

PREGEQUAL

*PREGNANCY IN WOMEN WITH
DISABILITY:*

*The Right to information, Knowledge
and Quality on Prevention and
Accompaniment*



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PARTNERS

Centro de Direito da Família, Faculdade de Direito da Universidade de Coimbra, Coimbra, Portugal

Associação de Paralisia Cerebral de Coimbra - APCC, Coimbra, Portugal

Associazione C'ENTRO, Bologna, Italy

Fundatia Estuar, Bucarest, Romania

INFAD – Asociacion de Psicologia Evolutiva y Educativa de la Infancia y Adolescencia, Badajoz, Spain

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*HEALTH PROFESSIONAL AND WOMEN WITH
DISABILITY - THE RIGHT TO INFORMATION,
KNOWLEDGE AND QUALITY OF SERVICES*

TRAINING MANUAL



Pregnancy in Women with Disability

TECHNICAL SHEET

TITLE

TRAINING MANUAL

HEALTH PROFESSIONAL AND WOMEN WITH DISABILITY - THE RIGHT TO INFORMATION, KNOWLEDGE AND QUALITY OF SERVICES

AUTHOR

TRANSNATIONAL ERAMUS+ PARTNERSHIP: **PREGEQUAL**

Ana Rita Alfaiate, Portugal | CDF

Carla Barbosa, Portugal | CDF

Dora Redruello, Portugal | CDF

Joana Baptista, Portugal | CDF

Mário Veríssimo, Portugal | APCC

Rosa Duarte, Portugal | APCC

Casandra Cristea, Italy | Associazione C'ENTRO

Chiara Solda, Italy | Associazione C'ENTRO

Elena Littame, Italy | Associazione C'ENTRO

Amedeea Enache, Romania | ESTUAR

Clonaru Atena, Romania | ESTUAR

Kulcsar Evelin-Adel, Romania | ESTUAR

Vladoi Livia, Romania | ESTUAR

Ana Sánchez, Spain | INFAD

Florencio Vicente, Spain | INFAD

José Casas, Spain | INFAD

EDITION

TRANSNATIONAL ERAMUS+ PARTNERSHIP: **PREGEQUAL**

DESIGN

TRANSNATIONAL ERAMUS+ PARTNERSHIP: **PREGEQUAL**

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PART II | INTRODUCTION

1.1. PREGEQUAL PROJECT



Pregnancy in Women with Disability

- Reproductive, Pregnancy and Maternal Health is a priority for WHO, Unicef, United Nations and for all EU member-states.
- To ensure a safe pregnancy and a healthy baby it is argued that care and communication from healthcare professionals should focus more on women's abilities than their disabilities and that care and communication should be about empowering women.
- Despite the fact that women are the majority among the population of the disabled, issues as important to women as their sexual and reproductive health are still pending issues.
- In order to inform women with disabilities, health professionals should first be informed on disabilities issues of every woman and how these handicaps could affect the normal development of pregnancy.

WHAT IS PREGEQUAL PROJECT?

- Acronym of: Pregnancy in Women with Disability: the **Right to Information, Knowledge and Quality on Prevention and Accompaniment**
- Duration: 24 months: 05th of November 2018 / 04th of November 2020
- 5 Partners in 4 EU Countries: Portugal - Romania Italy - Spain
- The **PREGEQUAL** Project, through the different training and sensitization pathways that it will perform, addresses the fundamental right of the women with disability to constitute their own family and their right to make conscious choices on sexual, reproductive and maternal issues. In some of the partner countries, an open debate on this subject still encounters numerous cultural barriers.



OBJECTIVES

Improve the knowledge women with disability have on reproductive choices, voluntary interruption of pregnancy (VIP) and maternal health

Improve the psychological support women with disability get in front of reproductive choices, empowering their family members/partners

Improve the quality of the health services for women with disability by training the pre-natal and maternal health professionals

Conduct a research in each partner country on the access and the quality of prenatal and maternity services for women with disability

Create a community of practice between the project partners and their networks

1.2. OMS RECOMMENDATIONS



World Health Organization

<https://www.who.int/eportuguese/publications/pt/>

The experience of women is fundamental to transform prenatal care and to create prosperous families and communities.

The World Health Organization (WHO) idealizes a world in which all women and newborns receive quality care throughout pregnancy, childbirth and the postnatal period.

The Prenatal Care (PNC) is still an opportunity to communicate and support women, families, and communities in critical phases of women's lives.

It has been proven that with timely and appropriate implementation of evidence-based practices, PNC can save lives.

The process of developing these recommendations on PNCs has highlighted the importance of establishing effective communication with pregnant women about physiological, biomedical, behavioral, and socio-cultural issues, and of respectful and effective support, including their social, cultural, emotional, and psychological aspects.



A positive experience during pregnancy means physical and socio-cultural normality, a healthy pregnancy for mother and baby (including prevention or treatment of risk, illness and death), an effective transition to labor and delivery, and positive motherhood (including maternal self-esteem, competence and autonomy).

PART III THE DISABILITY

2.1. DISABLED PEOPLE



<https://www.mente.co.uk/2019/02/15/when-a-mental-health-condition-becomes>

Following the entry of the United Nations Convention on the Rights of Persons with Disabilities, disability is increasingly understood as a human rights issue. Similarly, in the European Union, participation in society is considered a fundamental right for all citizens as the EU Disability Strategy 2010-2020 aims at eliminating barriers, preventing discrimination and empowering people with disabilities to enjoy fully their rights and participation in society on equal terms with others.



It is now clear that the full citizenship of the person with disability is recognised in international and national law.

Citizenship expressed in the enjoyment of the rights of every human person, based on his or her eminent dignity, enshrined constitutionally, at the level of rights, freedoms and guarantees and also of social rights and duties.

Article 71 of the Constitution of the Portuguese Republic
(Disabled citizens)

- 1.** Citizens with a physical or mental disability shall enjoy fully the rights and be subject to the duties laid down in the Constitution, except for the exercise or performance of those for whom they are incapacitated;
- 2.** The State undertakes to implement a national policy of prevention and of treatment, rehabilitation and integration of citizens with disabilities and of support for their families, to develop a pedagogy that makes society aware of the duties of respect and solidarity towards them and to assume the burden of the effective realization of their rights, without prejudice to the rights and duties of parents or guardians;
- 3.** The State supports organisations of citizens with disabilities.

The implementation of these rights and of those recognised in legislation, which densifies and develops constitutional precepts, implies the establishment of a culture that considers social reality from a present and future perspective.



Despite the clear progress made, reality shows that the realization of the rights of each and every one of people with disabilities is still far from what is due and possible in a society that already has remarkable knowledge and reasonable means of intervention. Consider, for example, how much remains to be done in terms of accessibility, which is essential to guarantee independent living, support for the disabled within their family.

The quality of life of people with disabilities in society and in the institutions they use depends on the articulation of a complex set of organisational and relational factors which have as their core objective the respect and promotion of the dignity of each person, considered in their individuality as a subject of rights, holder of full citizenship.

Their natural environment, that is, the family environment, is the environment where the conditions for their well-being are normally ensured. When they leave this more protected family context, people with disabilities need special skills on the part of the leaders and collaborators of the institutions in which they live or to which they frequently turn so that the physical, psychological, intellectual, spiritual, emotional, cultural and social dimensions of the life of each person with a disability can be developed by them without limitations to their fundamental rights to identity and autonomy.

