially for women with intellectual disabilities. The change in the legal framework, which only allows sterilisation with the informed consent of the person concerned, was a significant success after years of lobbying by the disability rights movement, including 'CERMI Mujeres'. 'Plena inclusión' emphasised compliance with the UN *Convention on the Rights of Persons with Disabilities* and pointed out that people with disabilities must be supported so that they can exercise their parenthood. The organisation also stressed the importance of guaranteeing full sexual autonomy, preventing sexual abuse and promoting reproductive health through gynaecological examinations.

In response to the International Day for Sexual and Reproductive Rights, 'Plena inclusión' launched the #EsUnHechoSonMisDerechos ('#ItIsAFactTheyAreMyRights') campaign to address the inequality and stigmatisation of women with intellectual disabilities. This campaign, which involves

²⁰ Observatorio Estatal de la Discapacidad del Ministerio de Derechos Sociales y Agenda 2030 del Gobierno de España. (2022). *El discurso de las mujeres con discapacidad en torno al ejercicio de la maternidad y su derecho a formar una familia*. <https://www.observatoriodeladiscapacidad.info/el-discurso-de-las-mujeres-con-discapacidad-en-torno-al-ejercicio-de-la-maternidad-y-su-derecho-a-formar-una-familia/>

"sexual and reproductive rights promoters", empowers women with intellectual disabilities to lead micro-projects focussing on education and awareness in 13 autonomous communities. These promoters emphasise the need to raise awareness of sexual and reproductive rights and stress the importance of understanding and support from healthcare professionals, families and society in general.

In addition, the recent reform of Article 49 of the Spanish Constitution represents a significant step forward, as the term 'disminuido' (disabled) has been replaced by 'personas con discapacidad' (people with disabilities). This change reflects a renewed commitment to equality and the removal of barriers and recognises the essential contribution of women with disabilities.

In collaboration with 'Fundación ONCE' and co-funded by the European Social Fund, 'Discapnet', an initiative to promote the social and professional integration of people with disabilities, provides a platform dedicated to motherhood for women with disabilities. Their informative guide to pregnancy covers various aspects, including foetal development, physical changes, medical examinations and childbirth. Discapnet dispels myths about motherhood for women with disabilities

CYPRUS

Obtaining precise data on current disabled individuals in the Republic of Cyprus, including disabled women, is challenging due to limited availability. The Department for Social Inclusion of Persons with Disabilities reports 7,063²¹ individuals receiving disability benefits, with 3,449 being women, primarily covering mobility or visual disabilities. Efforts to gather comprehensive data, including reaching out to the Welfare Benefits Administration Service, have not yet yielded a response. [Eurostat's 2022 survey](#) reveals a consistent EU trend; disabled women outnumber men in Cyprus. The data shows 19.9% of disabled individuals are women.²²

Cyprus joined the *European Convention on Human Rights* (ECHR) in 1962, a foundational treaty crafted by the Council of Europe in 1950 to safeguard human rights. Effective since 1953, the ECHR, while not explicitly specifying rights for individuals with disabilities, mandates contracting states to ensure these rights and freedoms for everyone within their jurisdiction, as stated in [Article 1](#).²³ In 2007, Cyprus became a party to the *UN Convention on the Rights of Persons with Disabilities* (CRPD), symbolising a significant commitment to inclusive social policies for individuals with disabilities. The Convention, signed in 2007 and ratified in 2011, emphasised promoting, protecting, and ensuring the full and equal enjoyment of human rights for people with disabilities, aligning with the focus on upholding their inherent dignity. This commitment led to the

²¹ Email exchange with the Department for Social Inclusion of Persons with Disabilities (February 19, 2024)

²² Eurostat. (2022). *Disability in the EU: Facts and figures*. [Disability in the EU: facts and figures – Consilium \(europa.eu\)](#)

²³ Council of Europe. (1950). *European Convention on Human Rights*. https://www.echr.coe.int/documents/d/echr/convention_ENG

establishment of the Department of Social Inclusion of Persons with Disabilities in 2009 and the approval of the first *National Disability Action Plan* by the Council of Ministers in 2013, showcasing Cyprus's dedication to implementing the Convention's principles.²⁴

In March 2021, the European Commission introduced the *2021-2030 Strategy for the Rights of Persons with Disabilities*, succeeding the *2010-2020 European Disability Strategy*. Aligned with the *UN Convention on the Rights of Persons with Disabilities*, ratified by the EU in 2011, and in harmony with the *UN 2030 Agenda for Sustainable Development*, this strategy outlines priorities and initiatives for EU Member States to enhance the well-being of disabled individuals. In addition, Cyprus actively participates in the '[Council of Europe Disability Strategy](#)', emphasising human rights, democracy, and the rule of law. This strategy, adopted in 2016, complements the UN Convention, urging states to implement actions promoting equality, non-discrimination, awareness, accessibility, equal recognition, and protection from exploitation and violence.

The 'Ministry of Labour, Welfare, and Social Insurance' in Cyprus oversees the social protection system, managing both monetary and non-monetary benefits. Besides governmental entities, various NGOs, parents' associations, charitable organisations, community volunteer councils, and private sector entities contribute to providing welfare services for individuals with disabilities. The 'Department for Social Inclusion of Persons with Disabilities', established in 2009, plays a vital role, overseeing disability evaluation, administering social benefits, facilitating vocational rehabilitation, and coordinating the implementation of the *UN Convention for the Rights of Persons with Disabilities* and the *National Disability Action Plan*.²⁵

The [First National Disability Strategy](#) aligns with the Ministry of Finance's *Strategic Planning Guide*, incorporating a vision, values, goals, and objectives. Linked to recommendations from the UNCRPD Committee, the *European Disability Strategy 2010-2020*, and the Council of Europe's *Disability Strategy 2017-2023*,²⁶ this strategy guides state actions to enhance the quality of life for individuals with disabilities. The [Second National Disability Action Plan](#) (2018-2020) involves eighty-six actions across eight ministries, focusing on independent living, social inclusion, mobility, and social protection. It addresses employment, vocational training, education, environmental accessibility, health and rehabilitation services, and raises awareness on disability issues.²⁷

Individuals with disabilities, excluding paraplegic and quadriplegic individuals receiving care benefits, can access care benefits from 'Social Welfare Services'. Eligibility is tied to qualification for the Guaranteed Minimum Income, currently at EUR 480 per month, subject to specific criteria set by the 'Welfare Benefits Management Service' (Independent Authority for the Promotion of the Rights of Persons with Disabilities, 2016). For elderly individuals with disabilities, eligibility is determined through assessment and certification by a 'Disability Assessment Centre', following

²⁴ UNHCR. (2017). *Committee on the Rights of Persons with Disabilities considers initial report of Cyprus*.

<https://www.ohchr.org/en/press-releases/2017/03/committee-rights-persons-disabilities-considers-initial-report-cyprus>

²⁵ Rotarou, E. S. (2019). *Cyprus fact Sheet on Social Care & Support*.

https://easpd.eu/fileadmin/user_upload/Publications/easpd-cyprus_fact_sheet.pdf

²⁶ Department for Social Inclusion of Person with Disabilities. (n.d.). *Council of Europe Disability Strategy*.

http://www.dmsw.gov.cy/dmsw/dsid/dsid.nsf/dsipd9a_en/dsipd9a_en?OpenDocument

²⁷ Department for Social Inclusion of Persons with Disabilities. (n.d.). *National action plan on disability*.

http://www.dmsw.gov.cy/dmsw/dsid/dsid.nsf/dsipd8b_en/dsipd8b_en?Openform

European Union guidelines from 2018. Community Volunteer Councils, established by local authorities, play a crucial role in securing funding for services catering to the elderly, children, infants, and individuals with disabilities, relying on funding from Social Welfare Services.

According to the *European Semester 2022-2023 country fiche on disability equality*, the employment gap between individuals with and without disabilities in Cyprus has notably widened, reaching 27% points in 2021, surpassing the EU average. Despite the overall low risk of poverty or social exclusion in the country, certain groups, including people with disabilities and those born outside the EU, face elevated risks.

In alignment with the country's *Recovery and Resilience Plan*, there are measures encouraging local communities to transition to climate mitigation and adapt to changing conditions. This plan includes calls for investments in energy efficiency for buildings, renewable energy use, and sustainable urban and rural transport projects. These initiatives aim to reduce energy consumption, greenhouse gas emissions, and improve accessibility, particularly benefiting individuals with disabilities. However, despite these efforts, the disability employment gap remains a challenge, with labor shortages observed in various sectors. The 'European Social Fund Plus' (ESF+) supports active labor market policies to address these challenges. In the context of the evolving skills landscape, Cyprus faces a digital literacy gap, with only 50% of the population having basic digital skills, below the EU average. The early school leaving rate, though slightly reduced, remains above the EU average, posing challenges for specific groups, including non-EU-born individuals and persons with disabilities.²⁸

²⁸ Felix, A. (2023). *European semester Spring Package 2023: How well does it reflect the issues faced by persons with disabilities?*. European Disability Forum. <https://www.edf-feph.org/publications/european-semester-spring-package-2023-how-well-does-it-reflect-the-issues-faced-by-persons-with-disabilities/>

FOCUS GROUPS

METHODOLOGY

A focus group is a group of selected people involved in a discussion of a pre-established topic, with the aim of determining the basic ideas and orientations of a larger group of people. It usually lasts between 60 and 90 minutes and engages between 7 and 10 people.

The information collected in a focus group can vary according to the aim of the activity. For example, some women wanted to say their age and tell in brief their life and family composition, others didn't and directly started to discuss the topic of the project.

The main feature of this kind of qualitative investigation consists in the possibility of recreating a situation similar to the ordinary process of opinion formation, allowing participants to express themselves through a usual form of communication, discussion between "peers." The subjects involved define their position on the topic by comparing themselves with other people, while the researcher can limit his influence on their answers and distinguish more or less deeply rooted opinions.



FOCUS GROUPS - PERSONS WITH DISABILITIES

Phases and questions:

1. Presentation of the moderators and of the topic of the discussion.
2. Presentation of each participant.
3. Article 6 of the UN *Convention on the Rights of People with Disabilities* (UNCRPD) states the following:
 - a) "States Parties recognize that women and girls with disabilities are subject to multiple discrimination, and in this regard shall take measures to ensure the full and equal enjoyment by them of all human rights and fundamental freedoms."
 - b) "States Parties shall take all appropriate measures to ensure the full development, advancement and empowerment of women, for the purpose of guaranteeing them the exercise and enjoyment of the human rights and fundamental freedoms set out in the present Convention."

What are your feelings about these statements? Do you have any experiences to share related to Article 6 of the Convention?

4. How can women's right to choose and self-determination be respected?
5. There is a tendency to think that if a woman has difficulty taking care of herself, she will not be able to take care of a child. What do you think about this view?
6. What are the factors that do not allow full independence to girls and women with disabilities? What about these factors particularly when it comes to motherhood?
7. An African proverb states the following: "It takes an entire village to raise a child." In your experience, what role does the family (and the broader community) have in the journey of a woman through motherhood?
8. Do you think the government should invest more resources in emotional education and sexual education in schools and in society more broadly?
9. One of the UN's sustainable development goals expected to be reached by 2030 is gender equality (SDG number 5). Do you think that it is feasible to reach this goal within that time frame?
10. Conclusion of the focus group.

REPORT OF THE FOCUS GROUPS WITH PERSONS WITH DISABILITIES

ITALY - Turin Institute for the Deaf (Pianezza 29/01/2024)

1. **Presentation of the moderators and the topic of discussion.**
2. **Presentation of each participant.**

The focus group began with the presentation of the moderators (Carolina and Silvia) and the Italian Sign Language (LIS) interpreter. A trainee from the University of Turin was also present at the meeting.

