



UNITED NATIONS
SERBIA



 **AUTONOMY**
 **VOICE**
 **PARTICIPATION**
of persons with disabilities in Serbia

SEXUAL AND REPRODUCTIVE HEALTH OF WOMEN AND ADOLESCENT GIRLS **WITH DISABILITIES**



UN Partnership on the Rights of Persons with Disabilities

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#Acknowledgments

The issues of sexual and reproductive health and the rights of persons with disabilities in the Republic of Serbia are rarely the subject of research and there is not enough data which would depict the situation in this area in a more comprehensive way.

Thanks to the United Nations Partnership on the Rights of Persons with Disabilities (UNPRPD), the UN Population Fund (UNFPA) was given the opportunity to participate in the **Autonomy, Voice and Participation of Persons with Disabilities in Serbia** project and to conduct research about experience of women with disabilities in exercising their sexual and reproductive rights, within the project component related to strengthening integrity and improvement of the position of women and girls with disabilities.

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tional minorities, from Novi Bečej, the Center for care for the elderly, children and persons with disabilities, from Novi Beograd, Special school for Primary and Secondary education 'Milan Petrović', from Novi Sad and the Association of Dystrophy Disabled Persons of Zlatibor Region - from Užice, the Association of deaf and hard of hearing, from Vršac.

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We hope that this publication will contribute to better understanding of the current situation and create the road towards formulation of appropriate policies that will address necessary issues and improve the situation regarding sexual and reproductive health of persons with disabilities in Serbia.



SEXUAL AND REPRODUCTIVE HEALTH OF WOMEN AND ADOLESCENT GIRLS **WITH DISABILITIES**

Belgrade, December 2018



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#1 Introduction

The **Sexual and Reproductive Health of Women and Adolescent Girls with Disabilities** report presents the results of the research **on the experiences of women with disabilities in terms of sexual and reproductive rights** which was carried out under the United Nations Partnership on the Rights of Persons with Disabilities (UNPRPD).

In the framework of the United Nations Partnership on the Rights of Persons with Disabilities (UNPRPD), the project entitled **“Autonomy, voice, and participation of persons with disabilities in Serbia”** has been in progress since May 2018. The project is jointly implemented by the International Labour Organisation (ILO), the Office of the High Commissioner for Human Rights (OHCHR), the United Nations Development Programme (UNDP), the United Nations Population Fund (UNFPA) and the United Nations Agency for Gender Equality and Women Empowerment (UN Women) in partnership with the Government of Serbia and organisations of persons with disabilities and other civil society organisations.

The project aims at contributing to the improvement of the position of persons with disabilities by improving the opportunities for a higher degree of autonomy and participation of persons with disabilities, both in decision making and in other aspects. The expected results and project activities are based on the normative framework of the Convention on the Rights of Persons with Disabilities and the Concluding Observations on the Initial Report on Serbia of the UN Committee on the Rights of Persons with Disabilities, (2016).¹

The activities are in line with the policies included in the draft version of the National Strategy on the Rights of Persons with Disabilities in Serbia (2017-2020)², in order to take full advantage of the momentum and the readiness for political and broader cooperation of all relevant stakeholders in this field. The project's activities aim at initiating changes - from legislative interventions in stra-

tegic areas to changes in the cultural norms and awareness of the key stakeholders, to building and strengthening the capacity of the target groups and stakeholders, with a particular focus on women with disabilities and persons with psychosocial and intellectual disabilities.

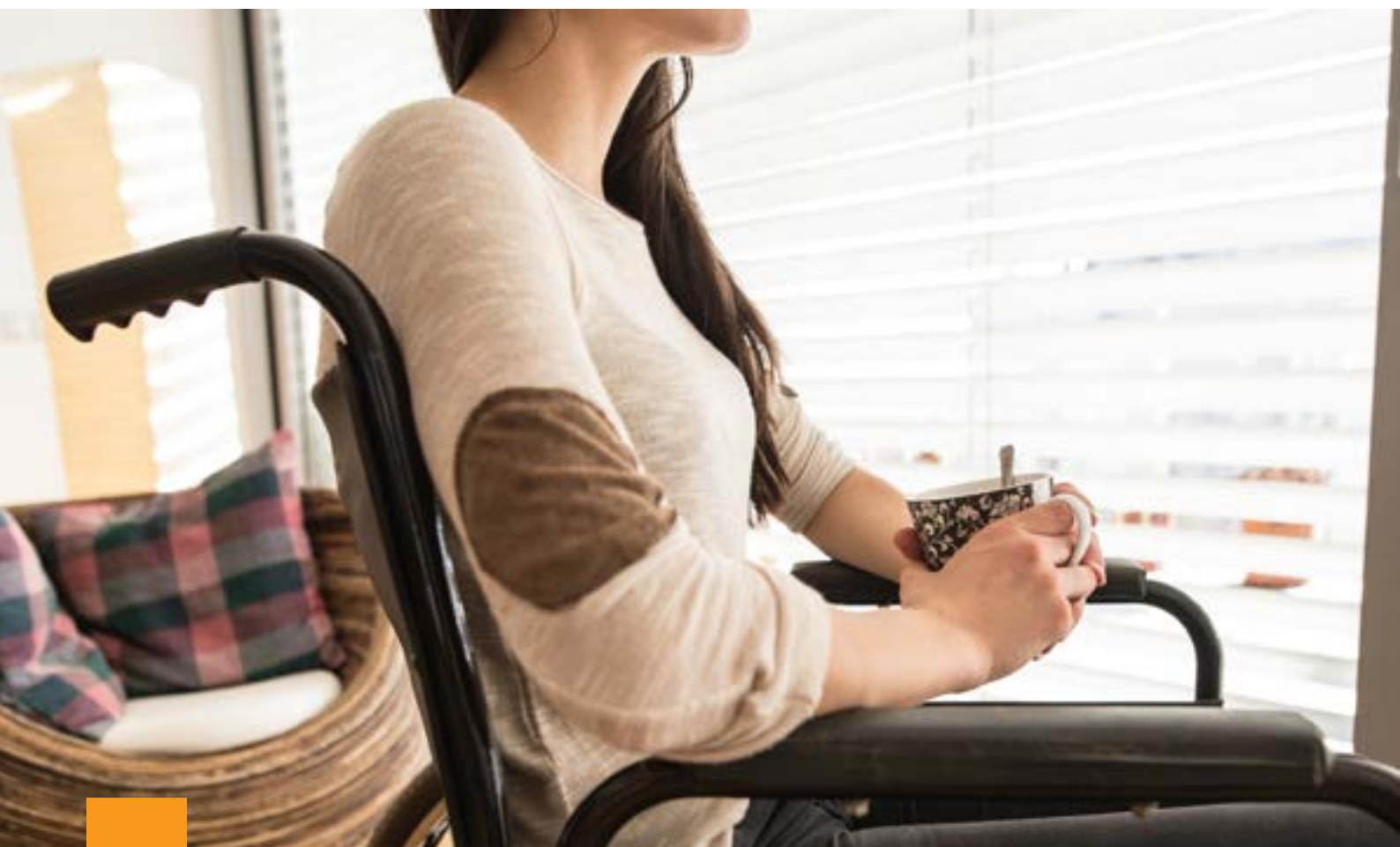
The project comprises the following three areas:

- Equality before the law and the right to legal capacity
- Strengthening integrity and improving the position of women and girls with disabilities as a particularly sensitive group
- Employment of persons with disabilities.

The UN Population Fund (UNFPA) participates in the component on strengthening integrity and improving the position of women and girls with disabilities, in which research on the experiences of women with disabilities in the exercising of sexual and reproductive rights has been conducted. The aim of the research was to document the awareness and attitudes of women and girls with disabilities on sexual and reproductive health and rights, as well as practical experiences in exercising these rights in the health care system.

¹ Analysis of the implementation of the recommendations of the Committee on the Rights of Persons with Disabilities in the Republic of Serbia <http://noois.rs/dokumenta-publikacije/publikacije/308-publikacija>

² This strategy has been prepared as draft and is available on the NOIS website http://www.noois.rs/doc/zakoni/Predlog_Strategija_OSI_2020.doc



#2 Rights and Public policies for Sexual and Reproductive Health

National Level of Sexual and Reproductive Health Policy

The public health policy focuses on socio-economic determinants of health and the reduction of health inequalities and integrates health care into all policies in accordance with the law governing public health. The Health in All Policies concept is an approach that is recommended

in response to the challenges and involves intersectoral cooperation and inclusion of all stakeholders in a society. It is an integrated approach which enables the achievement of the social goals of all government departments. An intersectoral, government-coordinated policy, common

goals and integrated responses to existing issues and challenges, a partnership with the non-governmental and private sector constitute the basis of joint governance, that is, the effective implementation of health in all policies. The health sector has a leading role in working with other sectors and providing direct support to the Government in developing important policies and achieving their goals. The successful implementation of this concept requires an institutionalized process of intersectoral problem-solving, establishing mandates and responsibilities, initiatives, financing, budgets and sustainable mechanisms for the operation of government institutions in the field of public health.

The normative and institutional framework in the Republic of Serbia for public health and intersectoral public policies is based on the following documents:

- **Health 2020:** the European policy framework supporting actions of all levels of government and society for health and well-being, adopted on the basis of the EUR/ RC62 resolution /Conf.Doc./8 of the WHO Regional Office for Europe.
- **The Third (EU) Health Programme 2014-2020**
- **The current national strategies of other countries** (the Republic of Finland, the United Kingdom, the Northern Ireland, the Federal Republic of Germany, the Republic of Croatia, Australia, etc.) represent invaluable assistance.
- **The United Nations Resolution “Transforming Our World: the 2030 Agenda for Sustainable Development”** is the basis for the Public Health Strategy.
- Numerous universal international documents guarantee to all persons, without discrimination, the right to health and the highest possible standard of health care, such as the **Universal Declaration of Human Rights (1948)** and the **International Covenant on Economic, Social and Cultural Rights (1966)**. The Convention on the Elimination of All Forms of Discrimination against Women (“Official Gazette of SFRY - International Agreements”, No. 11/81) was adopted at the UN General Assembly in December 1979 (CEDAW Convention, 1979), and came into force on 3 September 1981. The Convention is an international legislative instrument on human rights. The provisions of the Convention stipulate equality of men and women in respect of all economic, social, cultural, civil and political rights and determine measures to monitor their accomplishment. The Committee for the Elimination of Discrimination against Women supervises implementation of the Convention. The Republic of Serbia, as the successor of the former states, has been a Party to the Convention as of 12 March 2001, and, in accordance with Article 18 of the Convention, it is obliged to submit periodic reports to the Committee on its implementation.
- The Republic of Serbia signed the Convention on the Prevention and Combating Violence against Women and Domestic Violence (the Istanbul Convention) in April 2012 and ratified it in October 2013. The Convention is a comprehensive international document that regulates in detail the prevention, protection, and prosecution of violence against women and participation of victims of violence and introduces mandatory programmes for the perpetrators of violence.
- The International Conference on Population and Development (Cairo, 1994), the **Regional European Strategy for Sexual and Reproductive Health**, adopted in 2001, the Global Strategy for Sexual and Reproductive Health (Resolution WHA57.12, 2004), are particularly relevant in strengthening the activities on the preservation of reproductive health and rights.
- The rights of women in the field of health and health care receive their full affirmation in the **Declaration adopted at the Fourth World Conference on Women of the United Nations (Beijing, 1995)**.
- The issue of gender equality and the prevention of discrimination against women, persons with disabilities, as well as the prevention of violence against women and domestic violence, are the subject of several regional international documents: **the Strategy for Inclusion of Gender Analysis and Action (2009)**, **the Convention on the Rights of Persons with Disabilities (2008)**, **the Convention on the Rights of the Child (1990)**, **the Convention on Human Rights and Biomedicine (1997)** and **the Council of Europe Convention on the Prevention and Combating Violence against Women and Domestic Violence (2011)**.

In response to the challenges for a balanced development of humanity under the leadership of the United Nations, the **2030 Agenda for Sustainable Development (2015) and the Sustainable Development Goals (2016)** were adopted to replace the Millennium Development Goals (2000). In line with specially set goals, Goal 3 (Ensure healthy lives and promote well-being for all at all ages) and Goal 5 (Achieve gender equality and empower all women and girls) stand out as they should ensure universal access to health care and improved sexual and reproductive health, including family planning services, appropriate awareness and education and integration of reproductive health into national strategies and programmes by 2030. The adopted **Global Strategy for Women's, Children's And Adolescents' Health (2016-2030)** direct and promotes accomplishment of the Sustainable Development Goals.

Public health challenges in the Republic of Serbia are numerous and are associated with the consequences of the economic crisis, migration of the population and rising inequalities. They are examined through health and health determinants, the public health system and the public health policy. Health indicators and determinants of health indicate the following:

1. Decrease and aging of the population are the main features of the demographic situation in the Republic of Serbia;
2. A large number of inhabitants of the Republic of Serbia get ill, prematurely die or become disabled due to preventable diseases and injuries;
3. The most common diseases and injuries are linked to the social and economic determinants of health, that is, they are disproportionately present within the poor and the vulnerable population, which contributes to inequalities in health.