The success of this intervention by the different structures depends on the quality of a culture of thought and action, on the institutional and personal level, translated into the conception and realization of good practices, at all levels. A culture rooted in a constant concern for the respect, promotion and defence of the human rights of residents, the fundamental basis of their well-being and quality of life, is essential. On the other hand, the good practices continually assumed, reflected and evaluated, in an environment of transparency and trust, must be guided by that essential concern for the realization of the human rights of the person with disability, and also by the objective of the consequent personal and professional realization of all professionals committed to this mission, of such relevant social importance.



Nevertheless, people with disabilities are constantly facing barriers in their daily lives, which impede their full participation. Thus, many people with disabilities do not have equal access to health care, education, and employment opportunities, do not receive the disability-related services that they require and experience exclusion from everyday life activities. Disability is also an important development issue with an increasing body of evidence showing that persons with disabilities experience worse socioeconomic outcomes and poverty than non-disabled persons.

It is necessary to identify the adjustments/adaptations to be made when we are talking about people with disabilities, according to the specificities of each type of disability.

We must never forget that the focal point is the person with a disability, his/her limitations, it is necessary to consider the individual profile of each person and his/her characteristics.

It is necessary to understand that surrounding factors can interfere positively or negatively:

We may be faced with two types of interaction:



It is important to note that a particular device can be a facilitator for someone and a barrier for another person; for example, an activity on the audio device can be a facilitator for a person with altered vision functions and be an obstacle for a person with altered hearing functions.

As per Eurostat data, in the EU-28 in 2011, 44 million (14% of that age group) people aged between 15 and 64 had some form of disability. Some 35 million (11.0 %) people aged 15-64 in the EU-28 reported a disability in employment. The employment rate of people with disabilities in the EU-28 in 2011 was 47.3%, almost 20 percentage points below that of non-disabled people; practically meaning that less than 1 person out of 2 with disability was employed. The situation becomes worse if we talk about women with disabilities.

Regarding access to education, statistics show that disabled people leave education and training earlier, while the share of young people neither in employment nor in education and training among youth with disabilities was twice as high, compared to non-disabled young people in the EU-28. The situation with lifelong learning is similar: less than 10% of disabled people participated in education and training in 2011, compared to about 21% for those not disabled.

Support for disabled people's access to health, employment and education is among the key factors for their successful integration into society.

People with disabilities vary in their abilities, even when they have the same type of disability.

There are many factors that together condition the development of an individual's cognitive and physical functions. These include the level of education, the level of social integration, the family context and the economic condition, among others. The type and degree of disability represent only a fraction of these factors.



Professionals need to be aware that each person with a disability diagnosed will have his or her own distinctive characteristics and therefore particular needs which have to be met to facilitate the relationship between the person with disability and the health team. It is essential to create complicity and empathy with the health team.

It is important to collect as much information as possible, data on the health situation, both physical and mental, of the person with a disability must be collected. The aim is to build up a clear and comprehensive view of staff with disabilities.

Communication barriers can be created between the person with a disability and the health team, the presence of the family and/or partner can overcome these barriers and become a facilitating element.

HOW MANY PEOPLE IN THE WORLD ARE DISABLED?

- More than one billion people have been estimated to have some form of disability, a total of 15% of the world's population, with a prevalence of 10% estimated among women of childbearing age. The proportion of individuals with disabilities is rising.
- Disability can be physical, mental, sensory, or involve a learning disability, it may be recent or long-term, progressive or stable.

WHAT IS THE SITUATION OF WOMEN WITH DISABILITIES LIKE?

- Gender differences remain palpable, despite the fact that women are the majority among the population of the disabled.
- Women with disabilities who want to be mothers suffer the greatest discrimination because of:
 - The current society thinks that women with disabilities do not meet the current social stereotypes of "good" mother.



- They can also find difficulties in their environment since there is a general tendency to think that if a woman has difficulties to take care of herself, she cannot do it for her child.
- In most of cases, families are the first to resist in understanding the ability of women with disabilities to be wives and mothers, an opinion that is currently widespread in our society.

IS IT ONLY A PROBLEM OF ACCESSIBILITY?

- Women with disabilities experience not only difficulties in access but:
 - Also in receiving effective information and dissemination,
 - Involvement in decision making and support to build respect a trusting relationships with health care providers.

HOW DISABILITY IS REGULATED IN THE EU?

- The European Union policy for disabled people guarantees governmental responsibility for all disabled people in all of EU's member states.
- This policy operates in the framework of the subsidiary principle: if possible, one should improve at the national level, though in principle the EU will refrain from setting hefty laws in this area.

The main EU policy to take into consideration is the **European Disability Strategy 2010-2020** that distinguishes **8 priority** fields of actions:

1. **ACCESSIBILITY** – customization of services and goods to disabled people;
2. **PARTICIPATION** – making sure that the disabled are using all benefits and rights which belong to them from EU citizenship;
3. **EQUALITY** – promoting equal opportunities and the fight against discrimination,



4. **EMPLOYMENT** – increasing the share of disabled people who work in the labour market;
5. **EDUCATION, TRAINING** –ensuring equal access to education, which leads to full participation in society and the overall increased quality of life;
6. **SOCIAL PROTECTION** – fight against poverty, exclusion, and promotion of dignified living conditions;
7. **HEALTH CARE** - equal access to medical services;
8. **EXTERNAL ACTIONS** – promoting the rights of the disabled establishing international programs



2.1.1. MENTAL ILLNESS



<https://theconversation.com/es/topics/mental-disorders-9555>

Mental illnesses are extremely wide spread affecting millions of people from all over the world. The situation is more dramatic as it is estimated that in 2020, globally, the number of disabilities caused by a behavioural disorder will overcome those due to a physical illness. Therefore, at the global level, one from four people suffers from a mental illness.

Risk factors for mental illness are diverse, depending on the biological aspects but also by social and psychological ones.



BIOLOGICAL RISKS FOR MENTAL ILLNESSES

- Genetic factors
- Antenatal, affecting mothers' health during pregnancy
- Rh incompatibility
- Very low birth weight
- Sensory and emotional deprivation
- Physical trauma
- Malnutrition
- Toxic and drug consumption
- Physical chronically disease (leukemia, diabetics, asthma, cystic fibrosis, epilepsy and aids)

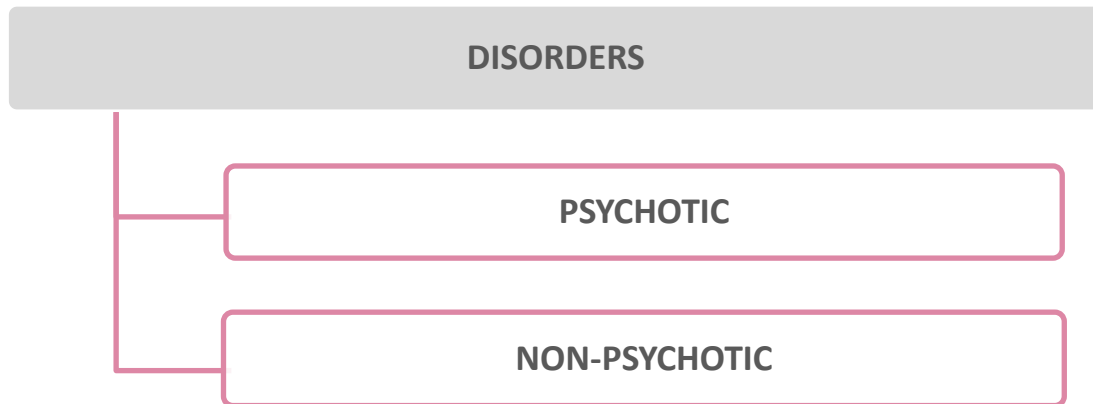


PSYCHOLOGICAL&SOCIAL FACTORS

- Bad quality antenatal care
- Extreme poverty
- Lack of health care
- Low social status
- Disorganized life
- Violence
- Luck or overcrowding of the house
- Traumatic events
- Abuse or neglect
- Absence of a family
- Domestic crime stress, which can trigger more types of disorders or can extend the acute illness episodes

Psychiatric disorders represent 5 out of 10 major causes of disability worldwide. The main mental illnesses leading to disability are: depression, bipolar disorder and schizophrenia. The stigma associated to mental illnesses creates a vicious circle for alienation and discrimination, which results to social and political isolation, as well as to insufficient medical treatment and resources in local communities from all over the world; despite high mortality rate, organizations dealing with mental illnesses get the littlest donations.