7 participants, Deaf women using Sign Language as mother language: 5 women with children (between 40 and 60 years old), 2 women without children (between 30 and 40 years old). The participants already knew each other, so the presentation was only made between moderators and three women from Ukraine, guests of a local association that helps war refugees.

3. **Article 6 of the UN *Convention on the Rights of People with Disabilities* (UNCRPD) states the following:**

“States Parties recognize that women and girls with disabilities are subject to multiple discrimination, and in this regard shall take measures to ensure the full and equal enjoyment by them of all human rights and fundamental freedoms.”

“States Parties shall take all appropriate measures to ensure the full development, advancement and empowerment of women, for the purpose of guaranteeing them the exercise and enjoyment of the human rights and fundamental freedoms set out in the present Convention.”

What are your feelings about these statements? Do you have any experiences to share related to Article 6 of the Convention?

Both as mothers, as deaf people and as women in general, we do not see this article put into practice. These are words, but not deeds: there is no total freedom, no guarantee of rights. There is a lack of sensitivity and information.

4. **How can women's right to choice and self-determination be respected?**

When a deaf person asks for a service or information, it is to improve their situation: it is therefore important to respect their choice. In practice, deaf women do not have much freedom of choice or self-determination, for example, if I go to the gynaecologist I also have to organise other people's commitments (the Sign Language interpreter). I am not even free to choose an interpreter because in hospitals where interpreting is provided, it is not possible to choose the person who accompanies you during the visit, an intimate one by the way! It would be nice to have a list of interpreters to choose from, provided by the public service, without having to arrange and pay for the translation myself. The perfect situation would be for the gynaecologist himself to know how to communicate in Sign Language, but if this cannot be done, at least a greater sensitivity towards the deaf and their needs would be appreciable.

Another example is having a gynaecological examination in the hospital and waiting due to staff delays or internal work: often the lack of adherence to schedules means that the interpreter cannot wait with the deaf person and has to leave early for other commitments. The deaf person is thus alone during the visit. Doctors don't understand this and don't pay attention to these situations, just as they don't want two people to come in for the visit. This last point is even more serious in the case of foreign deaf women (Ukrainians in the focus group): they have another sign language, so they would need two interpreters/mediators: one to translate from Italian to LIS and the other to translate from LIS to their mother tongue.

5. There is a tendency to think that if a woman has difficulty taking care of herself, she will not be able to take care of a child. What do you think about this view?

A lot of people say and think this about deaf women, but it's not true! We know how to take care of our children.

Deaf people don't think so, of course, but a lot of hearing people say "uuh, you're deaf, poor things!" or "but how do you raise a child if you're deaf?"

There are also many gynaecologists who are prejudiced against deafness: they worry that the deafness gene is passed down or propose cochlear implantation as a "cure for deafness" for newborn deaf babies.

6. What are the factors that do not allow full independence to girls and women with disabilities? What about these factors particularly when it comes to motherhood?

There is still a strong welfarism and pietism in society in general, but also on the part of health professionals. Even family doctors, for example, take one person as a reference for the whole family. Or many ask for the phone number of a hearing relative and find no other way to communicate with us directly.

7. An African proverb states the following: "It takes an entire village to raise a child." In your experience, what role does the family (and the broader community) have in the journey of a woman through motherhood?

There is no support either from the hearing society or from the older deaf community: the former look at us with pity, while the latter are too closed and severe. For example, older deaf people think that the younger generation should not ask for more support and independence, they say that we must endure and touch in practice the same difficulties that they have gone through.

8. Do you think the government should invest more resources in emotional education and sexual education in schools and in society more broadly?

Absolutely yes! Raise awareness among health professionals about the reception of deaf and deaf people, but also investments in communication support and the Sign Language interpreting service in public services (especially hospitals).

- 9. One of the UN's sustainable development goals expected to be reached by 2030 is gender equality (SDG number 5). Do you think that it is feasible to reach this goal within that time frame?**

No. Who knows if one day it will be achieved for real!

10. Conclusion of the focus group.

The women who participated in the focus group are curious to see the products of the project as they hope that anything can be useful to improve the situation in hospitals and in general in public reception places. An information booklet might be helpful.

The three Ukrainian deaf women did not contribute much to the discussion: from a later conversation of the moderators with the educators who followed the welcome of their Ukrainian families, it emerged that they do not want to express themselves without their husbands. We believe this is already a significant factor, which communicates more than a thousand words about the condition of women with disabilities in Ukraine: most likely they are patriarchal families that are still very closed.

BULGARIA, European Development Foundation (04/01/2024)

Phases and questions:

1. Presentation of the moderators and of the topic of discussion.

The meeting started with a short introduction of the moderators. We took a little more time to talk about the project, what are its goals and who are the partner organisations, from which countries, at what stage we are in it. We tried to break the atmosphere and explain that everyone can share additional things during the discussion.

2. Presentation for each participant.

The meeting was attended by 10 women, and due to various personal reasons, we will only give their first names.

Atanaska A. is 34 years old and has been diagnosed with neurosis and anxiety-depressive conditions.

Ioanna I. is 28 years old and has a congenital ear anomaly that causes permanent hearing loss.

Severina S. is 36 years old, has blindness in one eye, reduced vision in the other.

Madlen I. is 24 years old and has polyneuropathy.

Gergana P. is 39 years old with diabetes mellitus with eye complications.

Jivka K. is 42 years old with a disease of the musculoskeletal system.

Milena D. is 26 years old and believes that, according to the specialists treating her, she suffers from histrionic (theatrical) personality disorder.

Stanislava V. is 37 years old and suffers from obsessive-compulsive mental disorder.

Stoyanka M. is 57 years old with diabetes.

Kalina E. is 42 years old, 60 % of blindness.

- 3. The UN *Convention on the Right of People with Disabilities* says at article 6 “States Parties recognize that women and girls with disabilities are subject to multiple discrimination, and in this regard shall take measures to ensure the full and equal enjoyment by them of all human rights and fundamental freedoms.” And “States Parties shall take all appropriate measures to ensure the full development, advancement and empowerment of women, for the purpose of guaranteeing them the exercise and enjoyment of the human rights and fundamental freedoms set out in the present Convention.” Which are your feelings about that? Do you have experiences to share related to the article of the convention?**

All feel that they have faced and continue to face discrimination. They shared how difficult it is for them to try to find even part-time work, how even if they can handle a certain job they are not given a real chance to practise it, because they are simply classified as "seriously ill", "disabled" or "unfit for work." In addition, they have felt discrimination from the point of view of their illnesses, they admit that they often feel "outside" society

- 4. How to respect women's right to choose and self-determination?**

According to those present, there is no universal answer, because specifically in Bulgaria this is a "taboo" topic, and according to them, regardless of whether it is men or women, there is no particular difference. There was no unanimous opinion on the issue, rather the conclusion was reached that the topic of self-determination is long for discussion, but for the differences of the country it is not a question of discrimination or of gender, but rather of a conservative society that does not accept easily,, the different."

- 5. There is a tendency to think that if a woman has difficulty taking care of herself, she will not be able to take care of a child. What do you think about it?**

This question caused serious debate. On the one hand, some of the participants admit that it would be difficult for them to cope absolutely alone, and on the other hand, they believe that they are absolutely capable of giving their maximum to raise a child. Every single woman shared that at some point in her life she wanted to have children, regardless of her illness.

- 6. What does not allow full independence to girls and women with disabilities? In particular about motherhood?**

First of all, the country's conditions and policy regarding disabled people were indicated. Everyone has dealt with numerous problems in terms of administrative hurdles, going around a number of institutions to solve a basic case, endless phone calls and complicated medical consultations. All these things affect the daily life of people with disabilities, and in fact they themselves are also an objective cause of possible problems related to a future motherhood. Each of the participants shared that in the event of a possible pregnancy, even visits to the gynecologist would be a problem, suggesting that they would face

prejudice even from doctors, about their decision to be parents. Concerns were raised about how adequate medical care would be for pregnant women who have some kind of disability, whether there would be specialists who had experience of pregnant women with disabilities, etc.

7. An African proverb says “It takes an entire village to raise a child.” In your experience, what role does the family (and the community) have in the motherhood journey?

Here, all the participants were categorical that the family is extremely important when raising a child and during pregnancy. All of them believe that the family is the basis of a successful motherhood. They themselves rely on their close orders to deal with their illness and would rely on them for future motherhood as well.

8. Do you think the government should invest more energy in emotional education and sexuality in schools and society?

According to the participants, at this stage they receive emotional support mostly from their closest relatives, but they neither rely on government programs nor hope for measures regarding sex education. Yes, it is important for them to have such support not only in schools, but also in most centers for people with disabilities and hospitals.

9. One of the sustainable development goals to reach in 2030 is gender equality (goal number 5): do you think it will be really reached? And within that possible deadline?

There were mixed opinions on this question, the deadline for the participants is at least 2035, but even then they consider themselves part of the world, for example, Eastern Europe, women in general would be underestimated and, other things being equal, for example when applying for a job, between a man and a woman, the employer would choose the man because he would not have to go on maternity leave.

10. Conclusion of the focus group.

In general, we can summarise that specifically in Bulgaria there are many problems related to the disabled and people with disabilities in general. They do not feel like "equals" in society and even for them the subject of motherhood is very painful and even in this area they feel extremely insecure.

CYPRUS - Citizens In Power (23/02/2024)

Phases and questions:

1. Presentation of the moderators and of the topic of discussion.

The meeting commenced with the CIP members, Marialena and former Supervisor Glykeria, introducing themselves to the participants. Marialena took charge of coordinating the entire discussion. Following an overview of the MoMs project and its objectives, the participants felt more at ease interacting with the CIP members. Marialena then invited the participants to introduce themselves and provide insight into the disabilities they

experience. Once introductions were completed, the discussion officially began, with the CIP members posing questions to the participants.

2. Presentation for each participant.

Eleven women with disabilities attended the meeting:

Thekla: Experiences hearing impairments; married to a person with hearing impairments.

Marina G.: Deals with hearing impairments; a single parent.

Marina: Faces hearing impairments and has two children with the same condition.

Victoria: Experiences hearing impairments and has an immigrant background.

Marina I.: Lives with a mobility impairment.

Irene: Faces challenges due to a mobility impairment.

Rafaella: Is paraplegic.

Athina: Struggles with multiple sclerosis (non-visible impairment).

Themida: Also has multiple sclerosis (non-visible impairment).

Katerina: Coping with multiple sclerosis (non-visible impairment).

Georgia: Lives with multiple sclerosis and other invisible disabilities.

- 3. The UN *Convention on the Right of People with Disabilities* says at article 6 “States Parties recognize that women and girls with disabilities are subject to multiple discrimination, and in this regard shall take measures to ensure the full and equal enjoyment by them of all human rights and fundamental freedoms.” And “States Parties shall take all appropriate measures to ensure the full development, advancement and empowerment of women, for the purpose of guaranteeing them the exercise and enjoyment of the human rights and fundamental freedoms set out in the present Convention.”**

Which are your feelings about that? Do you have experiences to share related to the article of the convention?

All participants conveyed experiencing discrimination in their search for employment. They highlighted a profound lack of accessibility, particularly in healthcare facilities, exacerbating their feelings of being marginalised compared to the general population. Finding employment presents a significant challenge, compounded by insufficient state benefits that impede their ability to lead independent lives. Their shared sentiment emphasised the crucial role of family support in enabling them to navigate motherhood and achieve a semblance of independence.

4. How to respect women's right to choose and self-determination?

According to the participants, respecting women's right to choose and self-determination begins with challenging societal misconceptions through early education initiatives. By fostering understanding from a young age, we can empower individuals to respect women's autonomy. Additionally, it's imperative to recognize and address the unique needs of women within the disability sphere, where male-dominated governance often overlooks their perspectives. They also stressed that collective guarantees of rights must be reinforced to protect against neglect and ensure individual agency. Furthermore,

healthcare professionals must undergo training to better understand and assess disabilities, promoting inclusive and informed care.