The issues of sexual and reproductive health and related rights have been indirectly or directly considered in numerous national legal and strategic documents of the

Republic of Serbia. There is a visible shift that is reflected in the development and adoption of the legislation in the field of health, in particular, public health, as well as through interdisciplinary approach and multisector cooperation in other areas. The basis for policy-making is contained in documents that recognize the importance of sexual and reproductive health: however, the specificity of the sexual and reproductive health of persons with disabilities has not been sufficiently highlighted.

The field of public health is regulated by **the Public Health Act**³ and numerous other laws and by-laws. The Public Health Act stipulates the remit of public health, jurisdiction, planning, and implementation of activities related to the preservation and improvement of the population health. The legal basis for the protection of sexual and reproductive health and rights is defined in the Health Care Act and the Health Insurance Act.

The Health Care Act⁴ provides the principles on which health care is based, so that every citizen has the right to exercise health care while respecting the highest possible standard of human rights and values, that is, he/she has the right to physical and psychological integrity, the security of his/her personality and to the respect of his/her moral, cultural, religious and philosophical convictions. The legal basis for family planning and the protection of sexual and reproductive health and rights is defined by this law. It also prescribes that social care of health in the territory of the Republic of Serbia is achieved, inter alia, by providing health care for women in terms of family planning and during pregnancy, childbirth, and maternity, up to 12 months after childbirth.

Under the Health Insurance Act⁵, women are identified as a particularly vulnerable category of insured persons who exercise rights from health insurance in situations when they do not fulfil the prescribed conditions for acquiring the status of the insured person in connection with family planning, during pregnancy, during childbirth and maternity, up to 12 months after childbirth.

Some provisions of the Health Care Act are also contained in the **Patients' Rights Act**⁶ which regulates the right to equal access to the health service, without discrimination with respect to the financial status, place of

³ The Public Health Act, ("Official Gazette of RS") No.15 / 2016.

⁴ The Health Care Act, ("Official Gazette of RS", No. 107/2005, 72/2009 - state law 88/2010, 99/2010, 57/2011, 119/2012, 45/2013 - state law 93/2014, 96/2015, 106/2015, 113/2017 - state law and 105/2017 - state law)

⁵ The Health Insurance Act, ("Official Gazette of the RS br. 107/2005, 109/2005 - corr., 57/2011, 110/2012 - Decision, 119/2012, 99/2014, 123/2014, 126/2014 - Decision, 106/2015 and 10/2016 - state law)

⁶ The Patients' Rights Act ("Official Gazette of the RS " 45/2013),

residence, type of disease, time of access to the health service or some other diversity that can be the cause of discrimination; the right to information; the right to preventive measures; the right to be notified; the right to free choice of proposed medical procedures; the right to privacy and confidentiality; the right to freely decide on everything that concerns his/her life and health.

Also relevant here are: the **Anti-Discrimination Act**⁷, which in Article 27 regulates issues related to the delivery of health services and prohibits discrimination on any grounds in the provision of health services, and the **Anti-Discrimination against Persons with Disabilities Act**⁸, which further regulates the provision of health care and prohibits discrimination against persons with disabilities in health care.

The Gender Equality Act⁹ specifically highlights the prohibition of gender discrimination and provides that every person in the reproductive age is entitled to health care and the provision of health services related to family planning, and that partners are equal in the planning of the number of children, access to information, education, and means that allow them to use these rights. The Gender Equality Act specifically highlights the prohibition of gender discrimination and provides that every person in the reproductive age is entitled to health care and the provision of health services related to family planning, and that partners are equal in the planning of the number of children, access to information, education, and means that allow them to use these rights.

The Protection of Persons with Disabilities Act¹⁰ prohibits discrimination in the protection of persons with mental disorders, inter alia, on the basis of sex.

The Pregnancy Termination Procedure in Health Care Institutions Act¹¹ provides the conditions and the procedure of terminating pregnancies, as surgical interven-

tions, in a health care institution. The law stipulates that a pregnant woman's request, as well as her explicit and written consent, is required for the termination of pregnancy for up to ten weeks of age. The law also stipulates conditions in which the termination of pregnancy is allowed after ten weeks and stipulates that termination of pregnancy cannot be performed when it is determined that it would damage the health or endanger the life of the woman.

In the Republic of Serbia, a number of strategic documents relevant to the field of sexual and reproductive health have been adopted.

The 2018-2026 Public Health Strategy in the Republic of Serbia¹² comprises goals that are to be achieved through all forms of partnership for health and emphasizes the importance of a comprehensive approach through interdisciplinary and multisector cooperation. The strategy specifies areas of public health action, framework, mission, vision, and principles of the Strategy, general and specific objectives, action plan and the implementation method, monitoring, evaluation and reporting on the implementation of the Strategy.

The National Programme for the Health Care of Women, Children and Youth¹³ defines activities for preserving and improving the health of women, including the area of sexual and reproductive health. **The Youth Health Development Strategy in the Republic of Serbia**¹⁴ and the **2015-2025 National Youth Strategy**¹⁵ also include provisions on the youth sexual and reproductive health care.

In the 2016-2020 **National Gender Equality Strategy**¹⁶, a number of activities aimed at improving the health of women and equal access to health services, including policies concerning sexual and reproductive health and women's rights, particularly those of women with disabilities,

⁷ The Anti-Discrimination Act ("Official Gazette of the RS", No. 22/2009)

⁸ The Anti-Discrimination Concerning Persons with Disabilities Act ("Official Gazette of RS", No. 33/2006 and 13/2016)

⁹ The Gender Equality Act, ("Official Gazette of the RS" No. 104/2009)

¹⁰ The Persons with Mental Disabilities Protection Act ("Official Gazette of the RS", No. 45/2013)

¹¹ The Pregnancy Termination Procedure in Health Care Institutions Act ("Official Gazette of the RS "No. 16/95 and 101/2005)

¹² The 2018-2026 Public Health Strategy in Serbia ("Official Gazette of the RS", No. 61/2018)

¹³ Decree on the National Programme for the Health Care of Women, Children, and Youth, ("Official Gazette of the RS " Number 28/09)

¹⁴ The Youth Health Development Strategy in the Republic of Serbia ("Official Gazette of the RS" No. ("Official Gazette of the RS" No. 104/06)

¹⁵ The 2015-2025 National Youth Strategy ("Official Gazette of the RS", No. 22/2015)
http://www.mos.gov.rs/wpcontent/uploads/downloadmanagerfiles/nacionalna_strategija_za_mlade0101_cyr.pdf

¹⁶ The 2016-2020 National Gender Equality Strategy with the 2016-2018 Action Plan ("Official Gazette of the RS", No. 4/2016)

women living with HIV, women in rural areas, as well as multiply-discriminated women: reduction in the use of abortion as a birth control method by increasing awareness and access to state-of-the-art contraception means that would be included in the formulary, while retaining the abortion opportunities, as it is currently legally and financially regulated, as well as considering the inclusion of abortion-related costs in the health insurance system.

The Birth Promotion Strategy¹⁷(2018), in addition to all specific objectives that include mitigating the economic cost of raising a child; harmonization of work and parenting; lowering the psychological cost of parenting; addressing infertility issues; ensuring healthy motherhood and population education and the activation of local self-government in ensuring these goals, introduces, by means of a special goal, also the preservation and improvement of reproductive health with an emphasis on the importance of timely education and the promotion of reproductive health of adolescents and the use of state-of-the-art contraception in the fight against infertility, protection of women during pregnancy, childbirth and postpartum.

The issues of sexual and reproductive health are also included in the **Strategy for the Prevention and Control of HIV and AIDS until 2025¹⁸**, which sets out, in its five components, the policies and activities to be undertaken in the prevention of the HIV transmission and treatment and support of people living with HIV; the protection of human rights and the reduction of stigma and discrimination; ensuring quality standards for services provided and ensuring strategic information for planning future

activities. It is of particular importance, like in the previous Strategy, to reduce the risk of HIV transmission from mother to child.

National Strategy for Prevention and Elimination of Violence against Women in the Family and in Intimate Partner Relationships¹⁹ devotes special focus to women who are or may be exposed to multiple discrimination, as well as to particularly vulnerable groups of women including women with disabilities, Roma women, mothers with disabilities or chronic diseases, rural women, elderly women, refugees, and internally displaced women.

A special protocol of the Ministry of Health (2010), which is responsible for the protection and treatment of women who have been exposed to violence is an instrument for identifying, recording and documenting gender-based violence in order to include health professionals in a comprehensive response and ensure that they act to detect, suppress and prevent violence against women.

The National Program for Safeguarding and Improving Sexual and Reproductive Health of the Citizens of the Republic of Serbia²⁰ is the first strategic document that deals with this issue comprehensively and sets out specific objectives and activities, based on human rights. The programme is in line with relevant international strategies and standards: the Global Strategy for Women's, Children's and Adolescents' Health²¹ (2016-2030). and the World Health Organisation's (WHO) Action Plan for Sexual and Reproductive Health²². The Programme clearly defines three major operational areas to promote sexual and reproductive health:

¹⁷ The Birth Promotion Strategy ("RS Official Gazette", No. 25/2018), available at <http://www.mdpp.gov.rs/doc/strategije/Strategija-podsticanja-radjanja-2018.pdf>

¹⁸ The Strategy on the Prevention and Control of HIV and AIDS until 2025 ("RS Official Gazette", No. 61/2018), available at <http://www.pravno-informacioni-sistem.rs/SlGlasnikPortal/eli/rep/sgrs/vlada/strategija/2018/61/2/reg>

¹⁹ The National Strategy for the Prevention and Suppression of Violence against Women in the Family and in Intimate Partner Relationships, ("Official Gazette of the RS", No. 27/2011)

²⁰ The Decree on the National Programme for the Preservation and Improvement of Sexual and Reproductive Health of the Citizens of the Republic of Serbia ("Official Gazette of the RS" No. 120/2017))

²¹ The Global Strategy for Women's Children's and Adolescents' Health, available at: <https://www.who.int/life-course/partners/global-strategy/globalstrategyreport2016-2030-lowres.pdf>

²² Action Plan for Sexual and Reproductive Health: towards achieving the 2030 Agenda for Sustainable Development in Europe – leaving no one behind (2016), available at: <http://www.euro.who.int/en/health-topics/Life-stages/sexual-and-reproductive-health/publications/2016/action-plan-for-sexual-and-reproductive-health-towards-achieving-the-2030-agenda-for-sustainable-development-in-europe-leaving-no-one-behind-2016>



1. Raise awareness and ensure all information needed to make informed decisions and exercise rights.
2. Assess the needs and risks and ensure good quality health services that will address the needs and contribute to the achievement of the highest possible level of sexual and reproductive health care and rights.
3. Ensure conditions for providing universally accessible sexual and reproductive health care without discrimination on any grounds, and the respect of sexual and reproductive rights.

The Programme states that the most important problems in the field of sexual and reproductive health are the dominant conservative birth control, the risky sexual behaviour of adolescents and young people and the unsatisfactory level of engagement in preserving the sexual and reproductive health of the entire population and especially that of the vulnerable categories such as the socially deprived and marginalized categories. The programme recognizes that special attention in this area should be paid to particularly vulnerable population groups, such as Roma, but also other categories of population, such as persons living on the poverty line, those from rural areas, women with disabilities and persons living with human immunodeficiency virus infection because they include the more unfavorable indicators of the sexual and reproductive health status.

The Programme highlights that persons with disabilities encounter many obstacles and prejudices in real life which makes it difficult for them to exercise their right to sexual and reproductive health.

It can be concluded that there is a satisfactory legislative and strategic framework in the Republic of Serbia. Nevertheless, additional activities are required in the implementation of strategies and action plans, as well as more consistent compliance with the law.

The Republic of Serbia is taking appropriate steps, including legislative and financial ones in allocating the funds for the advancement, sustainability and/or improvement of the quality of life of persons with disabilities. However, the system of support for the preservation and promotion of sexual and reproductive health of women with disabilities has not been developed, and the lack of information on this topic indicates that its relevance has not been recognized among relevant stakeholders, including organizations of persons with disabilities. There is currently no systematic monitoring of the situation and data collection in this area, nor is there an analysis of existing data in relation to certain vulnerable groups, including persons with disabilities.



#3 The analytical and methodological framework

To start with procedures for data collection were set up, with aim to accomplish research objectives, the analytical framework and methodology, including the conceptual approach, basic terms, and the analytical matrix and methodology procedures for data collection.

The approach to the subject of the research is based on a conceptual framework that is relevant for understanding the research field, interpreting the results and conceptualizing the outcomes, that is, the operating guidelines. Two issues are in the focus of this research:

- (1) sexual and reproductive health of persons with disabilities, and
- (2) challenges for sexual and reproductive health in individual life cycle segments.

They will be considered in a theoretical and methodological reference framework based on the **concept of human rights of persons with disabilities and the social model of disability**.

Human Rights of Persons with Disabilities

The UN Convention on the Rights of Persons with Disabilities is the first universal human rights treaty that explicitly imposes an obligation on the State Parties to take all the appropriate steps to eliminate discrimination on the grounds of disability. It is not fundamentally different from the previously enacted antidiscrimination treaties but perceives the rights of persons with disabilities in a broader and more complex context.