Below we present in short the issues of mental disorders affecting world population, issues which can be framed, for a better understanding, in **2 categories** of disorders.



- **PSYCHOTIC DISORDERS** (schizophrenia and bipolar disorder) are caused by a chemical imbalance at brain level, generating alterations in thinking, behaviour and feelings which can seem dangerous and threatening for those around, beyond the lack of effort for understanding the fear and confusion the persona affected by the illness gets through. However, with proper medication and support from medical staff, counsellors and, not the least, from the family, those affected by this type of disorder can live a normal life.
- **NON-PSYCHOTIC DISORDERS** appear when the conditions each of us gets through at some point- depression, sadness, tension or fear- can cause such a big discomfort determining difficulties in handling everyday life activities- at work place, in free time or in social relationships (phobia, anxiety, some type of depression, appetite disorder, and obsessive-compulsive disorders).

Symptoms people with mental diseases have can be physical or psychical.



Among physical symptoms with psychical equivalents (somatization) we include: painful sensations (headaches, back pain, muscle aches), faint feeling, fast heart bits, dizziness, tingling, heavy legs, vomiting or nausea, difficult breathing or asphyxia, lack of air, flushes and feeling a lump in the throat. Those symptoms are met frequently in case of anxiety, depression and rarely in schizophrenia.

Psychological symptoms are specially met in psychoses and they are of many types:

- **Hallucinations** (sensory perceptions for which there is no real stimulus, intensively lived by the respective individual, without criticism or with partial criticism);
- **Depersonalization and de-realization** (sensation of unreality of own person, sensation of losing own body, modification of body shape, yet we mention that the sensation of unreality can be met outside pathology, in fatigue, when waking up or going to sleep, but also in pathological states such as phobia, panic, schizophrenia);
- **Disorders of thinking pace**, like acceleration or retardation (slow speech);
- **Delusions**, (which are false, not in conformity with reality, but very real or the person and impossible to demolish, such as ideas on relationship, prosecution, guilt);
- **Obsessive ideas** (which generate anxiety, shame, absurd ideas, sometimes compulsive), depressive thinking, ideas of death or suicide, hypochondriac thinking, attention disorder, memory disorder, depression, anxiety, inadequate affectivity, sleep disorder, food disorder, sexual disorder.



Mental illness affect adults, elderly but also the young ones, the later ones remaining unidentified and without treatment for many years. In the absence of an adequate diagnosis and treatment, people can get sicker and this leads to low rate of recovery after treatment for elderly. Meanwhile, the person is suffering on many levels, not only on personal health. Socially, the person suffers from isolation, loss of existing relations or losing the partner, friends and family.

It is important to take note that mental illnesses can be treated. Psychological disorders can be today precise and accurate as majority physical diseases; some of them can be prevented, others can be taken care of successfully. People can get their mental health back, not only based on medication. With treatment and adequate support, recovery is possible.

Reintegration, starting from existing abilities, looking into the person's past and life experience, that person can discover he/she can do more things than known before.



2.1.2. INTELLECTUAL DISABILITY

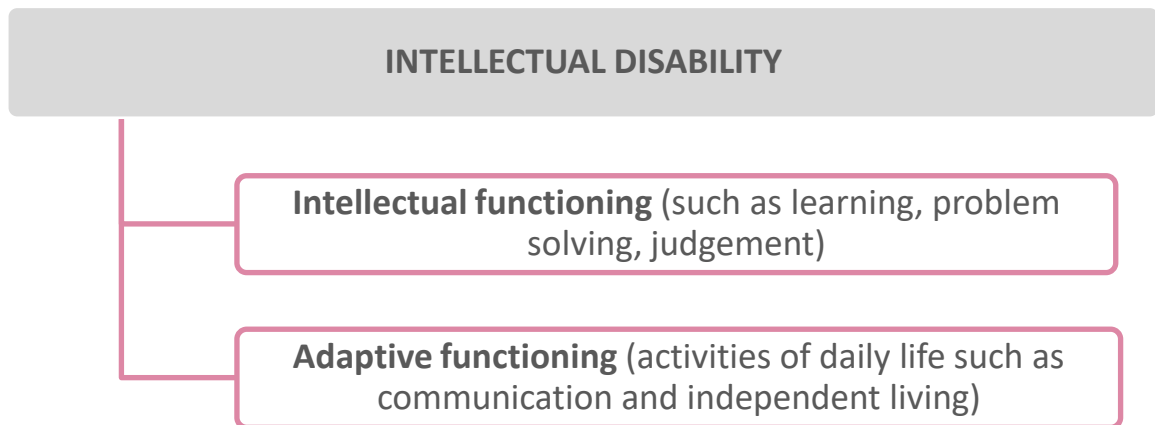


<https://vacursos.com./blog/como-ensinar-autonomia-na-aprendizagem/>

Intellectual disability affects about one percent of the population, and a more elevated percentage affects people with a mild intellectual disability. Males are more likely than females to be diagnosed with intellectual disability.

Intellectual disability is identified by problems in both intellectual and adaptive functioning. Intellectual functioning is assessed with an exam and through standardized testing.

Intellectual disability involves problems with general mental abilities that affect functioning in two areas:



Three areas of adaptive functioning are considered:

- **Conceptual** – language, reading, writing, math, reasoning, knowledge, memory
- **Social** – empathy, social judgment, communication skills, the ability follow rules and the ability to make and keep friendships
- **Practical** – independence in areas such as personal care, job responsibilities, managing money, recreation and organizing school and work tasks

Adaptive functioning is assessed through standardized measures with the individual and interviews with others, such as family members, teachers and caregivers.

Intellectual disability is identified as mild (most people with intellectual disability are in this category), moderate or severe. The symptoms of intellectual disability begin during childhood or adolescence. However, mild levels of intellectual disability may not be identified until school age when a child may have difficulty with academics.

Some mental health, neurodevelopmental, medical and physical conditions frequently co-occur in individuals with intellectual disability, including cerebral palsy, epilepsy, ADHD, autism spectrum disorder and depression and anxiety disorders. Identifying and diagnosing co-occurring conditions can be challenging, for example recognizing depression in an individual with limited verbal ability. However, accurate diagnosis and treatment are important for a healthy and fulfilling life for any individual.

The persons with intellectual disability vary in their abilities even when they have the same type of disability.

There are many factors that together condition the development of cognitive and physical functionalities of an individual. These include the level of education, level of social integration, family background, and economic condition, among others. The type and the degree of the disability represent just a fraction of these factors.

The health professionals conducting the process have to be aware that each person with diagnosed intellectual disability will have his/her own distinctive features and hence, particular needs.



2.2. RESOURCES AND STRATEGIES FOR INCLUSION

Is necessary to be aware of the remaining barriers and overcome them in order to combat discrimination and promote equality of persons with disabilities, as such, it behaves all of us think and apply mode strategies to which there is a full integration in society. Describe some accessibility considered important that can help to overcome obstacles.