5. There is a tendency to think that if a woman has difficulty taking care of herself, she will not be able to take care of a child. What do you think about it?

The participants stressed out that the challenges faced by women with disabilities in caring for themselves are not inherent to their disabilities, but rather stem from societal barriers. Despite disabilities not originating in the womb, societal attitudes often discourage them from embracing motherhood. However, the essence of motherhood lies beyond physical limitations; the soul, unimpeded by disability, can offer “boundless love.”

6. What does not allow full independence to girls and women with disabilities? In particular about motherhood?

All participants shared the view that access to health services is not easy at all for people with a motor disability, as many health centres lack appropriate infrastructure, for example lifts, dedicated parking, ramps and toilets. The same difficulty is faced by people with different forms of disability, for example people with visual or hearing disabilities (no sign language interpreters). In other words, there is no provision for a special assistant to help people with disabilities to access medical services and sometimes people with disabilities have to find ways to access these services on their own. In addition, they told us that they find it difficult even to make appointments with their doctors, they explained that it should be done online, there should be an accessible website that takes into account all types of disability, e.g. motor disability, visual, hearing, etc. They stressed that sophisticated technology should be an ally of government institutions, and they should use it to the fullest.

They also mentioned that there should be websites accessible to all to inform whether there are lifts in the medical centres, ramp access, whether there are stairs for those who can climb a few steps, whether there is adequate information on everything.

Regarding motherhood, they stressed that finding a well educated gynaecologist poses a challenge, to the point that, according to the participants, a lot of disabled women were forced to go abroad to give birth, in a more experienced healthcare environment.

7. An African proverb says “It takes an entire village to raise a child.” In your experience, what role does the family (and the community) have in the motherhood journey?

The participants unanimously emphasised two critical factors: the indispensable support provided by their families and the essential role of state assistance. They articulated a pressing need for governmental policy reform towards a more inclusive societal framework, particularly in addressing the shortcomings within the education system. They underscored the urgency of integrating disability awareness into early childhood education, believing that such initiatives would foster greater understanding and respect as children mature.

8. Do you think the government should invest more energy in emotional education and sexuality in schools and society?

All participants were in unanimous agreement regarding the necessity for the government to take proactive measures concerning emotional education and sexuality within both schools and society at large. Particularly, those with hearing impairments emphasised their significant lack of fundamental knowledge regarding reproductive rights.

9. One of the sustainable development goals to reach in 2030 is gender equality (goal number 5): do you think it will be really reached? And within that possible deadline?

The overwhelming consensus among participants is a scepticism towards the achievement of the Sustainable Development Goals by 2030, citing substantial work that Cyprus still needs to undertake. Many participants responded to the question with disbelief or amusement, indicating a lack of confidence in the current trajectory. While a couple of individuals expressed a glimmer of hope, their optimism was tempered by lingering concerns and uncertainties.

10. Conclusion of the focus group.

In conclusion, the focus group participants highlighted several critical issues that demand urgent attention. They unanimously identified a severe lack of access to healthcare and information, underscoring the urgent need for systemic reforms. Moreover, they emphasised the persistent disparity in opportunities between the general population and disabled individuals, stressing the importance of promoting inclusivity and equal access. Addressing these challenges requires multifaceted solutions, including comprehensive training programs for healthcare professionals to better understand and cater to the needs of disabled individuals.

Additionally, participants advocated for increased state intervention, including financial assistance, home support services, and improved dissemination of information tailored to the disabled community. By heeding these recommendations, policymakers can pave the way for a more equitable and inclusive society where all individuals have the opportunity to thrive.

SPAIN - COCEMFE SEVILLA (03/04/2024)

1. Presentation of the moderators, the topic of discussion and each participant.

The Focus Group began with a welcome and presentation of the project by the moderators (Álvaro and Encarni). On this occasion, we opted for a mainly face-to-face format, although there were two participants who did it online because they were from rural areas.

Afterwards, we made a round of presentations of all those present. A total of 19 people attended (3 M and 16 F), of which 3 were technicians, 5 observers (workers from our organisation) and 11 women with disabilities (WWDs). We can make three main distinctions within the group of women with disabilities;

- Women with a congenital disability: 4/11
- Women with disabilities who are mothers: 5/11
- Women with disabilities who have become mothers after having a disability: 2/11

With regard to the age of these women, we have counted a fairly broad spectrum ranging from 32 to 60 years old, the average being 49 years old.

In terms of education, the vast majority have basic education, with some very few exceptions, and only 2 people are currently in employment.

2. Debate

Introductory note: In order to speed up the development of this FG, we have agreed to group certain questions by thematic blocks given the nature of the questions.

The role of the state in shaping the rights of WWDs and as a guarantor of these rights.

- Question No. 3: *The UN Convention on the Right of People with Disabilities says at article 6 “States Parties recognize that women and girls with disabilities are subject to multiple discrimination, and in this regard shall take measures to ensure the full and equal enjoyment by them of all human rights and fundamental freedoms.” And “States Parties shall take all appropriate measures to ensure the full development, advancement and empowerment of women, for the purpose of guaranteeing them the exercise and enjoyment of the human rights and fundamental freedoms set out in the present Convention.”*
- Question No 8: *Do you think the government should invest more energies in emotional education and sexuality in schools and society?*
- Question No 9: *One of the sustainable development goals to reach in 2030 is gender equality (goal number 5): do you think it will be really reached? And within that possible deadline?*

The women with disabilities (hereinafter WDDs) participating in the discussion group unanimously pointed out the importance of this type of recognition at the legislative level as a starting point, although they claim that these statements often come to nothing because the political bodies do not put in place measures to make these words a reality.

Thus, they believe that the State must be the agent that acts as a mediator of social conflicts and as a protector of people's rights, guaranteeing these rights through its political actions and economic means (materials and services).

- In terms of political action, they call on the state to protect, in particular, the right to independent living and respect for the principle of women's self-determination. These two points are indeed key for any person with disabilities, but it is even more necessary for women with disabilities because of the greater discrimination they suffer due to a series of cultural barriers present in society (especially in their family environment) that prevent them from being subjects of full rights and, therefore, from self-realisation. "To be a woman is to suffer a double disability; because of the very condition of disability and because of being a woman" are some of the phrases that we can rescue from the conference.

As ways of overcoming this situation, a greater involvement of the State is demanded in the following areas:

- I. Sociocultural: WWDs continue to appear in the social imaginary under a view linked to traditional models that are very restrictive with regard to their independence. In order to change this conception, the State needs to carry out awareness-raising campaigns in society (working especially with families and professionals who care for people with disabilities), and to carry out greater monitoring of the capacities of its professionals in order to ensure compliance with inclusive and non-discriminatory standards of treatment. Examples given in the session were that of certain professionals in the health sector who, through their actions, infantilise WWDs, annul them as decision-makers (failure to respect the principle of self-determination), or do not comply with confidentiality and data protection protocols, which are some of the examples of abuses to which they are subjected.
 - II. Socio-labour: it is necessary to continue to support measures that facilitate the integration of PWD in the labour market as a reinforcement of the right to an independent life. The State must ensure that the necessary accessibility measures are complied with, but also that there is no discrimination in the treatment of PWD. Therefore, awareness-raising campaigns are also quite important within this dimension because professionals and executive members of companies have to be open-minded towards diversity. Several examples of discrimination in the workplace have been given, the most recurrent of which occur during a job interview. Let us recall that only 2 out of 11 WWDs are currently working, which is a symptom that this barrier is real.
- With regard to financial resources, criticism is quite harsh, as it is perceived that the failure to achieve its objectives is due to a lack of material resources and services that the State is obliged to cover by virtue of the commitments set out in its own legislation.
 - o Materials: This is one of the aspects that has been most emphasised and which has to do with universal accessibility, since without this right it is not possible to achieve full development as a person without enjoying social inclusion. Special attention has been paid to accessibility in the health sector and to mobility in

public spaces. Examples include the lack of basic equipment to carry out a review and specialised follow-up in the care of WWDs, or the inaccessibility of some urban areas and public buildings.

Just at this point, an interesting debate began on the "hierarchy of needs," with the vast majority understanding that not all needs have the same value, while others argued that it is not a question of quality but of respect for rights. The context for the debate arose from a Spanish law called "fertility law," whereby the government covers up to three attempts at highly complex assisted fertilisation techniques. Some people argued that it was unfair that all women, with and without disabilities, should be eligible for the same number of attempts despite the complications of each person (i.e. the case was presented as an example of discrimination).

However, one participant commented on the absence of specialised instrumental means for certain medical treatments. The dilemma would be whether, in this particular case, being a mother is considered a physiological need for a woman, and if so, would this right be on the same level as others related to primary health care or specialised treatments that impact on quality of life. No definitive conclusions were reached, but there was a call for more State involvement at the level of benefits, and particularly for politicians to develop greater empathy, as well as to give more voice and prominence to PWD themselves in defending their rights.

- Services: the absence and development of the professional figure of the Personal Assistant is particularly noteworthy. The latter is seen as the indisputable tool for achieving independent living, but the lack of financial resources to promote this profession, especially in our region (Andalusia), means that the enjoyment of this service is merely a mirage of what in theory should be present according to current legislation. Similarly, there is general criticism of the State's direct management of services intended for dependency assistance, and calls for the liberalisation of these services.

The rights of WWDs on maternity and sexuality; a sociological perspective.

- Question No 4: *How to respect women's right to choose and self-determination?*
- Question No 5: *There is a tendency to think that if a woman has difficulty taking care of herself, she will not be able to take care of a child. What do you think about it?*
- Question No 6: *What does now allow full independence to girls and women with disabilities? In particular about motherhood?*

- Question No 7: *An African proverb says "It takes an entire village to raise a child." In your experience, what role does the family (and the community) have in the motherhood journey?*

We have already noted in the previous section that one of the main demands focused on the actions that the state should take at a legislative and social awareness-raising level to ensure that the principle of women's self-determination and the right to an independent life is respected. From a societal point of view, the participants admit that there has been progress in society on issues related to gender equality, diversity, inclusion, tolerance and respect, but there is still a long way to go to achieve full equality and inclusion. This would be demonstrated by the personal experiences that the participants shared, where we can observe behaviours based on prejudices whose basis is misinformation and the pre-eminence in some sectors of the population of ways of thinking that are far removed from a diverse and inclusive vision.

Most examples, however, are found within the family due to overprotection, which is considered to be another major obstacle to the development of a WWDs' right to independent living. This issue is even more visible in rural areas. Overprotection is usually accompanied by the imposition of a series of "traditionally feminine roles" of patriarchal origin where they have to look after other family members because they are women, which is contradictory to other types of messages and ideas such as the fact that "they cannot be mothers because they do not have the capacity to take care of themselves". This denial of self-determination, they say, has a number of negative consequences on an emotional level, as it attacks women's self-esteem.

Returning to the issue of motherhood, they agree that this is an inalienable right of every WWDs, but there is no agreement on the implementation of this right. In other words, they are all against any form of forced sterilisation or eugenic abortion process that is motivated by third party pressure, but when it comes to exercising this right, some women said that the State should guarantee with all its means that any woman with a disability can exercise the right to be a mother (for example, by assigning a PA to fulfil these roles), while the other part of the group was reluctant because they needed to bring the individual context of the person into the equation and because they also considered not only the right, but also the duty of the mother towards the child (in this sense, a phrase we rescued was: "having a child is not a wish, but a responsibility in which you have to take into account the physical and also the psychological part)."