The decision to add to it universal human rights instruments specific for persons with disabilities is based on the fact that persons with disabilities, despite having theoretically acquired the right to all human rights, still do not actually have the fundamental rights and fundamental freedoms that most people have.

After the adoption of the UN Convention on the Rights of Persons with Disabilities and its ratification in certain countries, **the issue of disability is a matter of respect for human rights**. Persons with disabilities, as human beings of equal value who equally belong to the community, are entitled to the same rights and freedoms as all members of that community.

The social model of disability

Throughout history, the medical model was the dominant point of view in the perception of disability. It is based on the idea that disability is an individual problem caused by diseases, injuries or other forms of deterioration of the health condition. Within this model, the mitigation of disability was possible only through treatment, rehabilitation and providing support to persons with disabilities to adapt to their condition.

the personal experience of persons with disabilities and does not contribute to the development of an inclusive way of life. The currently accepted social model highlights the attitude of society towards persons with disabilities as its key issue.

The social model explains that disability should be viewed in relation to the way society is organized and not in relation to one's limitation or diversity. It is necessary to remove obstacles that limit the life choices of persons with disabilities. When obstacles are removed, persons with disabilities will become autonomous and equal members of the society, they will have a choice and control over their own lives. Obstacles are not just physical. The attitude of the society is based on prejudices and stereotypes that prevent persons with disabilities from enjoying equal opportunities and becoming part of the society in which they live.

The strong global impact of the persons with disabilities movement has contributed to the creation of a new paradigm for understanding disability at the end of the last and the beginning of this century.

This new paradigm is known as the social model of disability. The traditional medical model does not explain

The UN Convention on the Rights of Persons with Disabilities had a significant impact on the acceptance of a new paradigm in the perception of disability. The purpose of this Convention is to promote, protect and ensure full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities and to promote respect for their endangered dignity. The definition of disability contained in the Convention reflects the

essence of the social model of disability: **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 social model of disability has also been accepted in Serbia and definitions in recent documents and laws reflect a new approach to disability that **does not address the issue of treatment of persons with disabilities only as a segment of social policy but as a matter of respect for human rights.**²³

Sexual and reproductive health

*Reproductive health is, according to the UN Guidelines on Reproductive Health, a state of physical, mental and social well-being in all areas related to the reproductive system at all stages of life. It implies that people are able to have a satisfying and safe sex life and that they have the capability to reproduce and the freedom to decide if, when and how often to do so. Implicit in this last condition are the rights of men and women to be informed and to have access to safe, effective, affordable and acceptable family planning methods of their choice and the right of access to appropriate health care services that will enable women to go safely through pregnancy and childbirth.*²⁴

changes in the body's appearance and functioning of the organism, the experience of the outside world, the way of thinking and making contact with other people. In this period, a young person is exposed to many risks that may damage his/her reproductive health. Individual needs differ; however, an inappropriate response to reproductive health needs has important implications for later health and developmental problems.

Sexual and reproductive health is a universal concern for both men and women, but it is especially important for women in reproductive age as it significantly affects the general health of women for the rest of their lives. As reproductive health is

Healthcare in the field of reproductive health is a set of methods, techniques, and services that contribute to reproductive health and well-being through preventing and addressing reproductive health problems. Reproductive health includes sexual health, the purpose of which is the enhancement of life and personal relations, and not merely counselling and care related to reproduction and sexually transmitted diseases.²⁵

The reproductive health care includes education on sexuality and reproductive issues, family planning counselling, reproductive health care, prevention, diagnosis and treatment of various diseases and disorders, safe pregnancy termination if termination is necessary, as well as the prevention of sexual abuse and care for the victims.

The care for reproductive health begins at birth, and is especially important in the period of youth, with major

an important component of general health, it is also an important prerequisite for social, economic and human development. The right to sexual and reproductive health is linked to other human rights, including the right to life, the right to liberty, the right to health, the right to privacy, the right to education and the prohibition of discrimination. The Committee on Economic, Social and Cultural Rights and the Committee on the Elimination of Discrimination against Women (CEDAW) made it clear that women's right to health includes sexual and reproductive health.

In this sense, the awareness of the sexual and reproductive health characteristics and factors which determine it are the starting point for the assessment of health needs and the activation of resources available to meet them, or to improve sexual and reproductive health in the context established for health policies expressed in the initiative for safe maternity.

²³ The Draft Strategy for Improving the Position of Persons with Disabilities in the Republic of Serbia for the period until 2020 (http://www.noois.rs/doc/zakoni/Predlog_Strategija_OSI_2020.doc)

²⁴ Guidelines on Reproductive Health (<http://www.un.org/popin/unfpa/taskforce/guide/iatfreph.gdl.html>)

²⁵ Guidelines on Reproductive Health (<http://www.un.org/popin/unfpa/taskforce/guide/iatfreph.gdl.html>)

Methodology

Methods used for collecting data and the sample are key elements of the methodology and the plan for the implementation of the research. Data collection procedures implemented in this research are as follows: desktop study, survey, focus groups, interviews with women with disabilities and interviews with key people.

The survey on the experiences of women with disabilities in terms of sexual and reproductive rights for collecting data for quantitative analysis was conducted through “face-to-face” interviews and by electronically filling in a questionnaire that was available on social networks. The majority of participants in the survey were women and adolescents in the network of Organization Providing Support to Women With Disabilities ... IZ KRUGA – VOJVODINA who participated in the focus groups. Women from organizations of persons with disabilities in Valjevo, Kragujevac, and Belgrade also participated in the survey.

The focus groups for data collection for qualitative analysis of the experiences of women with disabilities in the field of sexual and reproductive rights were held from June to October 2018. 10 focus groups took place in the following Serbian cities and towns: Belgrade, Kruševac, Novi Sad, Raska, Zajecar, Uzice, Vrsac, Becej, and Curug. Women and girls with different types of disabilities, aged 15-50 took part in focus group discussions. The Plan, Guideline, and Protocol for focus-group discussions were prepared and implemented by the ...Out of Circle – Vojvodina.

Interviews with key persons allowed the research to better understand the social context and public policies of relevance to the sexual and reproductive health of women with disabilities. Interviews were held with decision makers and public health representatives from the Ministry of Health, sexual and reproductive health experts from the Institute of Public Health, one member of the Parliament, President of the National Organisation of Persons with Disabilities, Secretary of the Association

for the Assistance to the Mentally Underdeveloped Persons of Serbia (the Persons with Mental Disabilities Assistance Alliance of Serbia) and Director of the Centre for Adult Persons with Disabilities.

The sample for the survey was formed by an appropriate selection of units using two key parameters: (1) the representation of all age groups (elderly women, younger women and girls/adolescent girls) and (2) types of disabilities (sensory, physical, mental, intellectual and psychosocial).

162 women participated in the survey. The survey was conducted in 11 cities and towns in July, August, and September. According to the self-assessment, all kinds of disabilities were represented: motor (44%), sensory (22%), mental (10%), intellectual (5%), psychosocial (7%) and multiple (9%). The help of another person in day-to-day activities was used by 27% of them, sometimes and for some types of activities by 49%, while 24% of surveyed women were completely autonomous and do not use other people's help.

The majority of women in the survey are middle-aged women from 40 to 59 years of age (44%). Together with the elderly women, over 60 years of age (7%) they make up one half of the sample. In younger age groups, the largest number of women are aged between 30 and 39 (24%) and 20 to 29 (19%). There is very little participation of women below 20 years of age (1%).

Mostly better-educated women with disabilities participated in the survey: most of them with secondary education (49%), college and university (31%) and the least of them with primary education (20%).

The majority of respondents are unmarried women (49%). 27% of them were married and 9% live in a partnership (extramarital) relationship. Those without a spouse include 10% divorced and 4% widowed women.

In terms of their working status, the share of the unemployed (36%), employed (29%) and retired women (30%) were almost equally represented. There are 2% of women entrepreneurs among the surveyed women. There was little participation of students and pupils (3%) in the survey.



#4 Research results

The aim of the research is to document, based on empirical data, the level of information on sexual and reproductive health and the rights of persons with disabilities, practical experiences of exercising these rights in the health care system and, ultimately, the attitudes of women with disabilities towards marriage and family.

The results are presented in three chapters:

- [1] Awareness,
- [2] Sexual and reproductive health facilities, and
- [3] Attitudes towards marriage and family.

4.1 Awareness

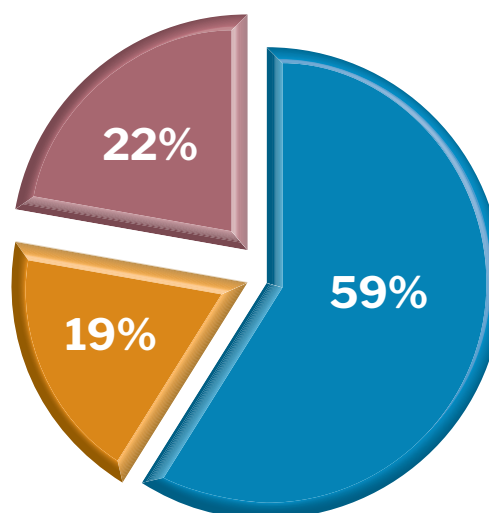
The right to information and education implies that all people have the right to acquire knowledge and skills that will help them protect their reproductive health. It also obliges them to apply the acquired knowledge.

Asked to assess their awareness of the sexual and reproductive health issues, the majority of surveyed women with disabilities (59%) believe that they are **well informed**.

#FIGURE 1

Self-assessment of the sexual and reproductive health issues awareness level

- sound
- mediocre
- poor



One in five women with disabilities (19%) believes that she is poorly informed of these issues. If we also consider the mediocre level of information (22%) as insufficient, it can be concluded that a relatively large number of women with disabilities (41%) **do not exercise their right to getting timely and good quality information on sexual and reproductive health.**²⁶

A more complete picture about the level of awareness is available through additional information.

Primarily, this includes questions about the sources of information on sexual and reproductive health and about their knowledge all the important topics, which implies good quality awareness level.

The main interlocutors on sexuality are friends (70%) and women with disabilities (54%). Peer closeness and common experience are a direct link in discussions on important but also intimate topics.

Initially, I refused to think about the needs for emotional connection, intimacy, and sexual needs. When it happened to me, I enjoyed the feeling of infatuation - I had the feeling of strength and energy and that I could do everything. However, my body is not only mine – it requires other people's help.

A person with disabilities (PWD) - motor disability, born in 1991.

^{26]} If we consider that more educated and active part of the population of persons with disabilities participated in the survey it is not an exaggeration to say that one in two women with disabilities does not have the basic prerequisites to exercise her right to sexual and reproductive health.

*Respondents mostly remember **the transition from childhood to girlhood** by a new inner feeling, new interests, bodily sensations and needs, the first time they fell in love.*

- ***I lost interest in some of the things I had been interested in during childhood, I felt the urge to have a boyfriend, to look nice. It all comes naturally somehow.***
- ***Then I used to fall in love, everything seemed kind of different.***
- ***I did not want to play in the park anymore, I wanted to go for walks and have a boyfriend.***

From the focus group

One in two persons with disabilities (51%) discussed their sexuality with a doctor as well. In future research it would be helpful to add an additional explanation as to when and on which occasion the discussion with the doctor

takes place, whether it is within the framework of raising awareness of one's own sexuality, empowering sexual and reproductive health capacity, or whether it only takes place during medical examinations and interventions.



The fact that only one in five women with disabilities (20%) discussed sexuality issues at the counselling center, and that one in ten discussed them with teachers or educators (9%) indicates that the share of the professional structures (counselling and educational facilities) in informing women with disabilities about sexual and reproductive health is very low.

In addition to friends and women with disabilities, mothers (44%), sisters and other female relatives (44%) have a significant share in providing information about sexuality. This leads to the conclusion that for persons with disabilities, the **main source of information on sexuality are their families and other informal sources.**

I'm studying but I took a break, I'm facing barriers, I have a long-time boyfriend. We started to go out together when I was healthy. I encounter many (physical) barriers at the university during the studies and in everyday life.

PWD - motor disability born in 1993.