They are different resources and strategies that are considered important for inclusion of people with disability as:

- Significant others and attitudes
- Services, systems and policies

SIGNIFICANT OTHERS AND ATTITUDES

It is important to perceive the beholder of disability as the keystone of all the working process, being for this reason the one responsible and interested. This understanding will enhance his/her involvement and active participation across the process and the defining of aims and results to achieve.

SERVICES; SYSTEMS AND POLICIES

There are services, support mechanisms and local and national policies that facilitate or create barriers and can improve or worsen the functionality of people with disabilities.

It is all important to define global policies in order to facilitate integration in the community. We should think in transport, information technology, accessibility, and in the change in mentality of the population so the integration of disabled people to will full and they can participate actively in an increasingly competitive society.

2.3. SUPPORT SYSTEM

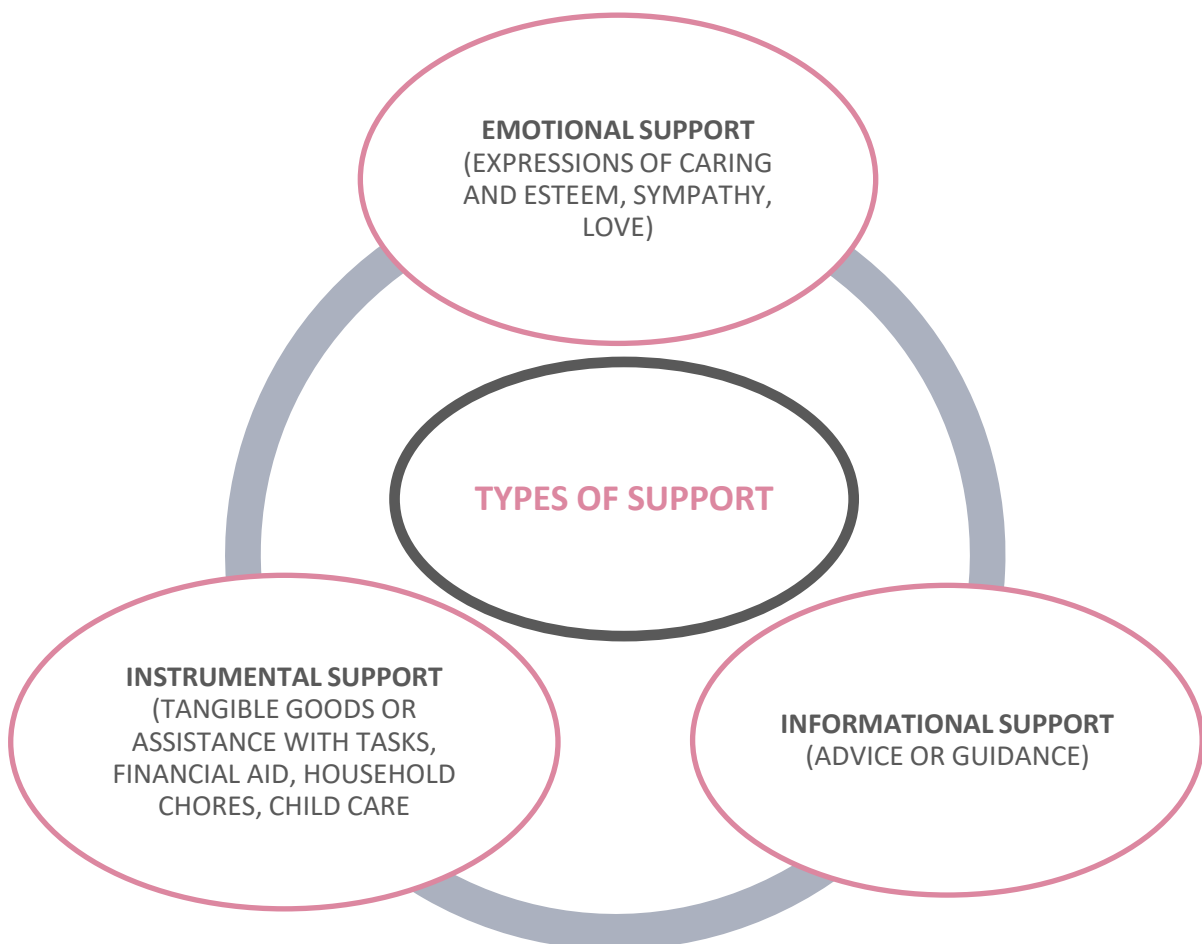


<https://www.hrmagazine.co.uk/article-details/a-negative-outcome-for-positive-discrimination>

Pregnancy constitutes a time of significant life change and challenge requiring major psychological adjustments, often associated with anxiety and stress. A lack of psychosocial and emotional adjustment during pregnancy/maternity constitutes a risk factor for the mother. Social participation providing emotional and instrumental support is protective by buffering the impact of life stress on emotional well-being of the mother.

Social support is a complex and multifaceted concept referring to the voluntary action from one person toward another, which leads to a positive response. Social relationships play a central role in shaping the quality of people's lives. Support may be a critical resource for successfully managing many life challenges, such as pregnancy.

TYPES OF SUPPORT





SUPPORT PROVIDERS

- Family and community support
- Educational and social services
- Medical and health services

EFFECTS OF SOCIAL SUPPORT ON MENTAL HEALTH

- May enhance feelings of well-being, personal control
- Helps women to perceive pregnancy-related changes as less stressful
- Prepare for parenthood and manage their emotional responses
- Decrease in postpartum depression
- Increase in life expectancy
- Better results in pregnancy outcomes

EFFECTS OF SOCIAL SUPPORT ON PHYSICAL HEALTH

- Supportive companion 'doula' during labor dramatically reduced labor length and complications
- Social support may be one determinant of lifestyle habits and relevant health behaviors, including substance use such as alcohol and tobacco, as well as dietary habits
- Better labor progress and babies with higher birth weight and higher Apgar scores

PART IIII HEALTH LAW

3.1. DISABILITY AND HEALTH LAW



<https://katedewhirst.com/blog/2017/07/28/what-is-health-law/>



- The UN convention on the rights of persons with disabilities - Convention on the Rights of Persons with Disabilities (CRPD)
- The Convention on the Rights of Persons with Disabilities (CRPD) was developed by the United Nations. Australia ratified this treaty in 2008 and has also ratified its Optional Protocol. The purpose of the CRPD is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms for all people with disability, and to promote respect for their inherent dignity.
- The CRPD does not define 'disability' or 'persons with disability' but in Article 1 it is made clear that the class of persons to whom it applies includes persons with long-term impairments. This certainly includes people with mental health conditions.
- The Optional Protocol to the CRPD allows an individual to make a complaint to the United Nations Committee on the Rights of Persons with Disabilities if they believe one or more of their rights set out in the CRPD have been violated, where there is no reasonably available domestic remedy for that violation.
- The CRPD comprises 50 articles, 20 of which articulate specific human rights as they relate to the needs and concerns of persons with disability. Among these rights are some that have particular significance to the specific forms of human rights violation disproportionately experienced by persons with mental health conditions. These include the right to equal recognition before the law (Article 12), which recognises and protects the right of persons with disability to exercise legal capacity, protecting the integrity of the person (Article 17) which seeks to protect persons with disability from unwanted, non-consensual interference with their person, and living independently and being included in the community (Article 19) which recognises the right of persons with disability to live in the community with support and prohibits institutionalisation. The right to Health (Article 25) and the right to Habilitation and Rehabilitation (Article 26) also contain elements that have specific significance for persons with mental health conditions in that they both stipulate that health care and rehabilitation must be provided on a voluntary basis, and seek to protect persons from involuntary treatment. Additionally, the right to Habilitation and Rehabilitation recognises and protects the rights of persons with disability to receive rehabilitation in the



community in a manner which supports inclusion rather than segregation from community life.