This last group of participants argued that different factors should be studied, such as whether the disabled woman has the tools and competences to be a mother, to study the family or friendship support that the mother can access (the issue of family was particularly highlighted), or to take into consideration other aspects that can guarantee the safety and quality of life of the child and the mother, such as economic resources, etc. Therefore, as a conclusion to this aspect, we could say that no one supports the idea of an imposition of the obligation to have children on the mother, but it is mentioned by half of those present that not everyone has the right background to be one, and therefore there is a disparity of ethical-functional opinions on the relevance and feasibility of the issue.

On investigating the matter, we found that the WWDs considered that the most influential factors for them in wanting to become mothers was not having physical independence from their family nucleus materialised under the creation of a new family home (right to independent living). In spite of wanting independence from their family, they consider the family as the central element of all the required support. Therefore, we have this option ahead of other issues such as having a partner or a stable employment situation as well as a favourable personal financial situation. However, lack of information on sexual matters and specifically on motherhood (in some specific cases it was linked to the lack of cognitive accessibility) were also put as main reasons, which influences the fact that they do not feel able to conceive this idea of bringing life into the world by themselves. Likewise, factors related to ideology (moral-religious) are another element to take into account as it exerts a negative pressure with messages such as "you are selfish if you think of bringing a child into the world in your condition." Thus, it is a multifactorial issue, in which, on the one hand, there is an influence that would have to do with access to economic resources (in this case in the form of their own home), but also other aspects such as education and the support they receive from the family (mainly).

With regard to sexuality, we could say that all the participants agree that sexuality and motherhood are two totally different things and do not have to go hand in hand. They accuse society, especially family members and counsellors/educators/health professionals, of treating them as children and seeing them as asexual beings. This materialises in reprehensible and unprofessional behaviour where, in the best of cases, their self-determination is undervalued.

On the other hand, the importance of working on self-concept has also been discussed as a way to improve interpersonal relationships (especially with partners) and one's sexual and mental health. A disability or the acquisition of a disability can be a very traumatic event on an emotional level, so the WWDs must have the necessary resources to be able to continue to maintain a normal life within her new context. In this case, not only is help in the form of benefits or services provided by the state sought, but also a process of self-criticism is carried out in which, it is clear, WWDs must take an active part as a manifestation of their empowerment.

This empowerment is rooted in knowledge and improved skills, which brings us to the issue of sexual information and education. All those present agree that the State needs to invest more resources in everything that is aimed at the dissemination of sexual information (risk prevention campaigns, information points, accessibility of information, family planning). In addition to health centres, schools have been identified as one of the key points. A series of sexual education training courses should take place there on a regular basis, and that these training courses should be carried out by professionals. Sexuality cannot and should not be taboo, as it is a denial of part of a person's nature and of their freedom and determination.

As examples, they have spoken of all the barriers they encountered in reaching information on sexual matters when they were young, and this is because the means did not exist as they do

today (internet-smartphones), but neither did the culture, especially in the case of WWDs who had their disability before they became sexually active.

Final Conclusions

- Question 9: *Do you think the government should invest more energy in emotional education and sexuality in hospitals and healthcare institutions?*
- Question 10: *One of the sustainable development goals to reach in 2030 is universal access to sexual and reproductive health-care services, including for family planning, information and education (goal number 3.7): do you think it will be really reached? And within that possible deadline?*

Motherhood is an inalienable right of any WWDs, but in order to be able to exercise it properly, a whole series of measures are required:

- The State should be more involved in carrying out awareness-raising measures on disability, diversity, inclusion, gender, motherhood, as well as other types of political actions (including updating legislation on the rights of PWDs).
- Provide spaces for the participation of PWDs and especially WWDs in decision-making bodies so that, in a co-productive way, they can contribute ideas to help design and implement changes in those areas that most influence them, such as accessibility.
- To give greater visibility to the group in order to bring about normalisation in society, especially for those WWDs who are mothers.
- Work closely with the families of WWDs so that they internalise respect for basic issues such as the principle of self-determination and stop being a barrier to the development of WWDs, whether motivated by an overprotective attitude or because of a more traditional gender view.
- Work with WWDs on self-acceptance and other issues related to psychological trauma due to disability status.
- Provide more accessible information to WWDs on rights, motherhood and sexuality.
- Provide greater financial and service support to WWDs to enable them to exercise their rights.
- It is also important to involve not only women with disabilities in this problem of rejection and denial of rights and freedoms, but also other groups in society, because if they continue without interaction with the group of women with disabilities, there will continue to be an ongoing rejection and misunderstanding of these rights and freedoms.
- On the other hand, although it may not seem so at first glance, maternity and sexuality

are variables that can have an influence on the social exclusion of women with disabilities, so that they cannot be considered in sentimental relationships with a sexual component or with a maternal and filial component. Because social exclusion is also about this, about not granting rights and freedoms to women with disabilities that are inherent to them simply because they are women.

- It is also necessary to gradually set aside the existing cultural paradigm towards disability as it is a major instigator of the restriction of these rights and freedoms.

SPAIN (Cataluña) - LET HER IN (10/06/2024)

1. Presentation of the moderators and the topic of discussion.

The session began with a warm welcome and a brief introduction of us and our organisation. We explained the aims of the project, the partner organisations involved and our current progress. We emphasised that everyone was encouraged to share their thoughts and experiences openly, without any judgement.

2. Presentation of each participant.

The meeting was attended by 10 women: Aina (34), Joana (28), Marina (36), Laia (34), Núria (39), Alba (42), Mireia (26), Montse (37), Rosa (57), Marta (42). The participants were from "Down Tarragona", an organisation that advocates for the rights of people with Down Syndrome. It was a special group within the organisation called "Autonomous Women". Needs to be said that these women have discussed these topics often, so they have strong opinions about it.

3. The UN *Convention on the Rights of Persons with Disabilities* states in Article 6: "States Parties recognize that women and girls with disabilities are subject to multiple discriminations and, in this regard, shall take measures to ensure their full and equal enjoyment of all human rights and fundamental freedoms." And "States Parties shall take all appropriate measures to ensure the full development, progress and empowerment of women, with a view to ensuring their exercise and enjoyment of the human rights and fundamental freedoms set out in this Convention."

What are your feelings about it? Do you have any experiences to share related to the conference article?

The participants expressed that they often encounter discrimination, especially when looking for work. They often feel excluded from society and are denied opportunities because of their disability.

4. How can women's right to choice and self-determination be respected?

Some think that in Catalonia there seems to be a growing recognition of the importance of respecting women's autonomy in decision making. They argued that every woman, regardless of her disability, should have the right to make her own decisions about her life, including whether or not to become a mother. They emphasised that society must move beyond outdated stereotypes and paternalistic attitudes that undermine women's agency. Instead, they advocated for policies and support systems that empower women with disabilities to make informed decisions about their reproductive health and family planning.

5. There is a tendency to think that if a woman has difficulty taking care of herself, she will not be able to take care of a child. What do you think?

It is a common misconception that a woman's ability to care for herself correlates with her ability to care for a child. This assumption ignores the individual strengths and abilities of women with different abilities. Although some of them face challenges, many of them have the resilience, determination and ability to care for their child. They would like to have people recognise and support their pursuit of motherhood and provide them with access to resources, education and comprehensive support networks, similar to this group, to empower them on their journey to motherhood.

6. What prevents girls and women with disabilities from becoming fully independent? Specifically on motherhood?

Women who desire and have the ability to become mothers face challenges due to societal misconceptions and lack of support. It is crucial to address these barriers through thorough education, accessible healthcare and inclusive social policies that recognise and respect their rights and aspirations in relation to motherhood.

7. An African proverb says, "It takes a whole village to raise a child." In your experience, what role does the family (and community) play in the path of motherhood?

Family and community support plays an important role in the journey to motherhood for them, like with all other mothers. A caring and inclusive environment where families and communities provide understanding, support and encouragement can greatly improve their experience of motherhood. Providing them with access to support networks and ensuring their involvement in family and community activities would be essential steps in promoting their autonomy and well-being.

8. Do you think the government should invest more energy in emotional and sex education in schools and society?

The government should prioritise investment in emotional and sexual education and ensure that it is accessible and tailored to the diverse needs of people with different abilities. Comprehensive education programmes that are integrated into both schools and society can empower women to make informed decisions about their sexuality and reproductive health.

9. One of the Sustainable Development Goals to be achieved in 2030 is gender equality (goal number 5): do you think it will really be achieved? And by that possible deadline?

Achieving gender equality, including the rights and empowerment of women with different abilities, requires a big effort from the government. Some of them aren't too sure about reaching gender equality by 2030. It isn't just because of the laws, it's also about how people see them.

10. Conclusion of the focus group.

Reflecting on our discussion, it is clear that the path to motherhood for women with disabilities is filled with both unique challenges and high hopes. Participants emphasised the importance of societal change towards greater inclusion and empowerment. They emphasised that policies and support systems should be designed to respect and empower the autonomy of women with disabilities, especially when making decisions about their reproductive health and family planning.

The importance of family and community support was another important point.

Participants emphasised that a supportive and understanding environment can have a great impact on their experience of motherhood. This support is vital in promoting their autonomy and wellbeing and enables them to thrive as mothers despite societal misconceptions.

Education is a fundamental area that requires attention. Comprehensive and accessible educational programmes, particularly in the area of emotional and sexual health, are essential. Such programmes should be integrated into schools and the wider community to empower women with disabilities to make informed decisions about their sexuality and reproductive health.

Mixed feelings were evident when discussing gender equality by 2030. While there is hope, there is also scepticism due to persistent societal attitudes and barriers. Participants believe that while legal frameworks are important, real change requires a shift in societal perceptions and attitudes towards women with disabilities.

FOCUS GROUPS - PROFESSIONALS

Phases and questions:

1. Presentation of the moderators and of the topic of discussion.
2. Presentation of each participant.
3. The UN Convention on the Right of People with Disabilities says at article 9 “States Parties shall take appropriate measures to ensure to persons with disabilities access, on an equal basis with others, to the physical environment, to transportation, to information and communications, including information and communications technologies and systems, and to other facilities and services open or provided to the public, both in urban and in rural areas.”
Do you think the health services are accessible for all?
4. How to respect women's right to choose and self-determination about their health care?
5. There is a tendency to think that if a woman has difficulty taking care of herself, she will not be able to take care of a child. What do you think about it?
6. What does not allow a full independence to girls and women with disabilities? In particular about motherhood?
7. An African proverb says “It takes an entire village to raise a child”. Do you think the health care services feel part of the community when talking about education and taking care of children?
8. Do you think the government should invest more energies in emotional education and sexuality in hospitals and healthcare institutions?
9. One of the sustainable development goals to reach in 2030 is universal access to sexual and reproductive health-care services, including for family planning, information and education (goal number 3.7): do you think it will be really reached? And within that possible deadline?
10. Conclusion of the focus group.

REPORT OF THE FOCUS GROUPS WITH PROFESSIONALS

ITALY - Turin Institute for the Deaf (08/02/2024 and 23/02/2024)

The first focus group with healthcare and educational professionals was held in online mode with 2 professionals working for the '[Il Fior di Loto project](#)':

- Giada M.: psychologist at the Passepartout Service – Coordination of Interventions and Integrated Services for 'Motor Disability' of the Municipality of Turin, manager and coordinator of the Fior di Loto project
- Alessia G.: psychologist, psychotherapist and sexologist who collaborates with the Fior di Loto project

The Fior di Loto is a project of the "Verba" association (a non-profit association that promotes and favours equal opportunities for people with disabilities), in collaboration with the Local Health Authority (ASL) and the "Passepartout" service of the Municipality of Turin (service for the coordination of initiatives for the removal of barriers that hinder people with disabilities). For ten years, she has been involved in gender-inclusive medicine, the fight against violence and cancer prevention for women through a fully accessible clinic.