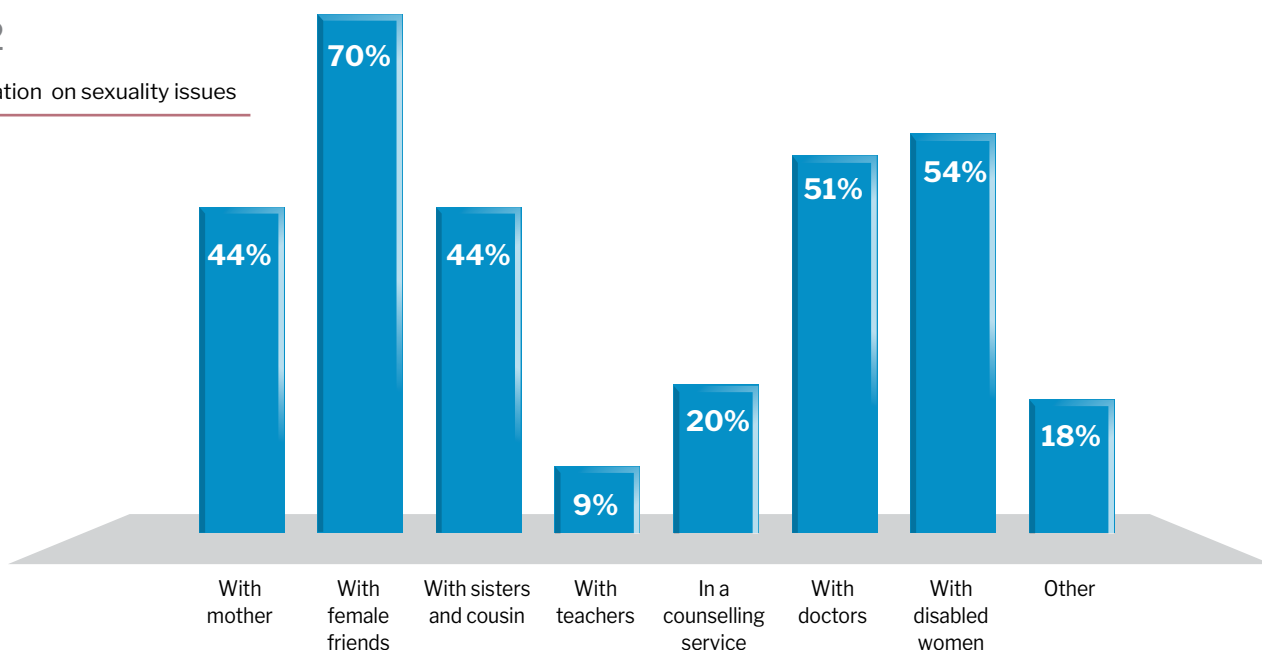
The first menstrual period was a traumatic experience for many respondents, because due to the tabooing of these natural processes they remained uninformed, unprepared, and left to their own devices during developmental cycles. Neglect of natural development is more present in the experiences of girls with disabilities due to the inherent stereotype that they cannot be women in the true sense of the word (sexual, desirable as partners, mothers).

- *I was crying all night. I felt terrible. What happened to me, what is it now? **Nobody ever informed me.***
- *My mother did not teach us anything, not just me as an invalid, **but being an invalid, I was additionally disadvantaged.***
- *It felt embarrassing to buy sanitary pads at that age, everyone is watching. It was **really very traumatic.** Today it's a bit different – the things that come out of your TV screen ...*

From the focus groups

#FIGURE 2

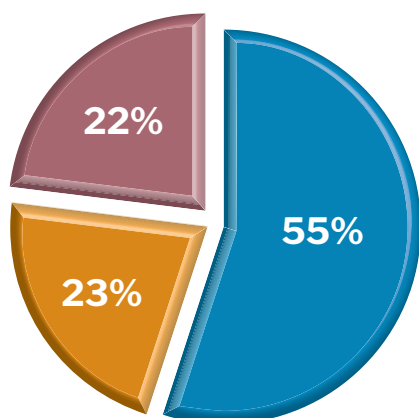
Sources of information on sexuality issues



The reason for that is, among other things, the fact that in most cities, according to the respondents, there is no counselling service where the women with disabilities can seek advice about their sexual and reproductive health. Only 5% of women with disabilities (22%) reported that they had the opportunity to seek advice from an institution, service or counseling center in their home city in order to get information about their sexual and repro-

ductive health. Although subjective perception is not an objective assessment of institutional and organizational capacities, it is important data for an overall assessment on exercising of the right to information.

Only one in five women with disabilities (22%) stated that they had the opportunity to seek advice from an institution, service or counselling center in their home city in order to get information about their sexual and reproductive health.



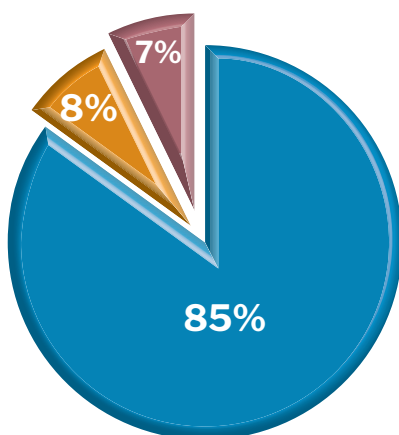
The majority of women with disabilities who responded (55%) said that they did not know if there was such an institution in their home city or town. One in four (23%) decidedly declared that there was no such thing in their city or town.

#FIGURE 3

Is there a counselling center for sexual and reproductive health in your town?

- Not aware
- No
- Yes

This practically means that **three in four women with disabilities are not well informed** because there is no counselling service in their city or town or because they are unaware that there is a specialized institution/service to which they can refer to for advice.



The fact that a relatively small number of cities and towns have counseling centers and other institutions where sexual and reproductive health counseling can be provided is the reason that doctors are unable to make adequate referrals to get timely and comprehensive information. **One in six respondents received a counseling referral from a doctor in the community health center.**

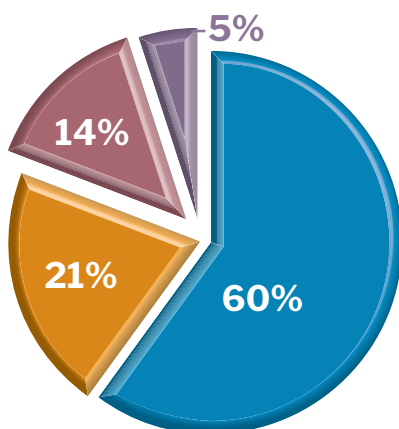
#FIGURE 4

Referrals to the counselling center

- No, never
- Yes, several times
- Yes, once

Half of them received a referral only once and the other half more than once. The majority of respondents (85%) have never had this opportunity.

The majority of women with disabilities who have been to the counselling center (73%) say that they found it very useful.



#FIGURE 5

Benefit from the counselling center

- I did not go
- I went and it was useful
- Yes, but it was no use
- No answer

However, it must be borne in mind that only 14% of the respondents reported that they had used the services of the counselling center.

Does this affect the comprehensiveness of information and in what way? This can be checked through questions on specific topics. That is why we asked the question: **Do you know how to use contraceptives listed here?** The options provided concerned both familiarity with and the use of particular contraceptives.

Women with disabilities in the majority of cases opt for the “Yes, but I do not use it” option in answering this question.

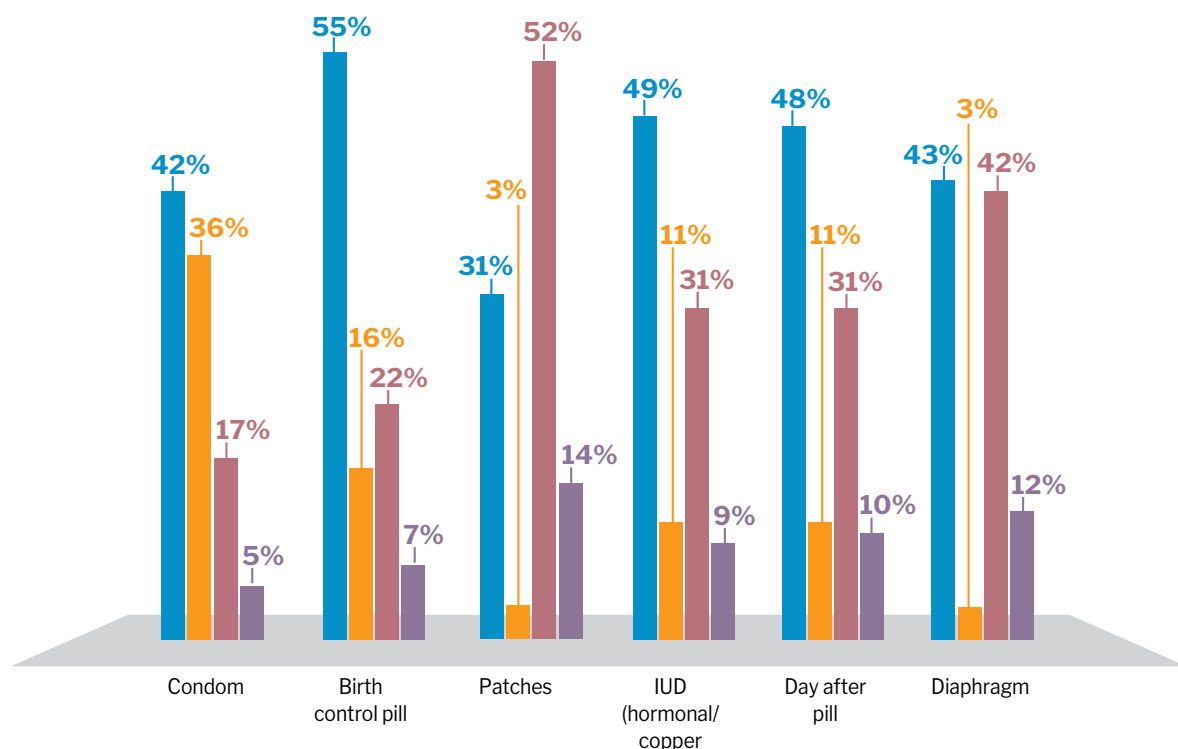
The largest number of women with disabilities using contraceptives (36%) opt for a condom. As for other means of contraception, the majority of women with disabilities are familiar but do not use them.

However, the number of women who are not even familiar with certain contraceptives is not small: 17% do not know how to use a condom, 22% a contraceptive pill, 31% an IUD, 31% day-after pills, 42% a diaphragm and 52% patches.

#FIGURE 6

Familiarity with and use of contraceptives

- Yes but I do not use it
- Yes and i use it
- No
- I do not want to answer or no answer

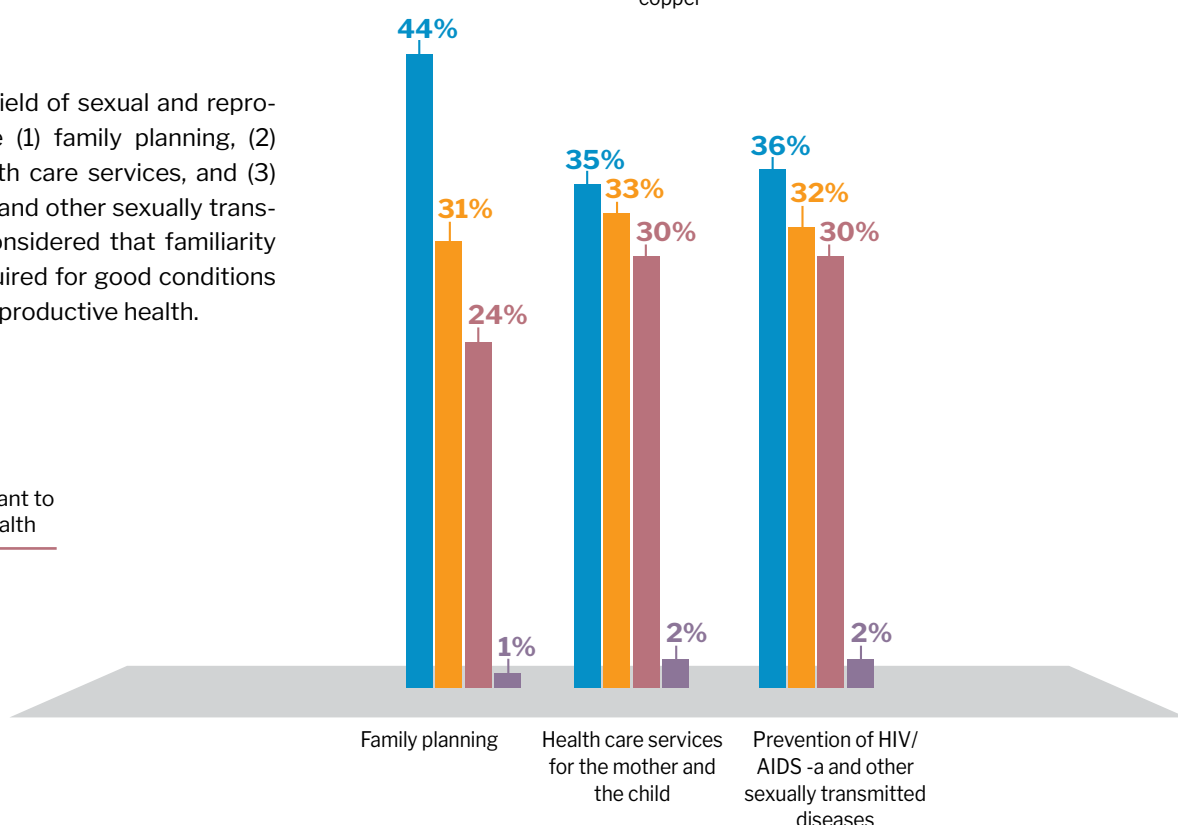


The main topics in the field of sexual and reproductive health care are (1) family planning, (2) maternal and child health care services, and (3) prevention of HIV/AIDS and other sexually transmitted diseases. It is considered that familiarity with these topics is required for good conditions in terms of sexual and reproductive health.