- International Covenant on Economic, Social and Cultural Rights (ICESCR) and International Covenant on Civil and Political Rights (ICCPR)
- The International Covenant on Civil and Political Rights (ICCPR) and the International Covenant on Economic, Social and Cultural Rights (ICESCR) are the two main international treaties that expand in detail on the principles in the Universal Declaration of Human Rights and set them out in a legally binding agreement between countries. Both are treaties developed by the United Nations. Together with the Universal Declaration of Human Rights, these treaties are sometimes referred to as the 'International Bill of Rights.' The Second Optional Protocol to the ICCPR enables individuals to make a complaint to a United Nations committee if they believe one or more of their rights set out in the ICCPR have been violated, in circumstances where there is no reasonably available domestic remedy for this violation. Article 12 of the ICESCR recognises the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.
- Convention Against Torture and other Cruel, Inhuman or Degrading Treatment or Punishment (CAT)
- Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW)
- Convention on the Rights of the Child (CRC)



WHO ARE THE PREGNANT WOMEN WITH DISABILITY THAT WE CONSIDER?

We consider only pregnant women over 18 years old:

- We don't consider pregnant women under that age because, even if they have disability, they are a very specific public of neo natal health care;
- We don't consider pregnant women under that age because, even if they have disability, they are covered by the typical legal representation of minors;
- We don't consider pregnant women under that age because the number of live births of adolescent mothers has been decreasing in Portugal;

CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES

- It advocates respect for difference and acceptance of people with disabilities as part of human diversity and humanity; and **non-discrimination**;
- It establishes that States should take all appropriate measures, including legislation, **to modify or repeal existing laws, norms, customs and practices that constitute discrimination against persons with disabilities**;
- It stipulates that States parties shall take all appropriate and effective measures to **eliminate discrimination** against persons with disabilities in all matters relating to marriage, **family, parenthood and personal relationships**, on conditions of equality with the others, in order to ensure:



- the recognition of the **right** of all persons with disabilities who are of legal age to contract matrimony and **to form a family** based on the free and full consent of the future spouses;
- the recognition of the rights of persons with disabilities to decide freely and responsibly on the number of children and the spacing of their births, as well as access to information appropriate to the age, reproductive and family planning education and the provision of the necessary resources to permit them to exercise these rights;

THE RIGHT TO HAVE A FAMILY

Art. 68.º/2, 3

- Motherhood and fatherhood are eminent social values;
- **Women have the right to a special protection during pregnancy and after childbirth.**

Art. 71.º

- **Citizens with physical or mental disabilities have full rights...**
- The State undertakes to carry out a national policy of prevention and treatment, rehabilitation and integration of citizens with disabilities and awareness of the duties of respect and solidarity towards them.



PATIENT RIGHTS

1. **The patient has the right to be treated with respect for human dignity.**
2. **The patient has the right to be respected on her cultural, philosophical and religious convictions.**
3. The patient is entitled to receive appropriate care to her health, within the framework of preventive care, curative, and rehabilitation.
4. The patient is entitled to the provision of long-term care.
5. **The patient has the right to be informed about existing services, skills and levels of care.**
6. The patient has the right to obtain a second opinion about her health situation.
7. The patient has the right to be informed about her health situation.
8. **The patient is entitled to give or refuse her consent before any medical act or participation in research or clinical training.**
9. **The patient has the right to confidentiality of all clinical information and identifying elements.**
10. **The patient has a right of access to data recorded in her clinical process.**
11. **The patient has the right to privacy in the provision of any medical act.**
12. **The patient is entitled, by herself or by who represents, to submit suggestions and complaints.**



DUTIES OF THE PATIENT

1. The patient has the duty to provide her state of health. This means seeking to ensure the most comprehensive restoration and also participate in the promotion of her own health and on the health of the community in which she lives.
2. The patient has the duty to provide health professionals all the information necessary to obtain a correct diagnosis and proper treatment.
3. The patient has the duty to respect the rights of other patients.
4. The patient has a duty to collaborate with health care professionals, in compliance with the indications that are recommended and, for itself, freely accepted.
5. The patient has the duty to respect the rules of operation of health services.
6. The patient has the duty to use health services in an appropriate manner and to collaborate actively in reducing unnecessary spending.

WHO ATTENDS THE PREGNANT WOMEN WITH DISABILITY?

THE FAMILY DOCTOR

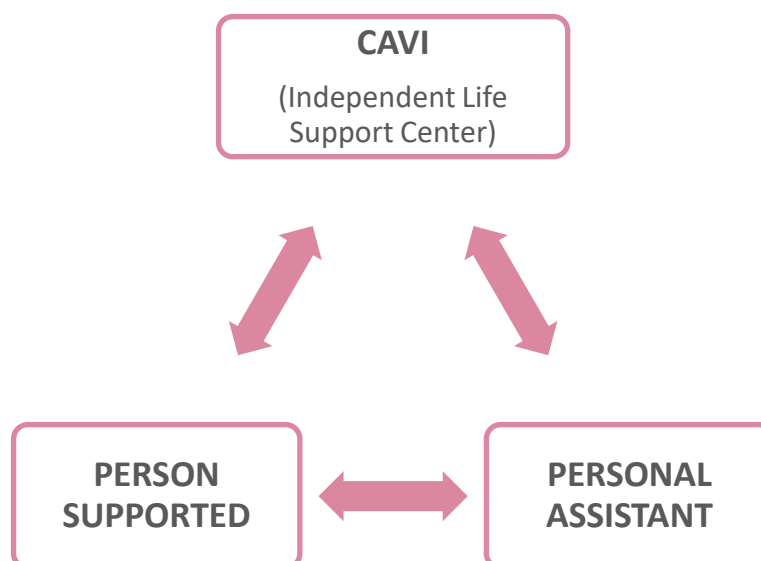
- Regardless of the stage of gestation process (planning, suspicion of pregnancy, pregnancy confirmed, months of pregnancy, childbirth approach, post natal), the family doctor will always be the first contact between the patient and the Health System.
- This will be assisted by a professional nursing, which also will assist the woman.
- The woman can be forwarded to specific services of a Hospital or Maternity, in particular because it is not possible to perform certain tests at the Local Health Center.

*AND IF THE PREGNANT WOMAN CANNOT EXPLAIN OR UNDERSTAND
WHAT SHE NEED?*

- Between spouses:
 - Obligation to mutual help and aid
 - Take together the **responsibilities inherent in the life of the family** that they founded

INDEPENDENT LIVING SUPPORT MODEL (MAVI)

- Personal assistance for people with disabilities:
 - As a rule, no more than 40 hours per week;
 - Hygiene activities; power supply; health and personal care; domestic assistance; movements; citizenship participation; **mediation of communication**; employment context; frequency of vocational training; frequency of higher education and research; culture, leisure and sport;
 - **By someone who is not a familiar of the person supported, although he participates in the process of choosing his personal assistant.**





ACCOMPANIED ADULTS

Are people **older than 18 years** and who are unable, for reasons of health, **disability** or by behavior, to exercise fully, personally and consciously their rights or fulfill their duties.