Fior di Loto was born as a result of research conducted by the Department of Oncology and Hematology of the Le Molinette Hospital in Turin on the incidence of female cancers in women with disabilities. Research had revealed that women with disabilities are more at risk of developing female cancers due to a number of personal factors related to disability and external factors related to the environment:

- physical factors such as sedentary lifestyle, poor perception of pain, difficulty in performing breast self-examination, increased exposure to drugs and radiation, frequent absence of reproductive history.
- environmental factors due to the inaccessibility of places of care, especially counselling centres and hospitals, structural inadequacy, unpreparedness of health workers, lack of empathy, but also prejudices within families and with social workers.²⁹

Since 2014, the project aims to ensure that women with disabilities have access to cancer and gynaecological services, as well as to combat abuse and violence against people with disabilities. The Piedmont region, through the National Health Service, has been running the "Prevenzione Serena" program for years to prevent and combat breast, cervical and colorectal cancer: these are examinations and visits that for people with disabilities are not possible without suitable equipment. For example, mammography is a type of check-up that requires the woman to stand, a position that is not possible for many women with physical and motor disabilities. Or not all women with intellectual disabilities can understand or carry out these examinations independently, so it is necessary that health personnel know how to accommodate the needs of these women in an appropriate environment and in a longer timeframe.

²⁹ https://agendadelladisabilita.it/wp-content/uploads/2024/01/Il_Fior_di_Loto.pdf

With these objectives, the team of *Il Fior di Loto* is multidisciplinary, made up of gynaecologists, obstetricians, psychologists, sexologists and LIS interpreters for deaf women who sign.

Each visit is designed to last 45 minutes: longer times both for physical needs in the case of women with motor disabilities, and for the need for psychological and communicative support, to ensure the understanding of the visit and the results, especially this for women with intellectual disabilities or deafness (translation into sign language takes longer).

The doctors told how the clinic was born 10 years ago from research that states that women with disabilities have a higher percentage of having diseases because the visits and check-ups are not applied to them as well. There is an important social barrier: many health workers do not want to train and lack preparation to communicate with people with disabilities.

Fior di Loto professionals are highly trained in this sector and by collaborating with different institutions, associations and projects, they have understood over the years how it is possible to support the independence of women with disabilities only by doing effective networking. This networking must be translated into capacitating co-design. In addition, they explain that they also collaborate with CAVs (Life Help Centers) to support women with and without disabilities in the path of motherhood, implementing the right to self-determination.

The doctors are happy with the results achieved to date, but more resources would be needed to implement the services offered. In 1999 the "[Associazione Verba](#)" was founded in Turin with the aim of creating synergies between services for people with disabilities. In 2007 it entered into an agreement with the City of Turin – [Passepartout Service](#) for the implementation of the '[Prisma project – for Aid Relations](#)'. The Prisma project is aimed at women with disabilities, migrants with disabilities, victims of violence with disabilities, people with disabilities in situations of extreme socio-economic fragility, people with disabilities with an LGBTQI+ orientation through the launch of individualised and personalised paths. The **Fior di Loto** project was born in 2014 from the needs that emerged from the other projects as they were not yet covered. This chain of projects shows that the demand for knowledge and services is always high and that more and more investment from the government is needed.

In conclusion, the two professionals interviewed did not know the reality of the Institute well and this focus group was an excellent opportunity for both parties. The Institute was able to learn more about a service available to deaf/disabled women interested in accessible check-ups, while the Fior di Loto project was able to deepen the challenges and possible difficulties in interacting with the Deaf community that cannot be overcome only with the interpreting service in LIS.

The second focus group with healthcare and educational professionals from various entities and associations was organised on **23/02/2024**, again in online mode, since it is really difficult to find time and a common place to meet

- 1. Presentation of the moderators and the topic of discussion.**
- 2. Presentation of each participant:**

- Alessandra R.: psychologist and psychotherapist with a systemic-relationship approach who works in the Settimo Torinese area. She deals with domiciliary projects with psychiatric patients, including women who wish to build a family.
- Marcella B.: she is an osteopath and has specialised in paediatric osteopathy for 8 years: she deals with the approach to the pelvic floor, menstrual pain, pregnancy and paediatrics. During her years of working as a freelancer, she realised that the possibility of networking with other professionals in her field was limited. She therefore decided to found the "Progetto Nudā", of which she is President, to be able to create bridges between existing services (and also create new ones) and offer inclusive services to people of all backgrounds and with different needs. In recent years, the *Nudā Project* has collaborated a lot with "MIND THE GAP": it is an intersectional transfeminist festival in Turin that was born from the need to create a space in which to talk about gender gap, normalisation of bodies, sexuality, feminism.
- Irene S.: psychologist and psychotherapist with a systemic-relationship approach who works in the Obstetric and Gynecological department of the Sant'Anna Hospital at the psychology service: she works in the sphere of reproductive health of women and couples, from the search for a child to childbirth. At the same time, she collaborates with the Nudā Project in Turin: it is made up of health professionals, and not only, which deals with health dissemination from an intersectional transfeminist perspective. One of the projects carried out was that of birth accompaniment in a multidisciplinary key: the goal was to give access to people with disabilities or mental disorders in facing and managing this experience.
- Laura M.: She has decades of experience in the field of sensory disabilities and is a professional educator at the Institute for the Deaf. As playwright at her association, together with her colleague Marina Nucci she has launched several projects on two main aspects: on maternity ("Frattali Materni" workshop) and on the development of children's language in the 0-24 months range, in which Laura is a Baby Signs trainer. The drama therapy workshop is aimed at both parents.
- Cecilia C.: nurse and Facilitator of the Helping Relationship. With the "Respiro per Madri" (Breath for Mothers) project, it aims to facilitate processes of awareness of the personal potential of mothers and provide them with adequate tools in finding solutions that help them improve their quality of life. She holds meetings with mothers, both individual and group, to facilitate the sharing of experiences and experiences.

3. Article 9 of the United Nations *Convention on the Rights of Persons with Disabilities* states: "States Parties shall take appropriate measures to ensure that persons with disabilities have access, on an equal basis with others, to the physical environment, transport, information and communications, including information and communication technologies and systems, and other facilities and services open or provided to the public, in both urban and rural areas." Do you think healthcare services are accessible to everyone?

No professional knows the UN Convention and its articles, apart from Laura who works at the Institute but has never heard of it outside. It turns out that only in the courses of the Faculty of Educational Sciences is this topic addressed, although only on a theoretical level, because it always remains complex understanding how to apply these principles in real life. Becoming aware of this regulatory basis can help to activate adequate training in their work environments.

In fact, all professionals report that they have never received training on this subject. During the course of study, the theme of disability was addressed, but never combined with that of sexuality or parenthood. This total lack of training therefore has a major impact on their work when they first find themselves interacting in these circumstances. They recognize that you don't know who to ask and where to turn for more information or knowledge. Irene comments that comprehensive training is required for operators because they are alone in the examination room. Not receiving it either at University or in the workplace itself, professionals find themselves powerless without resources.

Marcella and Irene told how they collaborated with the Association "Verba" in the past and that in this way they came to know about the "Fior di Loto" project. The contact took place by word of mouth and it was an occasional collaboration that has not been repeated.

4. How can women's right to choice and self-determination be respected?

Alessandra tries to answer: it can be essential to have a support network and for professionals to truly network. She says that one of her patients with psychiatric disorders had a gynaecologist advised against pregnancy because of certain medications she had to take for treatment. However, it was later found to be incorrect information.

This communication malfunction can create serious problems: the person with a disability cannot feel independent because he or she does not have real support to draw from. Or sometimes the networking is not well organised and again the correct support is not provided to the person with disabilities.

There is often a lack of time and economic resources to understand how to implement one's training and network more and more.

5. There is a tendency to think that if a woman has difficulty taking care of herself, she will not be able to take care of a child. What do you think?

Professionals recognize that in their work environments there is still a lot of prejudice against people with disabilities, especially when they are planning to become parents. The phrase that is repeated in all their contexts (educational, psychological and health) is the same: will the woman with disabilities be able to handle all this?

And the answer is never sought, or rather not enough, in the structuring of a project that provides autonomy to the person with disabilities.

Unfortunately, most healthcare professionals often have this prejudice which, on reflection, can be caused by two factors:

- The short time available during the visits makes professionals hesitate to activate a multidisciplinary project but dwells only on one thought: will we be able to sustain all this back home? With the subsequent conviction that this is not possible.

- Ignorance in the broadest sense: the world of disability is not adequately known. For example, no one, apart from Laura, was aware of the variety in the world of Deafness and more and more practical tools are needed.

6. What are the factors that prevent girls and women with disabilities from becoming fully independent? What about these factors, particularly when it comes to motherhood?

As explained before, if there is no effective support network around the woman with disabilities it becomes very difficult, if not impossible, to carry out a project of full independence.

In the case of maternity, an even larger multidisciplinary team must be activated because several health professionals must be included, but they are not adequately trained in this area.

In fact, the professionals explain that they have not received training either during their university career or in their workplace and therefore the first factor is certainly complete and correct training.

Another factor is knowing how to communicate and ask the woman with disabilities what her desires and fears are, thus knowing how to put her at the centre of the project and not as the final recipient of a project decided only among professionals.

7. An African proverb says, "It takes a whole village to raise a child." In your experience, what role does the family (and community) play in the path of motherhood?

The family certainly plays an important role because it becomes essential as a support in the path of motherhood of any family, with or without disabilities. Motherhood and parenthood are intense and overwhelming experiences and the support of the family becomes essential to be able to go through all the stages in a stable and serene context. In the case of women with disabilities, this support is even more fundamental because society and the network of professionals are not adequately prepared and teamwork is required.

Society often judges a mother who tries to find time for herself and not just for her children. But in this way, the woman feels nullified and exhausted. Cecilia recounted how many mothers who participate in the meetings feel a strong sense of guilt when they take time for themselves as they feel judged by society and/or the family context.

In this framework, greater information and awareness about what parenthood is and what it entails can promote a psychological alleviation of inner conflicts for all those involved.

8. Do you think the government should invest more energy in emotional and sex education in schools and society?

Absolutely yes. Projects on emotional and sexual education are too few and incomplete on the issue of disability. In recent years, the rights of people with disabilities to have an independent life that also includes a sex life have been promoted more strongly in Italy. However, on the issue of parenthood there is a lot of resistance and opposition and few opportunities for discussion and training.

Marcella and Irene with the Project Nudə have the goal of promoting health through dissemination, education, psycho-physical and sexual well-being.

9. One of the Sustainable Development Goals to be achieved in 2030 is gender equality (goal number 5): do you think it will really be achieved? And by that possible deadline?

Unfortunately not. Certainly, work has begun to implement this equality and there have also been some good goals achieved. But at the national level, many obstacles and situations of discrimination can still be observed, just think of the different pay slips for the same number of hours worked or the questions during different job interviews: sometimes women are asked if they are mothers or want to become mothers in the future, while men are not asked questions related to the issue of family.

For all professionals, it is necessary to reconstruct society in terms of the rights of people with disabilities and the vision of disability itself. And the situation is even more complex for women with disabilities because they suffer double discrimination. So it is still too difficult to predict when it will be possible to achieve this goal.

10. Conclusion of the focus group.

It was useful and interesting to be able to compare between professionals who want to carry on the same cause but working in different settings. This focus group was precisely the representation of what it means to network and create bridges between different entities to be able to provide a complete service to those who need it. In fact, the comparison took place between professionals in the fields of psychology, education and health. After this meeting, their respective contacts were exchanged to continue the collaboration.