#FIGURE 7

Familiarity with topics relevant to sexual and reproductive health

- Good
- Partly
- Poor
- I do not want to answer or no answer



Based on self-assessments on the familiarity with these topics, it can be noted that **less than half of women with disabilities surveyed are familiar with these issues**. They are best informed about family planning issues. Given that friends and women with disabilities are the most prevalent source of information, it can be assumed that they are mostly well informed about protection against unwanted pregnancy.

Just under one in three women with disabilities declare that their familiarity with the key issues regarding sexual and reproductive health is rather poor. If they are added to the number of those who assess their familiarity as mediocre, it can be concluded that as many as **two in three women with disabilities are insufficiently familiar with the basic topics in the field of sexual and reproductive health**.

4.2 Access to Sexual and Reproductive Health Services

The right to health protection means that all people have the right to be provided with health care related to reproductive health. They are expected to go for medical

check-ups regularly and thus preserve their reproductive health.

Gynecological examinations

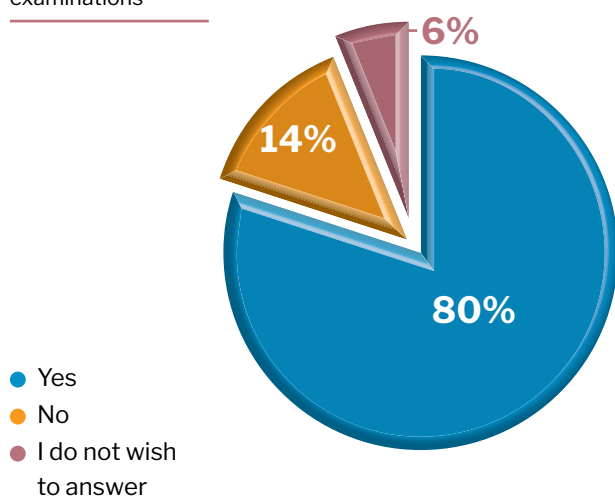
A gynecological examination is one of the most important conditions for the ensuring of sexual and reproductive health. Four in five women with disabilities (80%) have had a gynecological examination. One in seven women with disabilities has never had a gynecological examination.

In view of the fact that one in seven women do not want to talk about it, presumably due to reluctance to admit to never have visited a gynecologist, it is possible that **one in five women with disabilities has never had a gynecological examination**.

A visit to a gynecologist is a very important indicator of the use of services relevant to sexual and reproductive health. Therefore, a more comprehensive picture of the share of gynecological examinations in the function of sexual and reproductive health is gained through data on their frequency.

#FIGURE 8

Gynaecological
examinations



I go to see a gynecologist at least once a year. I use the services of a student clinic. I will have to change this soon because I will be 26 years old. I would like to stay with the same gynecologist, but they told me it was not possible. I'm very sorry about that. It means a lot to me and I have good communication with the doctor - I do not want to change my gynecologist. She understands me.

PWD - motor disability born in 1993.

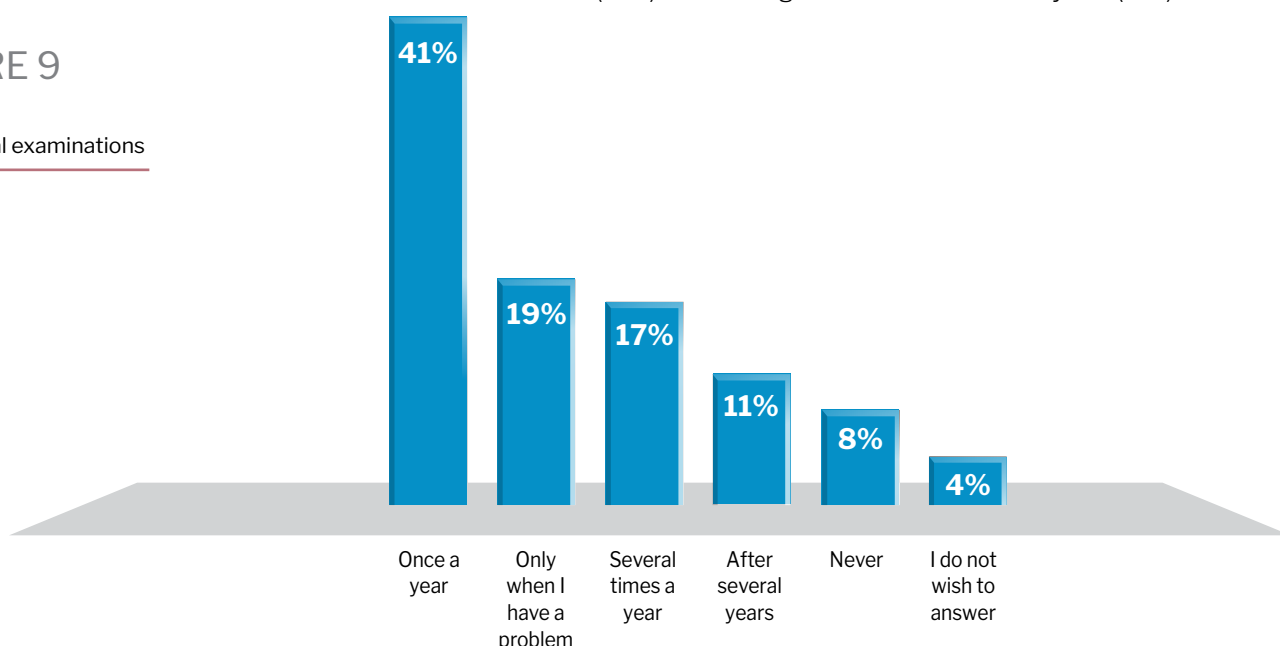
Most women with disabilities (41%) see a gynecologist once a year. Only 17% of respondents do so more frequently. If one visit to a gynecologist is considered to be the minimum for systematic control of the reproductive system, it can be concluded that only **one in two women**

with disabilities takes care of her sexual and reproductive health appropriately.

One in three women with disabilities do not regularly visit a gynecologist because they go only when there is a problem (19%) or after long breaks that last several years (11%).

#FIGURE 9

Frequency of
gynecological examinations



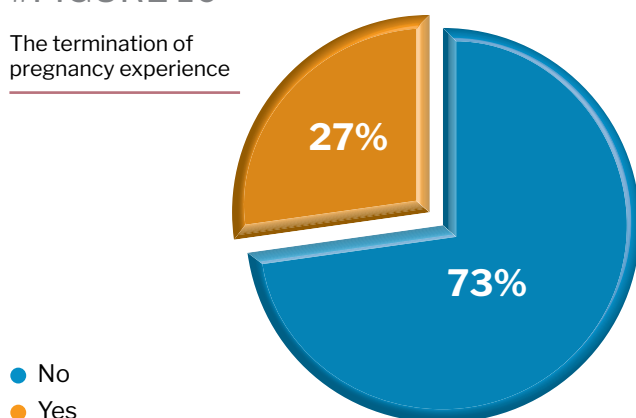
It is a matter of concern that a relatively high number of women with disabilities does not undergo a gynecological examination. One in ten women with disabilities (8% of those who declare it decidedly and 4% of those who did not want to respond) has never been to a gynecologist.²⁷

nancy. Just over a quarter (27%) have had a pregnancy termination. The termination of pregnancy is carried out mainly in public health care facilities (66%). Only 10% of women with disabilities have used the services of private gynecology clinics to terminate their pregnancy.²⁸

The majority of women with disabilities (73%) have not been in a situation of undergoing a termination of preg-

#FIGURE 10

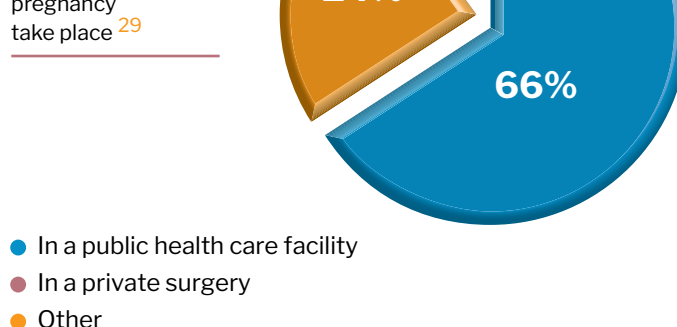
The termination of
pregnancy experience



● No
● Yes

#FIGURE 11

Where did the
termination of
pregnancy
take place²⁹



● In a public health care facility
● In a private surgery
● Other

^{27]} The difference in the number and percentages in relation to the previous question is probably in the “only when I have a problem” choice option that could include respondents who do not go to a gynecologist because they do not yet have “a problem”.

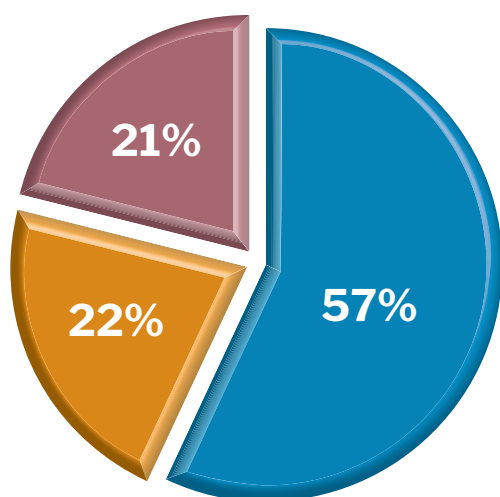
^{28]} A relatively large number (24%) chose the “other” option, but although it is offered as an option, they did not specify what that “other” implied, which deprived us of the opportunity to find out more about the alternatives to the standardized services. It can be assumed that this option, in fact, means avoiding giving a specific answer as to whose services are used in terminating a pregnancy.

^{29]} The percentages refer only to the total number of women who have had a pregnancy termination.

Availability of services

What is the reason for this? The weaknesses of the health care system or its failure to adapt to the needs of women with disabilities?

In this study, we could only check this second hypothesis. The question asked was whether all services available to women without disabilities in health care facilities were also available to women with disabilities.



One in five women with disabilities (21%) said that it was difficult to access the necessary health services. Most are undecided (56%) – they find it neither easy nor difficult. Only one in five women with disabilities (22%) think that access to health services is easy.

#FIGURE 12

Access to health services

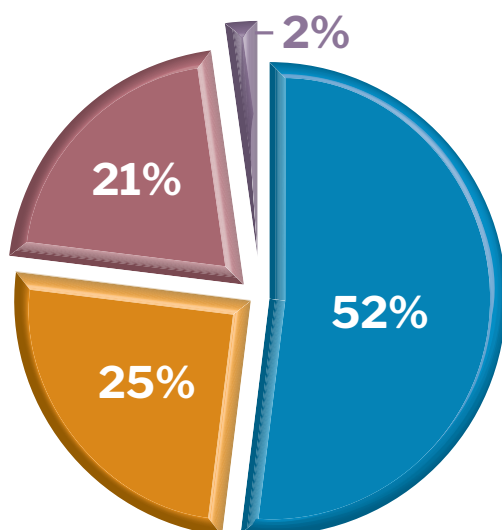
- Neither easy nor difficult
- Easy
- Difficult

One in two women with disabilities can use health care services just as well as women without disabilities.

One in four women (25%) is unable to do so. It is noted that there is a lack of facilities that are adapted to the needs of women with disabilities. There is a gap between the needs and the actual conditions which

constitutes an obstacle to being provided sexual and reproductive health care.

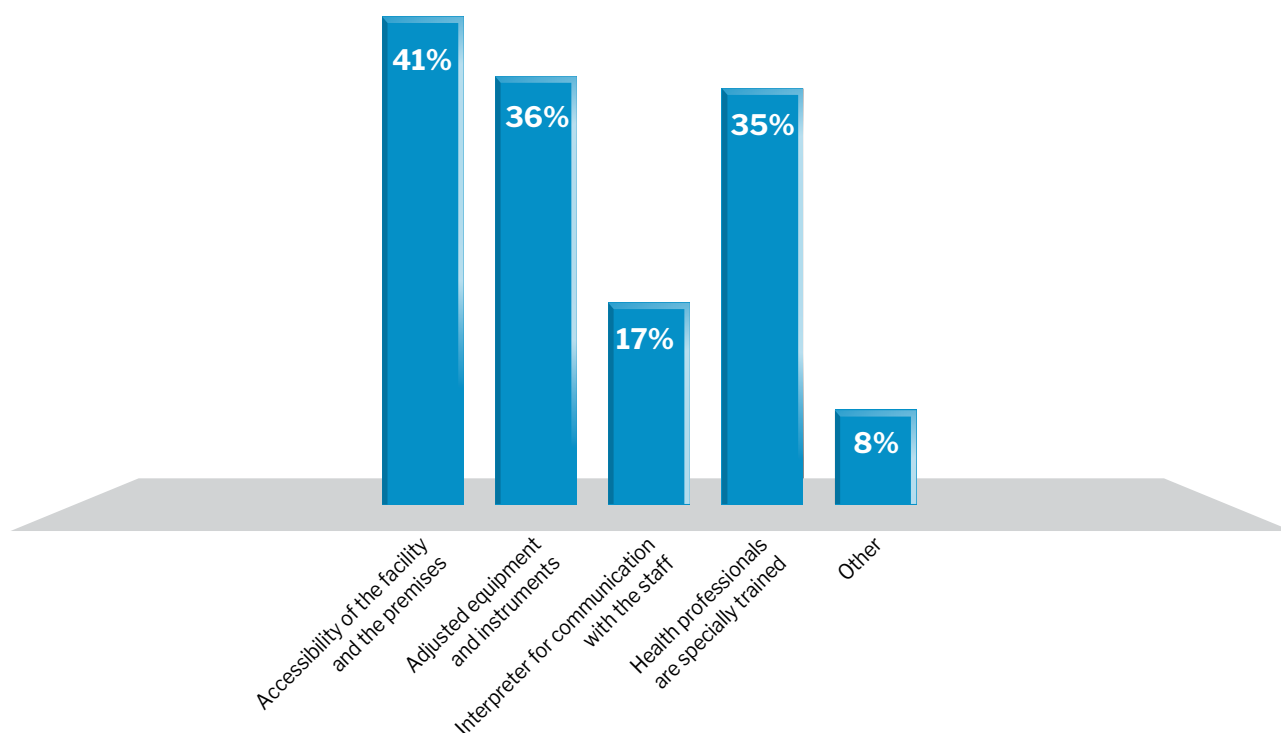
Bearing in mind that one in five women (22%) with disabilities says that she can only partially get the health care services that the other women are getting, it is obvious that only one in two can get the full extent of the health care services without particular difficulties.