- The accompaniment of adults aims to ensure their well-being, their recovery, the full exercise of all their rights and monitoring their duties.
- **The accompaniment of adults is limited to the necessary.**
- The accompaniment of adults can be modified or cease when it is appropriate.
- The accompanied woman is free to exercise her personal rights, such as:
 - **Have children**
 - Legally recognise their children
 - Adopt
 - **Care and educate their children**
 - Establish relationships with who wants
- Carry out the acts of normal life

UNLESS

Legal or court decision to the contrary!

- The company acts in the interest of the accompanied. The acts realized on its own interest can be cancelled.
- The company acts for free.
- The accompaniment is required:
 - By the woman herself (even if she is a minor, in the year preceding adulthood and to take effect from this)



- With permission of the own woman (that permission can be refused if she can't give it freely and consciously or when there are grounds of consideration)
- By Prosecutors
- The accompaniment is decided by the court and communicated to the registry office. It is reviewed, at least each 5 years.
- The accompanied adult to be is personally and directly heard and are considered all the evidence.

HOWEVER

In any time of the process it can be adopted certain provisional and urgent measures!!!

THE WOMAN IS NOT ALONE

- She can be informally assisted by her partner; if she is minor, she can be assisted by her parents.
- She can choose someone to be her personal assistant.
- She can still choose someone from her sphere of trust. The chosen person will assist the woman with the legal status of companion and its mission is to ensure woman well-being, her recovery, the full exercise of all her rights and the fulfilment of her duties.



JUDICIAL DECISION

- It is the Court that decides the person level of ability/inability;
- It is the Court that establishes what the woman can do alone;
- It is the Court that indicates the acts in which the woman has to be accompanied:
 - By the complexity, there may be need to accompany the woman on the exercise of some of **their rights**.
 - **The rights continue to be their rights, but her health condition prevents it from make some decisions by herself.**



THE WOMAN WITH DISABILITY:

- Has, like any other, the right to choose with whom she want to have children;
- Has, like any other, the right to have children;
- Has, like any other, the right to care for and educate their children;
- Has, like any other, the right to raise a family;

SINCE SHE IS ABLE TO DO THIS!

IT IS IMPORTANT THE OPINION OF THE WOMAN WITH DISABILITY?

- The woman with disability consent may not be enough to say that some act is not a crime;
- In fact, in Portugal, the consent requires a twofold criterion of effectiveness: the age of 16 years and discernment;
- This, of course, in addition to having to be free and clear, which means tailor information to the level of understanding of each woman.

NO ONE CAN DISPOSE OF THE BODY OF THE WOMAN, EVEN IF DISABLED!

- In some situations, there may be need to interrupt the pregnancy;
- Regardless of the situation, and unless this proves impossible, the pregnant woman should be heard on the reasons that may justify this interruption;
- The law and her opinion limited the action of the health professional.

ANY PREGNANT WOMAN HAS THE RIGHT TO UNDERSTAND WHAT IS HAPPENING!

- The health professional must adapt their explanations to the woman level of language understanding;
- He must repeat their arguments if she don't understand;
- He should be clear;
- He must be patient;
- He must do everything to ensure woman membership free and enlightened.



3.1.1. RIGHTS AS PREGNANT

1) RIGHTS

Everyone has rights and duties. One of my rights is to build a family, choosing the person I want to be with and whether or not I will have children. In order to make this right effective, I must be able to count on the support of the State, namely the Health Department - I must have a family doctor assigned, I must be followed periodically by him, I must carry out all the examinations necessary for the well-being of my baby and I must be always informed of all the steps of development of my pregnancy, with a language appropriate to my level of understanding.

2) Does the law protect disabled women who are pregnant?

There are international norms and norms of Portuguese law that specifically address the situation of persons with disabilities, seeking, more and more, to obviate any type of discrimination and promote the integration of these people in society, adapting the responses to their capacity and need.

3) Opinion of women with disability

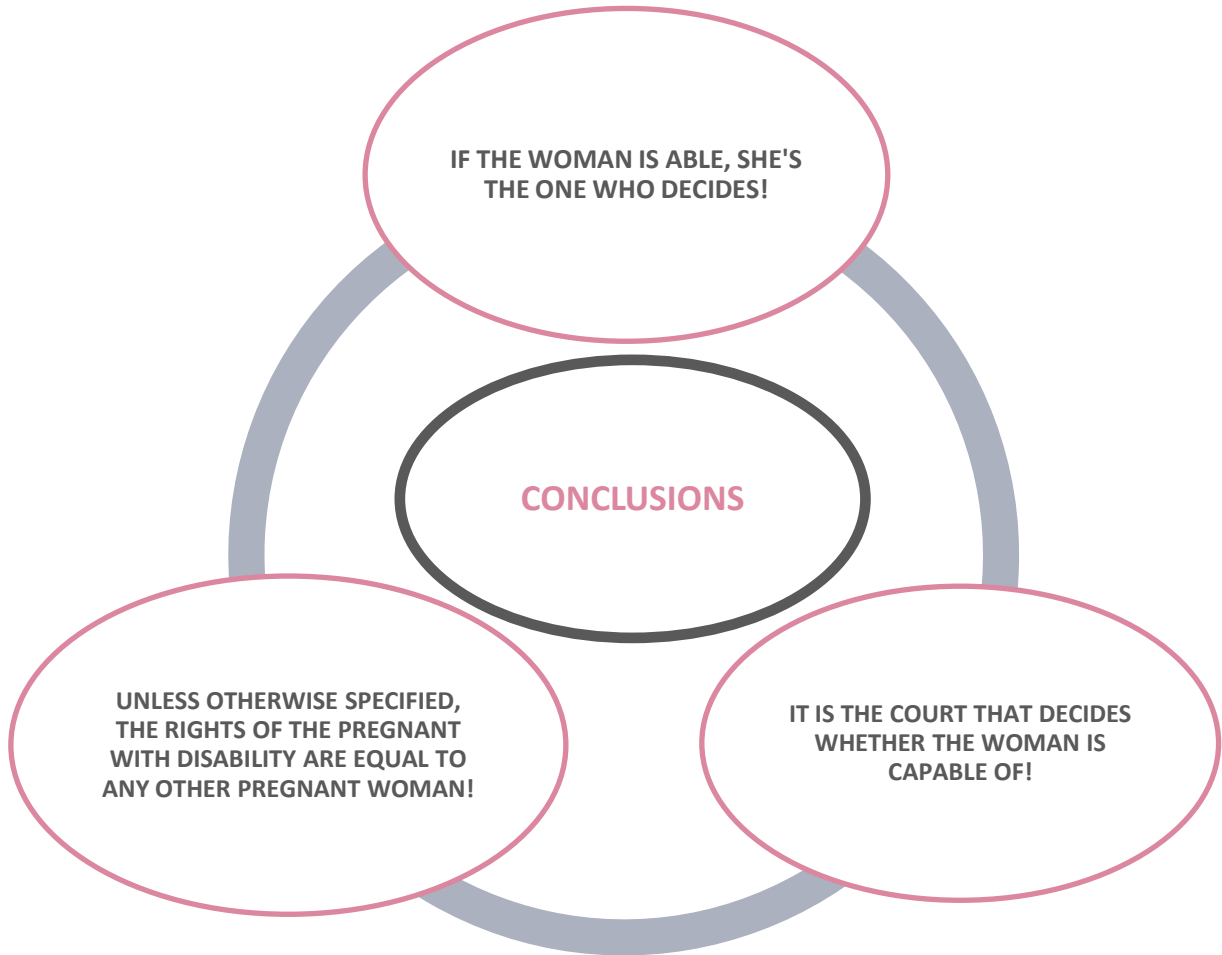
This concerns the exercise of a fundamental personal right of mine. So, my opinion is the most important opinion as long as I reveal the ability to understand that essential for decision making.