BULGARIA - European Development Foundation (05/01/2024)

Phases and questions:

1. Presentation of the moderators and of the topic of discussion.

Here, as with the previous group, we started with a brief presentation of the project, its current development, the target groups, our partners. We introduced the moderators and their experience briefly, emphasising the dialogue and exchange of experience.

2. Presentation of each participant.

The 10th participants introduced themselves and each of them briefly explained what they do. Among them we had a social worker, a psychologist, a clinic assistant, a personal assistant for people with disabilities, a resource teacher, a doctoral student in psychology and sexology, and a university lecturer. They each work in one form or another with people with disabilities and each shared their personal experiences working with them. At the very

beginning of the discussion, when introducing the participants, they started asking each other questions about their experience, how long they have been working in a particular place and other details that helped create a friendly atmosphere.

3. **The UN *Convention on the Right of People with Disabilities* says at article 9 “States Parties shall take appropriate measures to ensure to persons with disabilities access, on an equal basis with others, to the physical environment, to transportation, to information and communications, including information and communications technologies and systems, and to other facilities and services open or provided to the public, both in urban and in rural areas.”**

Do you think the health services are accessible for all?

According to the interviewees, legally this is regulated, but in practice things look quite different, but in a negative aspect. According to them, the healthcare system in the country needs an urgent reform, because regardless of whether we are talking about people with disabilities or not, free access to quality healthcare is a serious problem. On the subject of transport accessibility, it was concluded that even in the country's big cities there are serious problems with accessibility in general. The problem with the insufficient number of city buses with wheelchair platforms, the poor arrangement of the urban environment, the underpasses, which are an obstacle especially for mothers with children in baby carriages, was commented on. The regulation of traffic and sound signals when crossing for people with disabilities in the area, the lack of tactile surfaces, the lack of hotel facilities with rooms for the disabled, the size of the ramps for the disabled, their inclination, which is often outside the norm and makes them unusable, were mentioned too. There was mention of streets and sidewalks in urban environments that are dangerous and not particularly adapted for people with disabilities and quite a few other similar comments that led me to conclude that the rights of people with disabilities in terms of accessibility were being violated.

4. **How to respect women's right to choose and self-determination about their health care?**

According to those present, "how" is a matter first of all of the personal feelings of each member of society, but society itself needs "training" in terms of equality, women and people with disabilities.

5. **There is a tendency to think that if a woman has difficulty taking care of herself, she will not be able to take care of a child. What do you think about it?**

Objectively, the fact that some diseases are quite severe really hinders normal motherhood. The facts are that with severe disabilities there is no practical possibility for a mother with a disability to independently raise a child. However, this in itself does not mean that it is impossible for such a woman to be a full-fledged mother if she relies on help - from relatives, family, sisters, husband, etc. There are a number of objective facts that show that a person with a disability can be a parent. Around the world there are many good examples of parents who, despite their disabilities, raise and educate their children.

Limitations or prejudices should not be imposed, but the opportunities before each woman should be objectively assessed individually.

6. What does not allow full independence to girls and women with disabilities? In particular about motherhood?

Several points of reference were derived from the experience of professionals: the prejudices of society; the lack of public information; family support; medical assistance and medical consultations; personal care and counselling from specialists to understand and help a woman with a disability to make the decision to be a mother; confidence in the woman herself.

7. An African proverb says “It takes an entire village to raise a child.” Do you think the health care services feel part of the community when talking about education and taking care of children?

Professionals do not think that health services give special attention to motherhood in women with disabilities. In general, the health system in the country is not adapted to pay individual attention to each patient, even if only for moral support.

8. Do you think the government should invest more energy in emotional education and sexuality in hospitals and healthcare institutions?

Absolutely yes, the psychological support that women with disabilities need is extremely important and the role of the state in supporting each and every one of its citizens should not be underestimated.

9. One of the sustainable development goals to reach in 2030 is universal access to sexual and reproductive health-care services, including for family planning, information and education (goal number 3.7): do you think it will be really reached? And within that possible deadline?

It wouldn't be easy, but it's not impossible either. In recent years, the trend towards sex education and family planning has intensified. The global trend is towards more awareness, more non-governmental organisations that give voice to a number of important topics. We could not predict with accuracy whether this will reach its full potential by the time indicated, but all steps are leading to it.

10. Conclusion of the focus group.

All professionals thanked for the opportunity to express their opinion and share their experience. The general opinion is that there is still a long way to go before the country at the state level to help people with disabilities feel like full full-fledged members of society.

CYPRUS - Citizens In Power (16/02/2024)

Phases and questions:

1. Presentation of the moderators and of the topic of the discussion.

The meeting began with Marialena and former Supervisor Glykeria, representing the CIP, introducing themselves to the participants. Marialena provided an overview of the MoMs project and its goals before inviting the participants to introduce themselves. Each participant shared their name, profession, and their experiences working with disabled individuals. Once introductions were complete, Marialena initiated the discussion by posing questions to the group.

2. Presentation of each participant.

10 professionals that work with people with disabilities participated in the meeting:

- Louis Askotis - Physiotherapist
- Elisavet Michael - Nursing Officer
- Christiana Gregoriou - Representative from the Cyprus Disability Rehabilitation Organization of Limassol
- Margarita Kapsou - Representative from the Birthforward Organisation
- Irini Pavlou – Psychologist
- Panagiota Themistokleous - Sign Language Teacher
- Nikolas Papaioanou - Representative from a Non-Governmental Organization (NGO Π.Ο.Α.Α.)
- Yioula Pitsiali – Mother of a child with a disability, President of an NGO for people with disabilities and families
- Maria Avraam – Psychologist
- Stella Leontiou – Representative from the Nurses and Midwives Association

3. The UN *Convention on the Rights of People with Disabilities* says in article 9, “States Parties shall take appropriate measures to ensure to persons with disabilities access, on an equal basis with others, to the physical environment, to transportation, to information and communications, including information and communications technologies and systems, and to other facilities and services open or provided to the public, both in urban and in rural areas.”

Do you think the health services are accessible for all?

The sentiments expressed by participants in the Focus Groups resonate strongly with the principles outlined in Article 6 of the UN *Convention on the Rights of Persons with Disabilities*. The recognition of the multiple forms of discrimination faced by women and girls with disabilities underscores the urgent need for proactive measures to ensure their full and equal enjoyment of all human rights and fundamental freedoms. The experiences shared by participants illustrate the realities of this discrimination, particularly concerning access to sexuality-related activities and reproductive healthcare.

Furthermore, the Convention's call for the empowerment and advancement of women with disabilities aligns closely with the participants' advocacy for inclusive policies and

practices in Cyprus. Their experiences underscore the imperative for states to take concrete actions to address the systemic barriers faced by women with disabilities and uphold their rights to autonomy, dignity, and equality. Each participant emphasised the critical necessity to enhance the accessibility and disability-friendly features of healthcare facilities.

4. How can women's right to choose and self-determination be respected?

Respecting women's right to choose and self-determination requires a multifaceted approach, as underscored by the insights gleaned from focus groups with professionals. Firstly, there's a pressing need for better-educated and trained doctors to ensure that disabled women have equitable access to reproductive choices, including childbirth. By enhancing doctors' understanding and sensitivity towards the unique needs of disabled individuals, women can more easily exercise their autonomy in reproductive matters.

Moreover, participants emphasised the importance of including disabled individuals in the development of new legislative frameworks. Often, disabled people feel marginalised by government decisions that directly affect their lives. By involving them in the decision-making process, policymakers can gain invaluable insights and ensure that legislative actions are truly inclusive and reflective of the diverse needs of the disabled community. This proactive approach not only respects the autonomy of disabled individuals but also fosters a more inclusive and equitable society.

5. There is a tendency to think that if a woman has difficulty taking care of herself, she will not be able to take care of a child. What do you think about this view?

The consensus among participants was resolute: every woman, irrespective of disability, inherently possesses the right to pursue motherhood. However, they lamented the persisting prevalence of biased views within Cypriot society, which at times dissuade disabled women from embracing motherhood.

Despite these societal barriers, participants stressed the paramount importance of empowering disabled women with proper guidance and unfettered access to their reproductive rights. They underscored the indispensable role of robust support systems provided by both family and the state in facilitating disabled women's journey towards motherhood. Ultimately, the collective sentiment affirmed that with the necessary guidance, rights, and support structures in place, any woman, regardless of disability, can fulfil her maternal aspirations.

6. What are the factors that do not allow full independence to girls and women with disabilities? What about these factors particularly when it comes to motherhood?

According to participants, several factors limit the independence of girls and women with disabilities, especially regarding motherhood. They pointed out that inadequate education about sexuality and motherhood, along with a lack of trained doctors in Cyprus, undermines confidence and trust in healthcare. Additionally, inaccessible healthcare facilities further impede access to essential services for disabled individuals. These challenges hinder disabled women from making autonomous decisions about motherhood.

7. An African proverb states the following: “It takes an entire village to raise a child.” In your experience, what role does the family (and the broader community) have in the journey of a woman through motherhood?

In the journey of a woman through motherhood, the family and broader community play indispensable roles, as emphasised by the participants. Family support is paramount, serving as a pillar without which state benefits alone would not suffice for a disabled mother to contemplate motherhood. Beyond the family unit, the broader societal mindset is equally crucial. Participants underscored that a shift in societal attitudes towards respecting and aiding people with disabilities is essential. By fostering a culture of inclusivity and support, the entire community contributes to creating an environment where disabled women can navigate motherhood with dignity and empowerment.

8. Do you think the government should invest more resources in emotional education and sexual education in schools and in society more broadly?

All participants unanimously agree that the government should allocate more resources towards emotional and sexual education in both schools and society at large. They emphasise the crucial role such education plays in fostering healthy relationships, promoting understanding, and combating stigma surrounding sexuality and emotional well-being. Investing in these areas not only empowers individuals to make informed choices but also contributes to creating a more inclusive and supportive society overall.

9. One of the sustainable development goals to reach in 2030 is universal access to sexual and reproductive healthcare services, including family planning, information and education (goal number 3.7). Do you think that it is feasible to reach this goal within that time frame?

The participants expressed significant scepticism regarding the feasibility of reaching the Sustainable Development Goal of universal access to sexual and reproductive healthcare services by 2030. They conveyed doubts about the government's capacity to achieve this goal within the specified timeframe. Participants emphasised the urgent need for Cyprus's government to take more proactive actions towards inclusivity, particularly in enhancing accessibility to healthcare services for marginalised populations. Without substantial efforts in this direction, the participants doubted the attainability of the stated goal within the given timeframe.

10. Conclusion of the focus group.

The focus group participants unanimously agreed that substantial action must be taken at the national level to address the needs of disabled women and people in general. They emphasised that mere acknowledgment of the challenges faced by these communities is insufficient; concrete measures are imperative to effect meaningful change.

Participants stressed the importance of proactive policies aimed at enhancing accessibility, promoting inclusivity, and ensuring the full realisation of rights for all individuals, regardless of disability. It was evident that the participants were united in their call for concerted efforts to create a more equitable and supportive society for everyone.

SPAIN - COCEMFE SEVILLA (13/03/2024)

1. Introduction of the moderators and the subject of the discussion

The focus group started with the presentation of the project MoMs, its objectives and main activities by the moderators (Álvaro and Encarni). The profile of the people who participated in the discussion was also briefly introduced and it was announced that this discussion was the preamble to another focus group to be held on 3 April 2024, in which we will have the participation of women with disabilities and family members and representatives of organisations of people with disabilities.

2. Presentation of each participant.

The focus group held by COCEMFE-Sevilla for MoMs project was attended by a multidisciplinary team of 11 professionals (including the two technical staff members attached to the project) from different Spanish regions (Andalusia, Catalonia and Euskady). The profile of the multidisciplinary team was as follows:

- Field of psychology 4
- Field of education 3
- Social workers 3
- Human resources 1

In terms of demographic composition, the focus group had the intervention of 7 women and 4 men, whose approximate age was around 40-55 years old.