#FIGURE 13

Availability of health services

- Yes
- No
- Partly
- No answer



#FIGURE 14

Conditions for accessible and adjusted facilities for a gynecological examination

This practically means that exercising the right to access sexual and reproductive health services is still hindered by obstacles stemming from a health care system that is not adjusted to women with disabilities.

The most frequently stated conditions for the availability of gynecological examinations are as follows: accessibility of facilities and premises (41%), adjusted equipment (35%), special training of the healthcare staff (35%) and interpreters and assistants in communication with healthcare staff (17%).

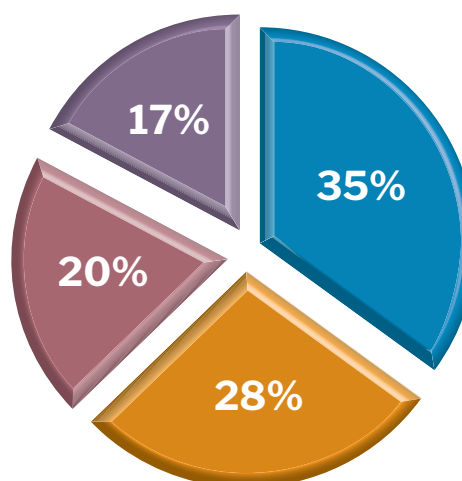
To understand sexual and reproductive health conditions, it is necessary to monitor the adjustment of facilities as 47% of women need full or partial adjustment of the conditions in order to be able to get a gynecological examination. When asked if special conditions were available, if required, one in three women with disabilities (35%) answered negatively. Only one in five (20%) answered positively.

The majority of women with disabilities (63%) do not have access to health services because the necessary conditions to provide quality examinations are lacking.

#FIGURE 15

Adjustment of gynecology facilities

- No
- Partially
- Yes
- No answer

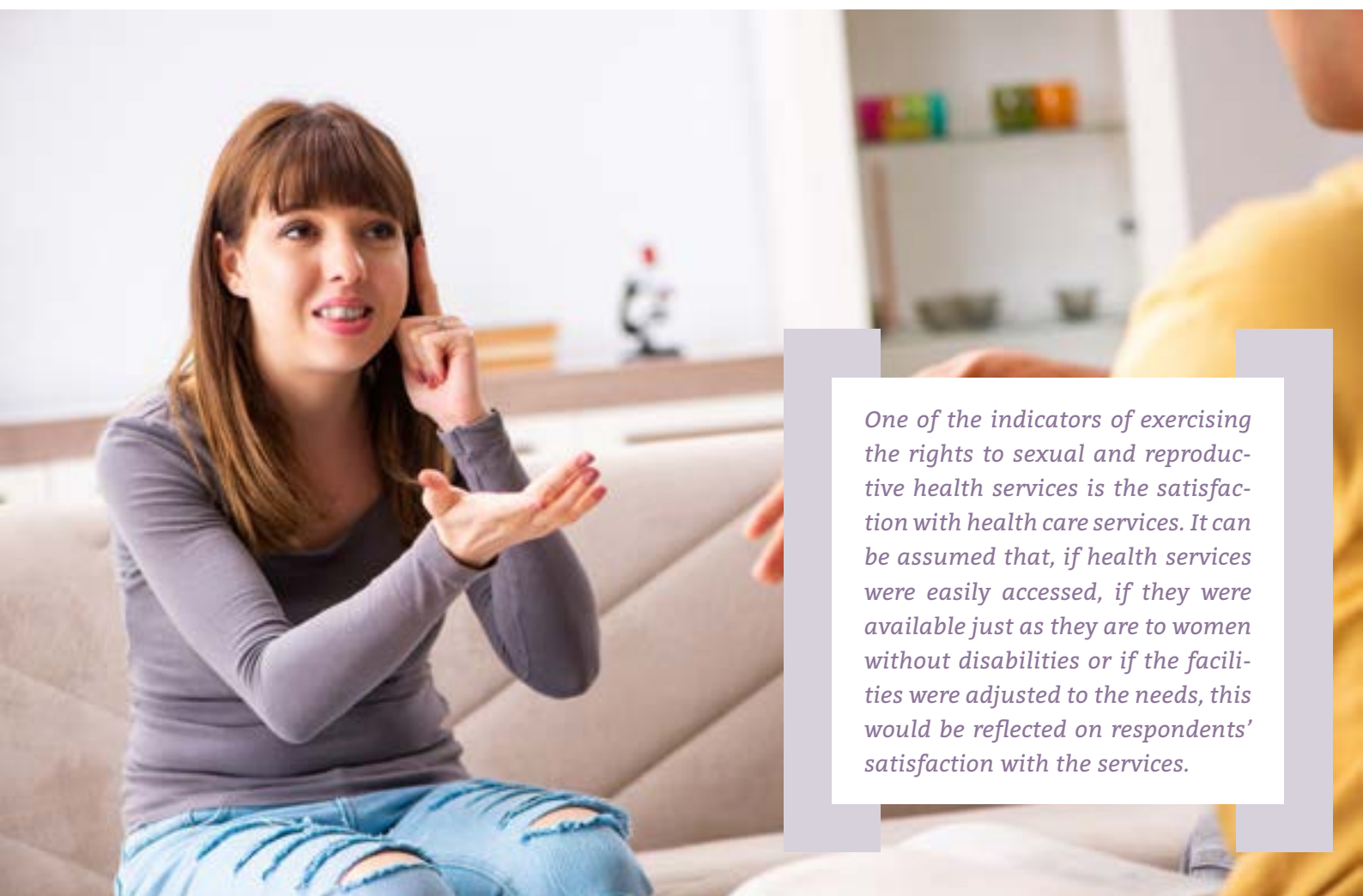


Women with motor disabilities claim that gynecology clinics are inaccessible and that they only saw the standard gynecological tables, which include a step at their base and they have not heard of hydraulic chairs. They need at least one assistant to be able to undergo an examination and when they come accompanied by someone, doctors frequently do not address them, but the person they came with.

- *They cannot understand that I need **extra support**.*
- *The doctor does not usually talk to me, **as if it were not about me**.*

From the focus group

Satisfaction with the services



One of the indicators of exercising the rights to sexual and reproductive health services is the satisfaction with health care services. It can be assumed that, if health services were easily accessed, if they were available just as they are to women without disabilities or if the facilities were adjusted to the needs, this would be reflected on respondents' satisfaction with the services.

Starting to go to a gynecologist was linked with the first year at the university. I exclusively use the services of private gynecology clinics. I do not have bad experiences with a gynecologist, they dedicate time to me and I can talk. I cannot make a visit to a gynecologist in a student clinic because of the barriers (inaccessibility, transportation, and toilet).

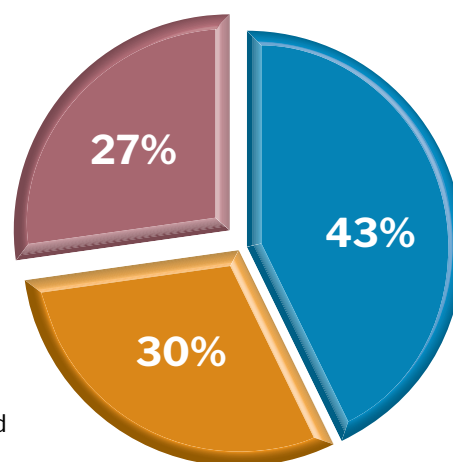
PWD – motor disability, born in 1991

Only one in three surveyed women with disabilities are satisfied with the services (30%). The majority are undecided (43%). It is significant, however, that slightly more than one in four women with disabilities (27%) is not satisfied with the health care services related to sexual and reproductive health.

#FIGURE 16

Satisfaction with sexual and reproductive health services

- I am undecided
- I am satisfied
- I am not satisfied



In addition to the availability of services, it is certain that attitudes of health professionals towards women with disabilities affect the quality and satisfaction with the services. That is why we included a number of questions on perception about health professionals and checked what women with disabilities thought about this.

Most respondents believe that women with disabilities do not receive the service from health professionals like all other women because there is a lack of special training

for health professionals to recognize the specific needs of women with disabilities (57%) or because they lack the skills needed to provide services in these circumstances (51%).

On the other hand, the respondents are undecided as to whether health professionals have a negative attitude toward them. Almost the same percentage of respondents agree (31%) or disagree (30%) with this claim. One in three is undecided (33%).

Speaking of experiences during pregnancy and childbirth, some women testify to having been exposed to humiliation and clearly demonstrated male power and professional arrogance that borders direct abuse:

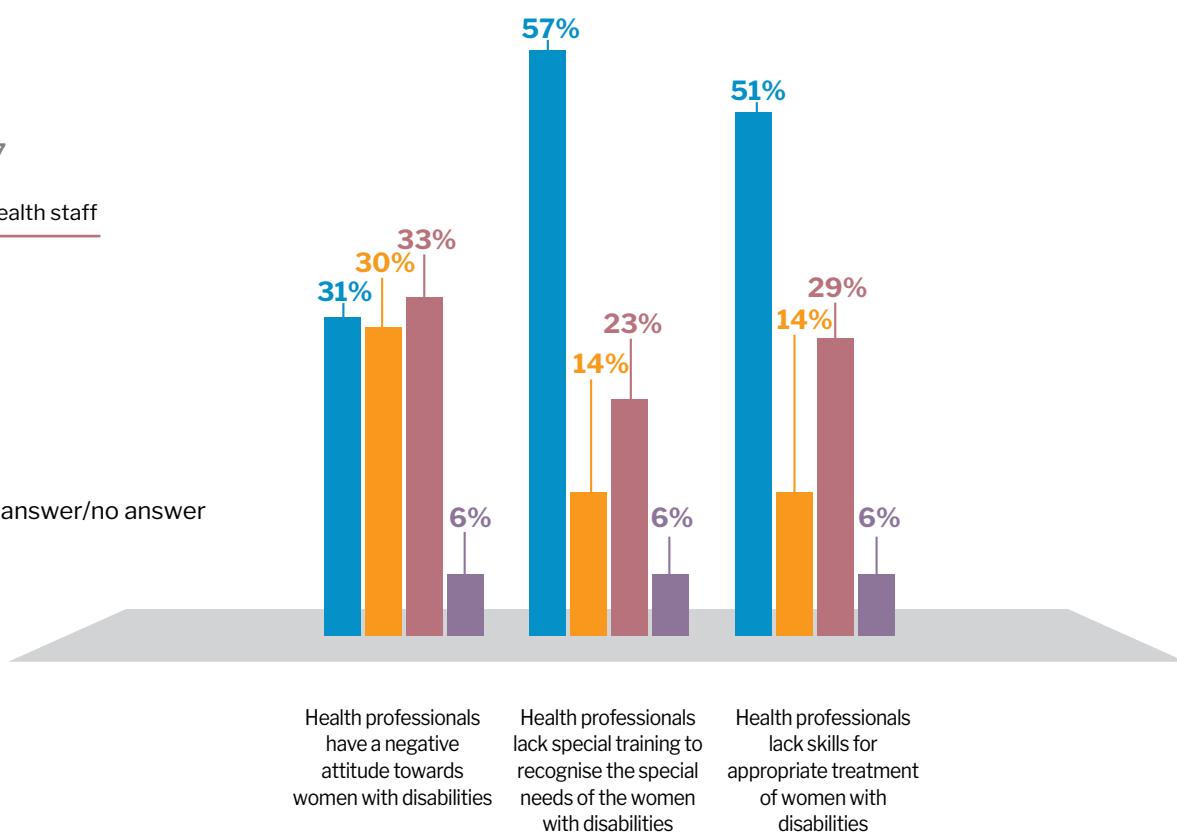
- **“You want us to sew it up so you can no longer have children?”**
- **“You knew how to spread your legs, now endure.”**
- **“Do you want the baby to live or you?”**
- **He told me that I could no longer give birth, and then he just said, “I’m joking.” – “We were” – he said – “only joking”.**

From the focus groups (<http://portalinvalidnosti.net/2018/07>)

#FIGURE 17

Attitudes towards health staff

- I agree
- I do not agree
- I can't decide
- I do not wish to answer/no answer



*Some people behave towards us, the invalids as if we were **second rate citizens** who do not have the same rights as they do. They behave towards us and treat us as if we were **cattle**, I have to say. Some women are **willing to stand up to this and to protect their own dignity**, but without support and change in the system, they cannot accomplish much.*

- *Hey, man, are you here to treat us or **yell** at us? You have to **respect us**, as we respect you and not yell and **abuse us**!*
- *I called the patient rights advocate and I said that the doctor had told me **offensive** things, and the advocate replied: "You can just change the doctor, it **might be better than suing**."*

From the focus group

4.3 Attitudes toward marriage and family

Considering that persons with disabilities have different opinions on and attitudes towards marriage and family, we have selected several characteristic attitudes and have asked women with disabilities to express their opinions.