4) Who can help women with disability?

This aid can be an informal help, provided, above all, by my partner, but also by a personal assistant. It is, however, possible to choose someone I trust to accompany me in the exercise of certain rights for which I do not have the capacity. This accompanying person is appointed by the court and will always act in my interest and limiting his intervention to what is strictly necessary. When in doubt, I can always go to the Public Prosecutor's Office, who will try to find the right person to accompany me.

5) And when my baby is born, what will happen

My health condition, except in exceptional cases and judicially defined, does not in itself determine any limitation in the exercise of my rights to care for and educate my children. Only the Court, therefore, can inhibit my exercise of parental responsibilities.





GENERAL HEALTH PUBLIC LAW

This law addresses the following issues:

- To promote individual, family and social interest in health through adequate health education of the population.
- To develop orientation programs in the field of family planning and the provision of the corresponding services.
- Everyone has the following rights before the different public health administrations: Respect for their personality, human dignity and privacy, without being discriminated because of their racial or ethnic origin, because of gender and sexual orientation, disability or any other personal or social circumstances.
- Information about the health services that a person can access and about the necessary requirements for its use. The information must be given in appropriate formats, following the rules set by the design principle for all, so that they are accessible and understandable for people with disabilities.
- The promotion, extension and improvement of systems for the early detection of disabilities and of services aimed at preventing and minimizing the appearance of new disabilities or the intensification of pre-existing ones.
- Public health actions will incorporate the gender perspective and will pay specific attention to the needs of people with disabilities.
- All health information will be provided disaggregated for its understanding according to the affected group, and will be available in a format that allows full accessibility to people with disabilities.

3.2. PUBLIC HEALTH LEGISLATION ON FAMILY PLANNING AND MATERNITY CARE

The law addresses the protection and guarantee of rights related to sexual and reproductive health in an integral mode. It introduces the definitions of the World Health Organization on sexual health and reproductive health and foresees the adoption of a set of actions and measures both in the health and in the educational field. It also establishes a new regulation of the voluntary interruption of pregnancy.

It is of vital importance in this law:

- The development of sexuality and the capacity for procreation are directly linked to the dignity of the person and to the free development of the personality and are the object of protection through different fundamental rights, notably those that guarantee physical and moral integrity and personal and family intimacy. The decision to have children (and when) is one of the most intimate and personal issues that people face throughout their lives, which integrates an essential area of individual self-determination. The public authorities are obliged not to interfere in such decisions, but, also, must establish the conditions for their adoption in a free and responsible manner, making available to those who need health care services, advice or information.
- Respect the right of persons with disabilities to decide freely and responsibly the number of children they want to have, to have access to information, reproduction education and family planning and to provide the necessary means to enable them to exercise those rights, as well as to maintain their fertility, on equal terms as others.



PART IV/ DISABILITY AND SEXUALITY

4.1. SELFIMAGEM

Having a disability may sometimes create an emotional or psychological burden for the individual with disabilities. They may feel inhibition about pursuing relationships, fearing rejection on the basis that they have a disability. Selfimage may suffer as a result of disfigurement, or lack of confidence. "Sexuality, travel, mobility, pain". Everything takes on a different dimension. Attempting to hide a disability or minimize its existence is not correct, is necessary accept the disability.

There is often fear associated with the intersection of sexuality and disability. Many people with disabilities embody a fear of being rejected due to the way they look. This hypersensitivity causes the individual with disabilities to keep interactions platonic. The "evaluative gaze" coming from others causes people with disabilities to feel judged and uncomfortable in their own bodies.

4.2. SOCIETY IMAGEM

Individuals with disabilities are rarely regarded in society as sexy or believed to be sexually active. When sex and disability are linked, it is common for marginalization to occur. Many people shy away from the idea that individuals with disabilities can have sex. This is due to a lack of information on the subject.

In society it is widely believed that women with disabilities are asexual. One reason for this belief is that Individuals with disabilities are seen as eternal children.

Others see the intertwine of sex and disability as an acrobatic act. It is difficult for many people to imagine an Individual with disabilities having sex, because of the restricting impairments. Viewing women with disabilities as asexual has its issues.

Women with disabilities are not viewed as physically attractive because society does not view them as sexually desirable. This results in women with disabilities to be limited and constrained to love and be loved.

The pleasure and sex have been largely ignored, especially when it comes to Individuals with disabilities.

In society sex is portrayed appropriate only for single, young, and able bodied people. Because of this spaces to express sexuality are minimized for Individuals with disabilities. Individuals with disabilities are marginalized so the intersection of sexuality and disability is not recognized. When an individual is sexually active, they tend to exclude people with disabilities from their



sexual space. These attitudes have served to shun out personal and public sexual pleasure for Individuals with disabilities.

In mainstream media people who are disabled are absent when it comes to sexual portrayals. This is also true when it comes to medical and scientific literature.

The biological idea that sex is meant for reproduction has been damaging to the sexual lives of Individuals with disabilities. Because some disabilities restrict an individual from having children, the idea of this person having sex is eliminated. After this the individual with disabilities is no longer a candidate for reproduction. This social cultural viewpoint creates the need in society to protect Individuals with disabilities from harm, by keeping them away from all sexual encounters.

THE NEED TO CHANGES



https://www.huffpost.com/entry/why-do-we-need-changes_b_11700296

Researchers have consistently shown that children and adolescents with ID have an increase drisk of multiple forms of abuse. The issue of sexual abuse in children and adolescents with ID confirm that there is a significantly higher rate of sexual abuse in this population than in non-disabled.

Demonstrating a need for change in the approach to providing sexual health information to students and young adults with intellectual disabilities. Women with ID were at a 3.5 times greater risk of sexual abuse.

The absence of the ability to develop healthy and appropriate sexuality may result in a variety of mental disorders (e.g., anxiety, depression, and impaired self-esteem) as well as putting individuals with ID at risk for sexual abuse and sexually transmitted diseases (STDs). The serious ramifications for those with ID if appropriate sexual education does not occur were illuminated. As mis-informed and uninformed individuals, an increased risk of sexual abuse, exploitation, and increased risk for sexually transmitted diseases (STDs). The lack of basic understanding of the consequences of unprotected sex demands better sex education for individuals with ID.

4.3. AFFECTIVITY AND SEXUALITY IN THE DISABLED PERSON



<https://super.abril.com/historia>

"From birth, it is the social group that transmits and defines the identity of the baby according to whether it is a boy or a girl. Early relationships with attachment figures are particularly important in childhood, as they will be the ones who will mediate sexuality throughout life and especially in this first phase. It is in this experience that the child acquires: the confidence and security that allows him/her to open up to contacts with his/her surroundings; the use and meaning of intimate and informal forms of communication; the use and meaning of emotional expressions; the ability to make explicit his/her needs as well as the ability to satisfy the needs of others".

(López, 1989; cf. Felix, 1995)

The human being is born with biological and genetic characteristics that define him as unique, and his identity and personality are built up throughout his development, simultaneously with affectivity and sexuality. Undoubtedly we are all social beings where the other (the people with whom we relate) assumes an important role. It is thus evident that we are all sexual beings, with our own impulses and needs, with different expressions of affectivity.

Although sexuality is constructed from childhood, it is in adolescence that its manifestations become more evident, raising specific questions linked to people in situations of disability.

In fact, several studies report that the physical and physiological modifications of puberty and the resulting impulses and desires appear in the person in a situation of disability at the same age as in the general population. However, these physical and physiological changes are also accompanied by psychological changes, which in the case of people with mental disabilities seem to occur more slowly.