The professionals involved develop their entire occupation in organisations that provide services and care for people with physical, organic and intellectual disabilities. It is important to note that the participants are people who have a lot of experience in working towards the effective social inclusion of people with disabilities in all areas of life. Values such as independent living and the right to self-determination of people with disabilities are the driving force of their daily work.

3. Debate.

Introductory note: In order to speed up the development of this FG, we have agreed to group certain questions by thematic blocks given the nature of the questions.

The right to accessibility for PWD and its real implementation. Study on the situation of accessibility in health services. The right to self-determination of women with disabilities.

- Question No. 3: *The UN Convention on the Rights of Persons with Disabilities states in Article 9: "States Parties shall take appropriate measures to ensure to persons with disabilities access, on an equal basis with others, to the physical environment, to transportation, to information and communications, including information and communications technologies and systems, and to other facilities and services open or provided to the public, both in urban and in rural areas".*
- Question 4: *Do you think the health services are accessible to all?*

- Question 5: *How to respect women's right to choose and self-determination about their health care?*

There has been much debate among professionals about the extent to which this right has been achieved, given its relevance to the full development of the person with a disability (hereinafter PWD), and in particular for women with disabilities (hereinafter WWD). This is due to the fact that, without access to the services and spaces (not only physically, but also cognitively), a person cannot fully develop and feel part of society by not participating in it.

We can point out that, unanimously, professionals are extremely concerned about the state of this issue in both public and private spaces, a reality that seems to be shared by organisations in different locations to a greater or lesser degree, although depending on the area of study (public/private transport, educational, health, counselling environments, etc.). Examples of this are the deprivations that PWD have in access to information or care within the social and health care environment, where many WWD cannot even receive basic medical services related to their gender or maternity because the necessary equipment and instruments are not available (adapted obstetric equipment, or essential diagnostic equipment for women, such as an adapted mammograph). To the above, they add, would be the training and awareness of certain professionals who care for PWD in these services, who are reluctant to make the appropriate adaptations to facilitate the right to autonomy of persons (as specific examples of the above, several scenarios of social and health care have been given where PWD do not receive an adaptation in the language and means used by the social and health care professional, or even the way of communicating with them, since they focus their attention on establishing communication with the person accompanying them and not with the patient).

Nevertheless, the present assembly agrees to give some credit to the significant progress in accessibility and awareness-raising that has been made in recent years. However, they demand improvements, as there is still a long way to go for the normalisation of PWDs in the exercise of their rights and, with particular concern, they point out that the new plans designed by political entities (such as the *European strategy on the rights of persons with disabilities 2021-2030*) do not take into account the reality present in social contexts where such accessibility is not present, thus creating regulations under frameworks that are far from the objective reality and that are eminently theoretical based on interests linked to political propaganda. In short, the disparity between the documents that draw up the right to accessibility and accessibility plans and the daily reality we face is clear.

This situation is even more serious in rural areas because there is a more latent lack of resources and services in these areas, which, due to the specific needs of disability, are more present. In addition to the above factors, there is a particularly relevant element, which is the power that societies in these environments (and families) have to exert discriminatory pressure on PWD, which is greater in the case of women for intersectional reasons. This pressure manifests itself in the form of stereotypes and taboos in conjunction with a marked overprotection of the family, the result of which is the

infantilisation and stripping of the dignity of the WWD as they are seen as a weak member who requires the paternalistic attention of a family environment that is often oppressive.

Interestingly, this description of rural WWD where we can most obviously glimpse the influence of stereotypes related to the "inability" of WWD to lead an independent life and even create a family of their own contrasts with the fact that, in many cases, these people continue to exercise the "traditional role of women", such as the central role in caring for others within the family.

The following measures are advocated as solutions to all the problems addressed:

- a) Encourage greater active participation of PWDs (and especially WWDs) as key elements in the implementation of new designs and policies related to the aforementioned spaces and rights.
- b) To make greater efforts in the form of campaigns to raise awareness and make the group more visible, especially by working with family members and various professionals (educators, social and health workers, social workers, those involved in politics), as these are key elements that can reverse certain processes based on a lack of knowledge.
- c) Work on awareness-raising with PWD so that they know not only the content of their rights, but also that these rights offer them an opportunity for participation and that we must promote when and how to exercise them (i.e. empowering autonomy and self-determination).
- d) Offer more support and means to PWDs, especially to WWDs, as they suffer situations of greater vulnerability and deprivation of their rights.

The right to sexuality and maternity for women with disabilities. Maternity and society.

- Question 6: *There is a tendency to think that if a woman has difficulty taking care of herself, she will not be able to take care of a child. What do you think about it?*
- Question 7: *What does not allow a full independence to girls and women with disabilities? In particular about motherhood?*
- Question 8: *An African proverb says "It takes an entire village to raise a child". Do you think the health care services feel part of the community when talking about education and taking care of children?*

This thematic block has generated more controversy than the previous one. While all those participants agree that the right to motherhood is an undeniable right for all women and therefore reject any measure contrary to it (such as forced sterilisation, etc.), there is disagreement as to the scope of application. The explanation lies in the fact that it is

considered that not all people have the information, support and/or economic resources to realise this right, regardless of their disability (although some participants pointed out that this condition could be an aggravating factor).

For the specific case of WWDs, there are two elements to take into account:

- On the one hand, there is the vision that society in general and the family in particular have of WWD, which they see as "a non-sexual being" (a reality shared with the male gender) and, therefore, it is not conceived that they can exercise this right even when it does not have a reproductive purpose. Another type of argument is also put forward in relation to a possible situation of inferiority as people in a situation of dependency (in some specific cases) and this would justify the fact that "if they cannot take care of themselves, how are they going to take care of their children?"

These arguments have been unanimously rejected because they are very stereotypical, although it is acknowledged that there are cases in which certain WWD have shown themselves to be unfit to perform the maternal function. However, we understand that these examples are very singular and, in any case, they could be perfectly used for the rest of the non-disabled population. Therefore, they are rejected as valid theses. In fact, the reality that professionals share is that WWDs are perfectly capable if they have the right tools. Here, perhaps, we find the point of divergence among those present; what tools are we talking about, how and by whom do we measure these issues, are we talking about a purely economic issue, about capacities? In short, who decides who is and who is not fit to start a family?

There have been attempts to find a justification for the above premises on legal grounds, others on ethical and common-sense grounds, others on maternal responsibilities towards the child and the child's own rights... and in turn, all of the above have been refuted with arguments drawn from issues such as the relativity of cultural values. Thus, there is no consensus in this respect due to the complexity of defining the abstract that we are trying to delimit, but there has been a dominant thought, which is that education/training is the basis of everything, which brings us to the second element to be taken into account.

- Education (especially in sexual matters and family planning) is key as an element of prevention and to increase a person's maternal capacities, thus avoiding risky or problematic situations resulting from lack of knowledge. Examples are the case of an unwanted pregnancy (due to lack of sexual education and/or lack of means), pregnancy as a synonym for achieving fulfilment as a person (it is mentioned that some WWD understand that to form a family is to free themselves from the ties they have due to the state of overprotection within their families), or a pregnancy under circumstances that could be understood as "not optimal."

This point has been more controversial again, but it refers to the conditions that are socially considered adequate to become pregnant, such as having a stable and healthy

relationship, having sufficient housing and income, etc.). As we have said, this last point reignited the discrepancies, since it was argued that education in the wrong hands could be a pernicious weapon by exerting a pejorative influence on the self-perception of a vulnerable person, making them believe in or give up their dreams and desires on the basis of a dominant X ideology. An example of this is the great psychological burden that many women carry throughout their lives, which has to do with the "dominant conception" of what is socially understood as "being a good mother." In any case, it is understood that education is something positive and necessary that should be universally accessible.

In short, it has been concluded that we have to differentiate between "having the right to" and "exercising that right," although as we say, we do not agree on defining that exercise or delimiting the powers that the law can/should apply to a WWD who would like to become a mother in terms of respect for the rights of the future child.

Curiously, however, unanimity again appeared in terms of society's commitment to the child born, as it is considered a responsibility of society to defend the right of the child. On the one hand, social responsibility is understood as political, which is why public authorities are required to provide full support to WWDs once they become pregnant. And on the other hand, there is the conception of society as a community of people who should play a supportive role towards WWDs in terms of their commitment to people in vulnerable situations, especially in the case of children. How far society's scope of action can or should go is an unresolved question, but it is understood that the support networks they offer, either individually or within a third sector organisation, are necessary to maintain a just society.

Remedies and legislation to be applied

- Question 9: *Do you think the government should invest more energies in emotional education and sexuality in hospitals and healthcare institutions?*
- Question 10: *One of the sustainable development goals to reach in 2030 is universal access to sexual and reproductive health-care services, including for family planning, information and education (goal number 3.7): do you think it will be really reached? And within that possible deadline?*

The issue of investment in resources has been a constant theme throughout the discussion among the participating professionals. Investment in educational and training resources that raise awareness and change the "look" towards PWD and specifically towards WWD as subjects with full rights in society is unquestionable.

In terms of education, the need to invest in the development of a curriculum that addresses

sex education in a more effective and realistic way, as well as in a way that is connected to the generational problems that affect today's society, has been pointed out. It should also take into account the problems posed by the use of technology and make use of it in a responsible and even educational way.

Finally, those present agreed that it was impossible to achieve the goals set out in the *2030 Agenda*. However, they stressed that progress will obviously be noticeable and positive, but insisted that governments must connect more with the reality of PWDs in the environment in which they live.

4. Conclusions

- a) The right to motherhood is an undeniable right for any woman with a disability, regardless of her context (there is disagreement from some present who emphasise that the context should define the practice of this right, although there is no agreement on how).
- b) The responsibility to exercise that right (or others) is an issue that needs to be worked on with WWDs through education, so that they know not only the content of their rights, but also when and how to exercise them (i.e. empowering autonomy and self-determination).
- c) Education is considered a key element to end misinformation not only among WWDs but also in their environments (family, community, etc.). Among the different subjects, one of them is related to sexual and reproductive health education, which must be universal.
- d) Society has to be a supportive environment, especially the family. This will be achieved through the promotion of educational policies in which awareness and visibility campaigns are fundamental elements (especially working with families and environments close to PWD). In this way, the needs and rights of the group can be understood and supported.
- e) Greater active participation of PWDs (and especially of WWDs) in the implementation of new designs and policies concerning the spaces and rights that concern them must be encouraged in order to create a truly inclusive society.
- f) Offer more support and means to PWDs, especially to WWDs, as they suffer situations of greater vulnerability and deprivation of their rights.

SPAIN (Cataluña) - LET HER IN (07/03/2024)

We have organised the report following the order of the questions, even though the conversation was fluid and moved back and forward. We tried to summarise it in a way that made sense and was not repetitive.

Introduction of the moderators and the subject of the discussion

The focus group session began with the introduction of Júlia, the moderator on behalf of DomSpain, who briefly introduced the project. She presented the objectives and main activities of the project and emphasised the importance of discussion for the development of these first steps.

Profile of participants

The session was attended by teams from three different organisations: 'Fundació Villablanca', 'Taller Baix Camp', and 'Aspercam'. *Fundació Villablanca* manages public services specifically aimed at people with severe and profound disabilities. *Taller Baix Camp* is a non-profit organisation dedicated to supporting people with intellectual disabilities and their families. Its model is centred on providing comprehensive, high-quality support that offers all the necessary resources and opportunities to enable people with intellectual disabilities to lead a happy, independent and normal lives from the end of their school years to old age. *Aspercam* is an organisation that supports people with autism and their families.