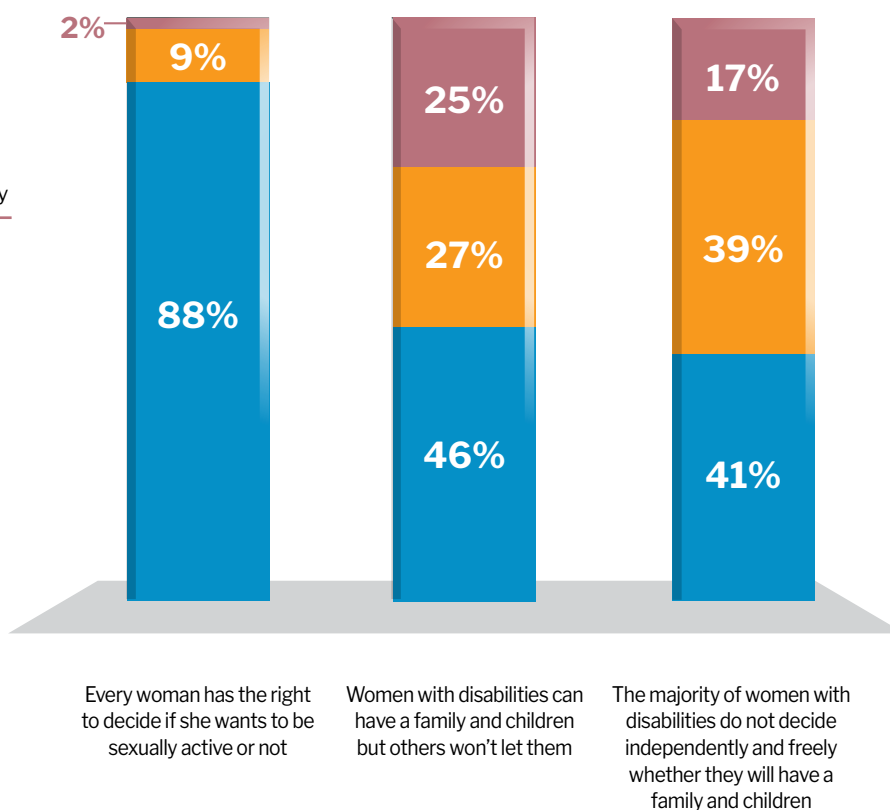
Women with disabilities have a liberal attitude towards sex life. Most (88%) think that it is every woman's right

to decide whether she wants to be sexually active or not. Only 2% of respondents disagree with such an attitude. Interestingly, there is a relatively small number of undecided (9%) on this question. Only one in ten does not have a view on the right to sexual life of women with disabilities. In some other statements, the number of those undecided amounts to as much as 39%.³⁰

#FIGURE 18

Attitudes towards sex life, marriage, and family

- I agree
- I can't decide
- I disagree



Women with disabilities have a positive attitude toward marriage. A large number of them (78%) disagree with the claim that persons with disabilities should not marry. Only one in ten women with disabilities agree with it. Similar number of them (79%) disagree with the claim that women with disabilities cannot have children and that they should terminate their pregnancy in case they get pregnant.

According to the majority of women, the social setting is an obstacle because, although they can have family and children, **others do not approve it (46%)**. However, one in four women with disabilities disagrees with this claim. Does this mean that they have won their right to decide on it independently and freely?

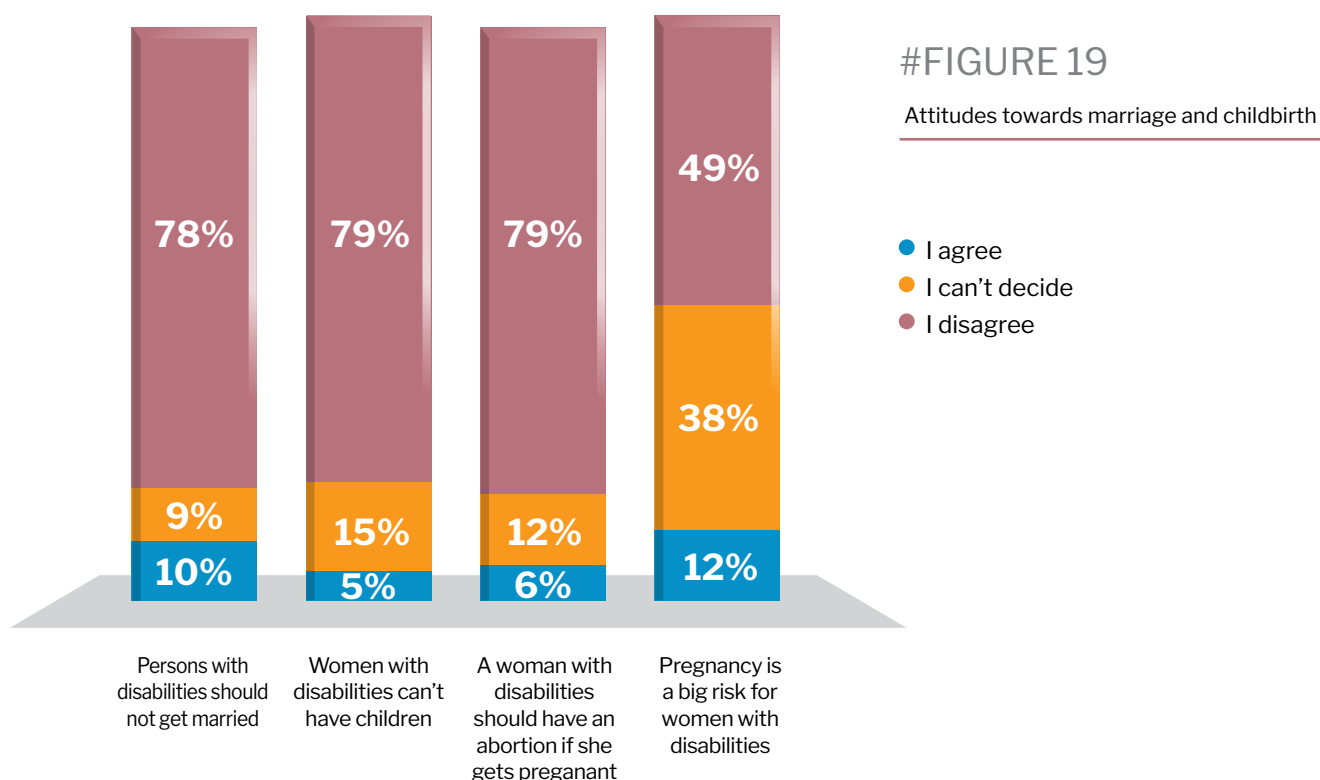
^{30]} The reason for such a high level of awareness about the sex lives of women with disabilities can be identified in the activities of the ...IZ KRUGA - VOJVODINA and the fact that the survey was conducted among the participants of this organization's focus-groups who were probably also the participants of the workshops to raise awareness and encourage the acknowledgment of their sexuality.

I have two daughters who are deaf from birth. We have adjusted our lives and plans in order to make them self-sufficient. Today, my daughters are grown-up, accomplished, employed and married women, they have deaf husbands, and one has two children (normal hearing) and lives in Serbia. The other has three children (deaf) and lives abroad (Italy).

My experience has taught me that I need to prepare the people around us and to create all the conditions so that my daughters would go through the childbirth smoothly. I taught the midwife sign language and arranged for her to attend the delivery and facilitate the communication between the gynecologist and my daughter. Going to see a gynecologist has always been problematic because my daughters, although they can lip read, cannot communicate with the doctor during a gynecology examination and especially delivery. Familiarity with the sign language, the presence of a midwife or nurse who is familiar with sign language is necessary. My daughter who lives abroad had this assistance organized through the system.

Today my daughters are satisfied women and mothers, happy with their family life and successful in the work they do.

Mother of two daughters with impaired hearing since birth



Roughly the same number of them (41%) agree with the view that most women with disabilities do not decide independently and freely whether they will have family and

children. A relatively large number of them are undecided (39%) in answering this question.

My thinking about children – it is a great responsibility. I do not refuse to think that I will have a child, but I do not want my child to suffer because I suffer. I am aware that I am unable to raise a child by myself, that I need someone else's presence (a partner has also other obligations). Is it a high price for the child and for me? Parenting is a serious and big issue for me. It is a great responsibility to take this decision that awaits me in the future.

PWD – motor disability, born in 1991

The majority of women (50%) also disagree with the claim that pregnancy is a major risk for women with disabilities. One in eight women with disabilities (12%)

agrees with the opinion that pregnancy is a major risk for them. Attention is drawn to the fact that a relatively large number of them (38%) are undecided on this issue.

Personal attitude towards marriage and family

The second important level in the research is the **personal attitude towards marriage and family**.³¹ One in four women with disabilities are married (28%), and if we include also those who are in an extra-marital or partner relationship, it can be said that one in three are married. Together with women who plan to get married (25%) and

women who have been married but do not want to do it again (12%) they make up the absolute majority. This confirms the finding that women with disabilities do not only have a **positive attitude towards marriage** but also have an inclination towards marriage in their own lives.

I was married, I gave birth to my daughter, and, in the first years of my daughter's life, I began to lose my sight. My husband left me. I have an unpleasant marital experience and a feeling of rejection. I thought I would not survive, but I fought. I gave birth to a daughter at 23, I remained alone at 30. I got a granddaughter at 50. I have the help of my daughter and her family. I organized myself to be as independent as possible; my granddaughter learned early on how to assist me. I have become a grandmother and this is a great joy. Still, I don't know if I would have given birth if I had been blind before I got pregnant. I often have a feeling that it's hard for the people around me and my family to be around me. It's a big burden. I put my intimate life aside after I had been left alone with my daughter and I have never thought about having a partner again. I taught my daughter that she had to take care of herself and my daughter takes care of me.

PWD without sight, 1938

³¹ In addition to the objective indicators and the fact that half of the respondents have been married and that now a little more than one in three are married or living in an extramarital relationship, it is useful to also check their personal attitude toward marriage.

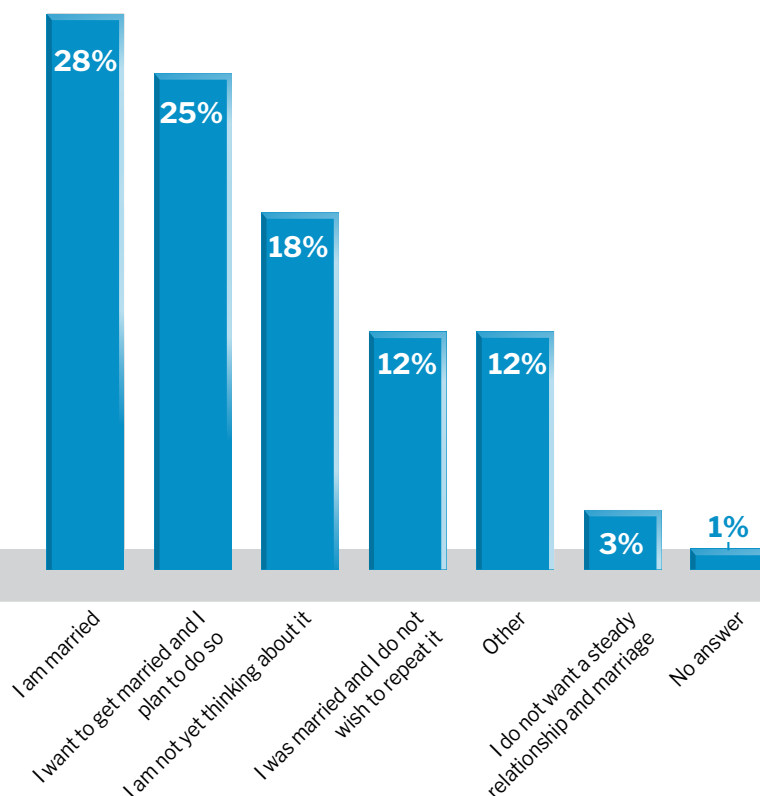
Only 3% of women with disabilities declare that they do not want a lasting relationship and marriage. A little less than one in five (18%) are not yet thinking about marriage. The number of those who do not want a lasting relationship and marriage (15%) is smaller than the number

of those who do want and are planning to get married. Among them, there are four times as many of those who have been married and do not want it again than those who do not want a lasting relationship and marriage.