In society, the idea that the person with a disability is an asexual being or the opposite idea, that he only thinks about sex, still prevails.

These postures are inadequate, since, despite the situation of a person with a disability, we are talking about a person, therefore a sexually impulse sexed being.

The exploitation of one's own body is a normal process of the development of our sexuality. At puberty, masturbation as a visible manifestation of this exploitation increases and becomes more frequent in both sexes.

These manifestations often raise problems for the family or for institutions, as they sometimes reveal themselves with some social inadequacy that can be linked to a psychological immaturity, which as we have mentioned does not always follow the same rhythm as the physical and physiological one, or even the lack of interiorisation of the difference between private (intimate) and public space and the implications of this difference.



In young people with disabilities, masturbation can often become their main form of sexual expression, so it is important to develop strategies and means for understanding the intimate/public contexts by promoting social skills, attitudes and behaviours, as well as access to adequate information.

Sexuality cannot be reduced to genital organs or sexual relations, it must be understood in a broader sense, linked to approval, sharing, support, appreciation and a sense of usefulness for the other. Affective-sexual behaviour is a fundamental need for the development and growth of the human being, and by suppressing it one is compromising one's development as a person.

4.4. ATTITUDES TOWARDS AFFECTIVITY AND SEXUALITY OF THE PERSON WITH DISABILITY

Within the family, respect for the right of the person with a disability to sexuality can also depend significantly on parents' and people's understanding of the cycle of belonging to the meaning and expressions of that sexuality and the quality of interaction in this area too.

It is common for sexuality in a disabled adult to be compared to that of a child. Such representation when espoused by parents and caregivers can potentiate limitations to the desirable process of autonomy. In a situation of disability, dependence on others can hinder and slow down the process of autonomy.

Another relevant idea in the attitudes of parents is those related to the consequences of an active sexual experience, namely fertility and reproduction. This is especially so because the limitation of the concept of sexuality to the sexual act that can lead to pregnancy is still present, an aspect that is frightening for many families. The idea that a person with a mental disability is incapable of caring for a child or that the child may also be born with a disability often conditions the attitudes of parents, even leading some to consider sterilization and to assume as theirs the right to consent to it.

While it is true that the recognition of the human rights of persons with disabilities as principles is accepted by parents, the issue takes on different forms when the experience of their own sexuality by their children is reported, in this case mechanisms of over-protection and devaluation of sexuality as a whole emerge.

It is important that the structures that accompany these families provide spaces for reflection and discussion on these issues.

Although the family is central, the structures in the ranks of technicians and other collaborators are primarily responsible for the realization of the rights of persons with disabilities, their well-being and full development.

With regard to sex education and counselling in the affective/sexual field, technicians are often conditioned by the very policy of the institution's structure, or lack of it, with regard to this subject. The lack of explicit rules and guiding norms leads them to act according to their own ideas, values and beliefs, conservatism, the preference for not addressing these issues and the reduction of sexuality in the disabled to masturbation, or to exhibitionism or to frivolous, aggressive or homosexual behaviour may prevail.

Although there does seem to be a greater tolerance on the part of technicians with regard to affective-sexual expression, there is a discrepancy between this tolerance and the effective creation of conditions by the structures due to the aforementioned duplicity between the feelings and interests of people with disabilities and that of their families.

Thus, in order to promote conscious and enlightened attitudes of technicians towards the theme of affectivity and sexuality in disability, it is important to receive technical information about aspects of psycho-sexual development in children and adolescents; to acquire skills to adequately evaluate the value and functionality of the behaviours exhibited by these young people; to intervene in a safe and enlightened manner.

Above all, issues of sexuality should be viewed naturally, but also with professionalism. Just as parents often need help in educating and accepting their children's sexuality, technicians may also need this support.

It is in becoming aware of their difficulties in intervention that the management of structures should promote training actions which enable the technical teams to act in a structured way, at the level of sexuality education of young people as in any other field, be it professional integration or the development of leisure activities.



Professionals should have activities planned, organised and guided by qualified teachers or trainers, so that professionals acquire or reformulate knowledge, develop skills and, above all, reflect on their personal way of dealing with issues of sexuality and, particularly, that of disabled people.

These programmes should initially take into account the awareness and training of technicians, meeting the difficulties and needs expressed by them.

Afterwards, the technicians should promote actions and activities that allow the transmission of this knowledge and experience to young people and their families.

According to Gordon, (1981) objectives must be established which are capable of responding to an adequate sex education for any type of population, whether disabled or not:

1. Recognition of sexuality as a source of pleasure and communication is a positive and fulfilling component in personal development and interpersonal relationships;
2. Valuing the different expressions of sexuality in the various stages of lifelong development;
3. Respect for the person of the other, whatever their physical characteristics or sexual orientation;
4. Promotion of equal rights and opportunities between the sexes;
5. Respect for the right to be different;
6. Recognition of the importance of communication and affective and loving involvement in experiencing sexuality;
7. Recognition of the right to a free and responsible maternity/paternity;
8. Recognition that autonomy, freedom of choice and adequate information are essential aspects for the structuring of responsible attitudes and behaviour in sexual relationships;
9. Refusal of forms of expression of sexuality that involve manifestations of violence and promote personal relationships of domination and exploitation;
10. Promoting the health of individuals and couples in the sexual and reproductive sphere.

Following this perspective, sexuality cannot and should not be treated as a separate issue, but as a component of life, as any other need.

In the entities, technicians have an important contribution to make in demystifying the taboo that continues to be sexuality in the disabled person.

Although individuals with ID are a heterogeneous group (e.g., degree of disability, familial influence, age, gender), it is apparent that, population specific sexual education needs to be considered a priority.

This is a an issue that needs to be explored in more depth with a focus on effective educational methods, specifically in the ID population, aimed at minimizing the negative consequences associated with a lack of knowledge and understanding.



PART VI / GOOD PRACTICE and POLICY RECOMMENDATIONS

5.1. GOOD PRACTICE

1. Increase reproductive/maternal health literacy in women with disability/mental illness.
2. Increase reproductive/maternal health literacy in family members and partners of women with disability/mental illness.
3. Increase disabled/mentally ill women's involvement and autonomy in decision-making processes.
4. Increase information accessibility for women with disability/mental illness.
5. Adapt information to the needs of women with disability/mental illness.
6. More training about disability and mental health for health professionals.
7. Increase involvement of disabled/mentally ill women's family and partners in reproductive/maternal healthcare.



5.2. POLICY RECOMMENDATIONS



<https://www.accdocket.com/articles/gc-s-public-policy-role-in-an-age-of-upheaval.cfm>

There are services, support mechanisms and local and national policies that facilitate and can improve the functionality of people with disabilities.

It is all important to define global policies in order to facilitate integration in the community.

We should think in transport, information technology, accessibility, and in the change in mentality of the population so the integration of disabled people to will full and they can participate actively in an increasingly competitive society.

It is necessary to be aware of the remaining barriers and overcome them in order to combat discrimination and promote equality for people with disabilities, and as such it is up to all citizens to think and implement strategies so that there is full integration into society.

The right of women with intellectual disabilities or mental illness to participate actively in the promotion of their reproductive and maternal health, to perceive correctly all the information transmitted to them by health professionals and to ensure adequate follow-up is a fundamental right and one of the common and essential principles and values of the European Union.

In recent years, the European Union, with the strong commitment of its Member States, has come a long way towards an equitable society in terms of the inclusion of people with disabilities in various ways. This is due to continuous work on various aspects, both at European, national and local level. However, this work is not yet complete, as we are far from achieving the full inclusion of people with disabilities, especially in areas such as the right to their reproductive and maternal health choices.



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