All participants were psychologists and work in organisations that care for people with physical, organic and mental disabilities. These professionals have extensive experience in promoting the social inclusion of people with disabilities, driven by values such as independent living and self-determination.

Debate

According to Article 9 of the UN *Convention on the Rights of Persons with Disabilities*, "States Parties shall take appropriate measures to ensure persons with disabilities access, on an equal basis with others, to the physical environment, transportation, information and communications, including information and communications technologies and systems, and to other facilities and services open or provided to the public, both in urban and rural areas." Do you believe health services are accessible to all?

Participants agreed that while there has been considerable progress in facilitating access to health services, there are still significant gaps. Public and private health services often lack the necessary adaptations for full accessibility. These include physical adaptations, appropriate medical equipment and training for healthcare professionals to communicate effectively with people with disabilities. In rural areas, these problems are exacerbated by a lack of resources and services.

How can women's right to choose and self-determination about their health care be respected?

In order to respect the women's right to freedom of choice and self-determination in healthcare, it must be ensured that they have comprehensive information and are able to make informed decisions. Participants emphasised the need for specific communication strategies and the availability of resources that support autonomy. In addition, healthcare professionals should be trained to liaise directly with women with disabilities and respect their preferences and choices regarding their health.

There is a tendency to think that if a woman has difficulty taking care of herself, she will not be able to take care of a child. What are your thoughts on this?

The participants unanimously rejected this stereotypical view. They felt that with the right support and resources, women with disabilities can be effective carers. The discussion highlighted the importance of providing the necessary tools and support systems rather than making assumptions about ability based on disability. It was noted that the same criteria for assessing parental suitability should apply to all, regardless of disability status.

What impediments prevent full independence for girls and women with disabilities, particularly regarding motherhood?

Barriers to independence for women with disabilities include societal attitudes, lack of information, inadequate support systems and insufficient resources. Overprotection by the family and societal stereotypes often limit their opportunities for independent living and motherhood. Education and awareness-raising were identified as key factors in empowering women with disabilities and promoting their rights.

An African proverb says, "It takes an entire village to raise a child." Do you believe healthcare services feel part of the community when discussing education and childcare?

This is also a saying in Spain, and it applies to all families, not just those with challenges. Our society doesn't make it easy for families to raise their children and conciliation is not possible most of the time. The participants felt that health services often work in isolation and not as part of a community network. More integrated approaches were called for, with healthcare providers, community organisations and families working together to support children's education, particularly in the context of disabilities. This holistic approach is seen as essential to promoting a supportive environment.

Should the government invest more in emotional education and sexuality in hospitals and healthcare institutions?

Yes, there was strong agreement that the government should invest more in emotional education and sexuality programmes in healthcare. Such investment would help to remove misconceptions,

reduce stigmatisation and give PWDs the knowledge and support they need to manage their emotional and sexual health.

One of the sustainable development goals to achieve by 2030 is universal access to sexual and reproductive healthcare services, including family planning, information, and education (goal number 3.7). Do you think it will genuinely be reached, and within the stipulated deadline?

Although the participants were optimistic about progress, they were sceptical as to whether this goal can be fully achieved by 2030. They emphasised that significant efforts are needed to bridge the gap between policy and reality. Continued investment and commitment from governments are crucial for significant progress.

Conclusion of the focus group.

In conclusion, the focus group emphasised the following key points:

- Women with disabilities need adequate support to exercise their rights, including motherhood.
- Rights come with responsibilities, and the provision of information and education is crucial to empowering women with disabilities.
- The rights of the child are paramount and require societal and governmental support.
- Greater investment in education and support systems is essential to address the particular challenges faced by women with disabilities.
- A community-centred approach to health and social services is needed to ensure comprehensive support for people with disabilities and their families.
- The active participation of persons with disabilities, particularly women, in policy and decision-making processes is crucial for the creation of an inclusive environment and inclusive services.

CONCLUSIONS

Conducting the focus groups taught us a lot: we were able to see firsthand the practical difficulties of many women not only in physical access to essential services, but also in the cultural acceptance of the environments they attend. Through their stories, we were able to understand how many unpleasant situations are the result of a lack of empathy and of adequate training, but also a lack of true communication.

From all the focus groups conducted with women/mothers with disabilities we could observe how there is a strong need for "well-being" in its best definition of "balance between body, mind and spirit." Not only the physical part, but also psychological and emotional support as a way to feel good alone and with others. This is the concept at the base of the bio-psycho-social model³⁰: it is an holistic approach, born in the '70s, that takes into consideration all the different aspects of people's life.

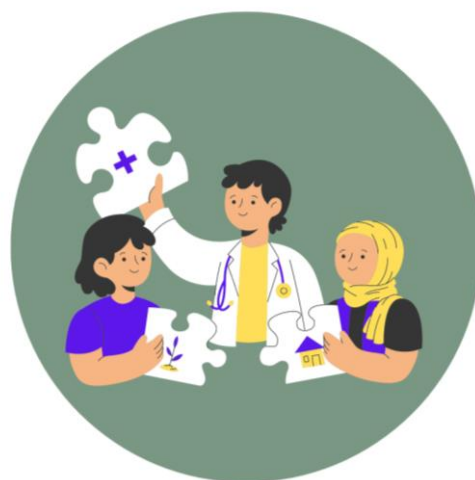
As regards health and educational professionals, what we can say is that they see a need for improvement in both knowledge and accessibility in services. They are all strongly in favour of supporting people with disabilities and, even if educational knowledge and empathy are missing, there is certainly a great will of improvement.

As regards women/mothers with disabilities, we would like to list below the points that were repeated in all groups and on which it is particularly important to focus attention because they highlight critical situations:

- to be treated as children, both as interests in daily life and as asexual beings;
- difficulties in finding well educated and respectful gynaecologist;
- lack of empathy from professionals;
- physical and communicative barriers in healthcare centres;
- higher risk of violence;
- not accessible healthcare websites for both making appointments and autonomously finding correct information.

From these main points we are able to state that even if at European level the rights of women with disabilities to motherhood and to sexual recognition is supported in Conventions and official documents, there is still a long way to walk from a practical point of view.

Pietism, stigma and stereotypes related to the world of disabilities are still a strong part of culture, well hidden, but still influencing social behaviours. The training of healthcare and educational professionals in the view of the bio-psycho-social model has to be pushed: well-being is the responsibility of all spheres of life, not just healthcare.



³⁰ https://applications.emro.who.int/imemrf/Ann_Punjab_Med_Coll/Ann_Punjab_Med_Coll_2007_1_1_11_13.pdf

RESOURCES

- BOE. (2003). *Ley 27/2003, de 31 de julio, reguladora de la Orden de protección de las víctimas de la violencia doméstica*. Jefatura del Estado, BOE-A-2003-15411
<https://www.boe.es/eli/es/l/2003/07/31/27>
- BOE. (2007). *Ley Orgánica 3/2007, de 22 de marzo, para la igualdad efectiva de mujeres y hombres*. Jefatura del Estado, BOE-A-2007-6115.
<https://www.boe.es/eli/es/lo/2007/03/22/3>
- BOE. (2010). *Ley Orgánica 2/2010, de 3 de marzo, de salud sexual y reproductiva y de la interrupción voluntaria del embarazo*. Jefatura del Estado, BOE-A-2010-3514.
<https://www.boe.es/eli/es/lo/2010/03/03/2/con>
- BOE. (2023). *Ley Orgánica 1/2023, de 28 de febrero, por la que se modifica la Ley Orgánica 2/2010, de 3 de marzo, de salud sexual y reproductiva y de la interrupción del embarazo*.
<https://www.boe.es/buscar/doc.php?id=BOE-A-2023-5364>
- Council of Europe. (1950). *European Convention on Human Rights*.
https://www.echr.coe.int/documents/d/echr/convention_ENG
- Department for social inclusion of persons with disabilities. (n.d.). *Council of Europe Disability Strategy*.
http://www.dmsw.gov.cy/dmsw/dsid/dsid.nsf/dsipd9a_en/dsipd9a_en?OpenDocument
- Department for social inclusion of persons with disabilities. (n.d.). *National Action Plan on Disability*.
http://www.dmsw.gov.cy/dmsw/dsid/dsid.nsf/dsipd8b_en/dsipd8b_en?Openform
- European Commission. (2021). *Union of Equality: Strategy for the Rights of Persons with Disabilities 2021-2030*.
<https://ec.europa.eu/social/main.jsp?catId=738&langId=en&pubId=8376&furtherPubs=yes>
- European Commission. (2022). *Proposal for a Directive of the European Parliament and of the Council on combating violence against women and domestic violence*. <https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=CELEX%3A52022PC0105>
- European Council. (2022). *Disability in the EU: facts and figures*.
<https://www.consilium.europa.eu/en/infographics/disability-eu-facts-figures/#0>
- European disability forum. (n.d.). *Women and girls with disabilities in Europe*.
<https://www.edf-feph.org/women-and-gender-equality/>
- Gazzetta Ufficiale della Repubblica Italiana. (1992). *Legge 5 febbraio 1992, n. 104*.
<https://www.gazzettaufficiale.it/eli/id/1992/02/17/092G0108/sg>

- Gazzetta Ufficiale della Repubblica Italiana. (2022). *La Conferenza Unificata*. <https://www.informareunh.it/wp-content/uploads/Presidenza-Consiglio-dei-Ministri-Conferenza-Unificata-Intesa-centri-antiviolenza-case-rifugio-14-9-22.pdf>
- Iceland Liechtenstein Norway grants. (n.d.). *Program: Local development, poverty reduction and enhanced inclusion of vulnerable groups 2014-2021*. <https://www.noveleea.bg/wp-content/uploads/2022/09/Tematichen-doklad-hora-s-uvrejdania-bg.pdf/>
- Instituto Nacional de Estadística. (n.d.). <https://www.ine.es/>
- Istituto Nazionale di Statistica. (2019). *Demographic Indicators*. <https://www.istat.it/en/archivio/226922>
- National Statistical Institute. (2021). *Health status of the population as of September 7, 2021*. <https://nsi.bg/en/content/19944/%D0%BF%D1%80%D0%B5%D1%81%D1%81%D1%8A%D0%BE%D0%B1%D1%89%D0%B5%D0%BD%D0%B8%D0%B5/health-status-population-september-7-2021>
- Observatorio Estatal de la Discapacidad. (2022). *El discurso de las mujeres con discapacidad en torno al ejercicio de la maternidad y su derecho a formar una familia*. <https://www.observatoriodeladiscapacidad.info/el-discurso-de-las-mujeres-con-discapacidad-en-torno-al-ejercicio-de-la-maternidad-y-su-derecho-a-formar-una-familia/>
- Simona. (2024). *EDF, per L'Unione Europea la sterilizzazione forzata non è reato, occasione sprecata*. Centro Gabriele e Lorenzo Giuntinelli. <https://www.informareunh.it/edf-per-lunione-europea-la-sterilizzazione-forzata-non-e-reato-occasione-sprecata/>
- Unione Italiana Lotta Alla Distrofia Muscolare. (2022). *Report progetto "sessualità, maternità, disabilità"*. https://uildm.org/sites/default/files/Report%20Donne%20Sessualit%C3%A0_UILDM.pdf
- United Nations. (2006). *Convention on the Rights of Person with Disabilities*. <https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-rights-persons-disabilities>
- United Nations. (2015). *Transforming our world: the 2030 Agenda for Sustainable Development*. <https://sdgs.un.org/2030agenda>
- United Nations Human Rights. (2017). *Committee on the Rights of Persons with Disabilities considers initial report of Cyprus*. <https://www.ohchr.org/en/press-releases/2017/03/committee-rights-persons-disabilities-considers-initial-report-cyprus>



MOMS

MOTHER MATTERS

The right of women with disabilities to motherhood

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