I'm thinking about having a family and children one day. Only this requires serious organization and assistance. In the health-care system, I manage well, for now, family members help me a lot. I would be happy to have the money to buy a good wheelchair.

PWD - motor disability, born in 1993.

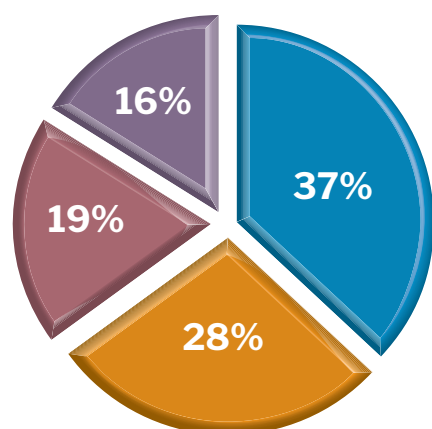


#FIGURE 20

Personal attitude towards marriage

One in three surveyed respondents (37%) has children. If we take into account that one in four (28%) wants and plans to have children, it can be concluded that **most**

women with disabilities have a very strong personal attitude towards having children and family.



#FIGURE 21

Personal attitude towards having children

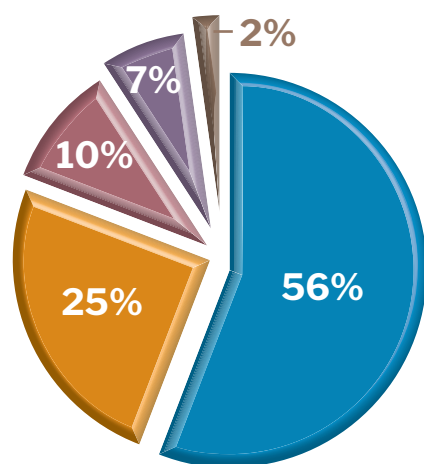
- I already have children
- I want children and I plan to have them
- Other
- I do not plan to have children

One in three surveyed women with disabilities do not plan to have children (16%) or was planning “something else” (19%).³²

Autonomy in deciding on marriage and family

An important moment in exercising the right to reproductive health relates to the autonomy in deciding on marriage and family, hence the question the question was “Are you free and independent to make decision about your own marriage and family?” was asked.

One in two surveyed women with disabilities (56%) is completely independent and free to decide about her marriage and family. One in four women (25%) does not have the autonomy to decide because she is only “partially free” to decide.



#FIGURE 22

Deciding about marriage and family

- Completely independently and freely
- Partly, not entirely independently
- Other
- No, I do not have a say in it
- No answer

Attention is drawn to the fact that one in fourteen respondents (7%) are not independent in deciding about marriage and family. Without a doubt, this basic human right is denied to them, because “they have no say in it” and their independence and freedom of choice are limited.

No one forced the majority of women with disabilities (94%) to marry. The limited autonomy in deciding on marriage and family results in, mainly, coercion into marriage

without respecting the will of the women respondents. One in seven with disabilities (6%) were forced to marry although they did not want to.

^{32]} With this answer option, we also asked: “What else?” Unfortunately, most of the respondents have not replied to this so we cannot claim with certainty what these women would choose.

4.4 Quality of life

The concept of quality of life is, in its broadest sense, everything that makes life worth living. Life with its quantitative and qualitative characteristics is an integral part of the real world of every individual. In that sense, having an understanding and awareness about what it means to have a meaningful and good quality existence requires recognition of the essence of one's existence and interaction with both social and physical environment. Health is only one of the factors that determines the quality of one's life, but there are also others like education, culture, religion, financial conditions, which significantly affect the quality of life of an individual. From a medical point of view, it has been defined by the World Health Organ-

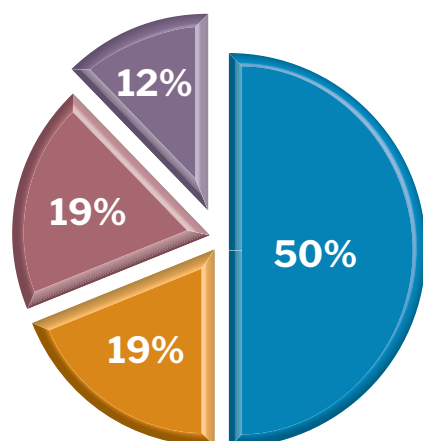
isation (WHO) as: **“an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and interests”**³³.

Numerous quality of life indicators have been developed within different scientific disciplines. It is beyond doubt, however, that the **quality of life is the subjective experience and feeling of an individual**. According to the definition, **reproductive health is a state of complete physical, mental and social well-being in all matters relating to the reproductive system**, at all stages of life (<http://zdravlje.nshc.org.rs/rzdravlje.htm>).³⁴

Given that the subjective experience is embodied in the concept of sexual and reproductive health, the primary goal of this research is not to question the quality of life of women with disabilities, we have thus included two issues related to the subjective experience and the feeling about (1) sex life and (2) to the overall life conditions.

#FIGURE 23

Can you say that you have a healthy and safe sex life?



- Yes
- Partly
- No experience
- No

The results show that one in two women with disabilities have a healthy and safe sex life. It is important that one in eight respondents (12%) considers that she does not have a healthy and safe sex life. One in five surveyed women do not consider to have a healthy and safe sex

life, noting that this statement is only partially true. This draws to a conclusion to highlight that one in three women with disabilities who consider the quality of their sex life cannot say that it is completely healthy and safe.

Victims of violence

The right of women to a satisfying and safe sex life and freedom to decide if they will have one, when and how, is often threatened by coercion into sexual intercourse against their will. Any form of violence against women, and especially sexual violence and abuse of women with disabilities, is a gross violation of personal dignity that have grave consequences, not only to the quality of life but also to the personality and overall experience of the social environment.

I have not experienced physical violence, only verbal, but it was embarrassing. It's a very unpleasant feeling that you cannot simply leave if you feel uncomfortable and you do not want to communicate. I cannot get away, run away, it's unpleasant.

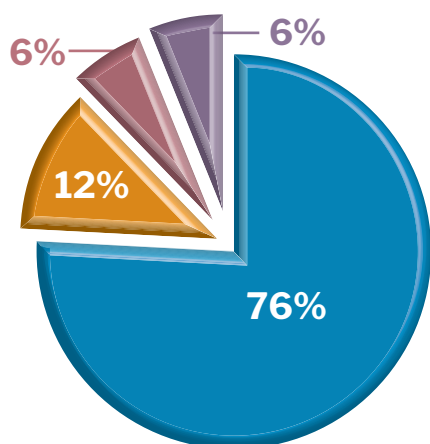
PWD with motor disability, born in '91

³³ Alison Carr; Irene Higginson; Peter Robinson (3. 12. 2002). Quality of Life. Wiley. ISBN 978-0-7279-1544-3.

³⁴ Guidelines on Reproductive Health (<http://www.un.org/popin/unfpa/taskforce/guide/iatfreph.gdl.html>)

In this research, in the context of sexual and reproductive health, we have asked one question that also refers to unpleasant sexual experiences, that is, coercion into sexual intercourse against their will.

The majority of women with disabilities (76%) have not had unpleasant sexual experiences, that is, they have not been victims of sexual violence as a result of coercion into sexual intercourse against their will.



#FIGURE 24

Sexual violence

- No, I have never been a victim of sexual violence
- There have been attempts at forcing me to have sex against my will
- Yes I have been a victim of sexual violence (rape)
- I do not wish to answer

It was noted that significant number of respondents (6%) did not want to answer this question. It can be reasonably

assumed that there are some victims of sexual violence among them.

*Testimonies by other women who suffered rape by **unknown** men, but also within their families and institutions:*

- *I was **raped** at 14 or 15. I used to **dress well** and I **attracted** many men. I had long, **beautiful hair**. Many men used to fall in love with me.*
- *One of them **raped me** at a cemetery... and then I went to him out of fear, and then I **married him**.*
- *When I was 14, I was raped by a **big man**, I **did not know him**. He threw me down the stairs, hit me hard on the head, so I fainted.*
- *My **late father raped me**. When he died, we got a stepfather. The stepfather takes really good care of me.*
- *Aunt, your husband raped me. - How did he rape you? – He got me drunk and raped me. Aunt says: - Are you pregnant?*
- *A man named Franc raped me here at my home.*

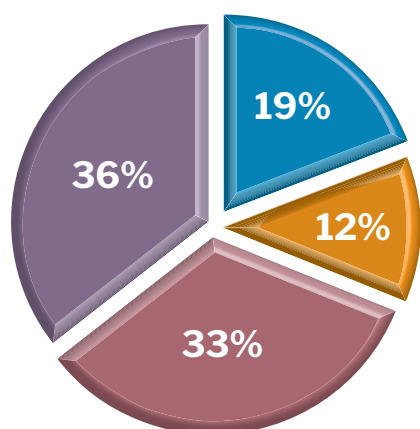
From the focus group (<http://portalinvalidnosti.net/2018/07/bila-sam-silovana-fokus-group>)

It is disturbing that the majority of women with disabilities (36%) do not know where they can get help if they experience sexual abuse or forced sexual intercourse. One in three (33%) think that they know, but not with

complete certainty. This practically means that **two in three women with disabilities cannot use mechanisms for protection against sexual violence because there is not enough reliable knowledge about it.**

Only one in five (19%) women with disabilities are well informed about where they can get help if they experience sexual assault or forced sexual intercourse. This number corresponds to the number of women who have

experienced an unpleasant sexual experience. It can be assumed that they only recognized it after they had become victims of violence.



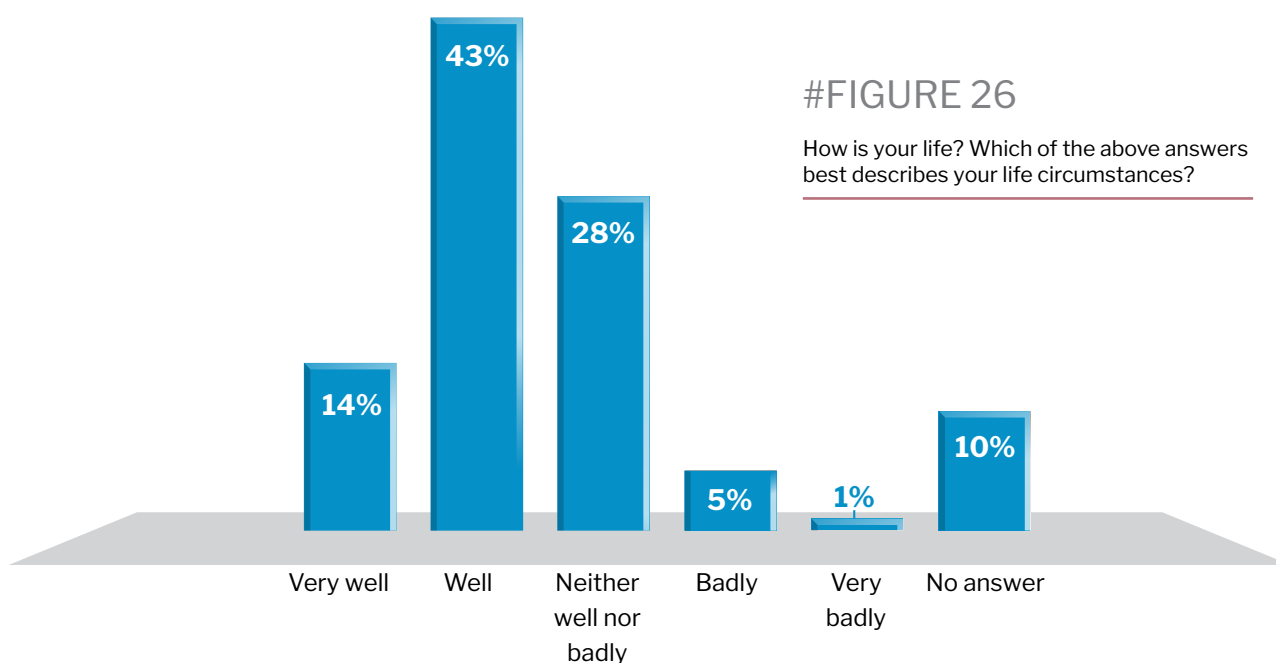
#FIGURE 25

Information about mechanisms for the protection of victims of sexual violence

- I don't know
- I think I know but I am not sure
- I know and I am well informed about it
- No answer

Finally, as one of the possible indicators of the subjective perception of **reproductive health as a state of physical, mental and social well-being**, we asked the question:

How is your life? Which of the above answers best describes your life circumstances?



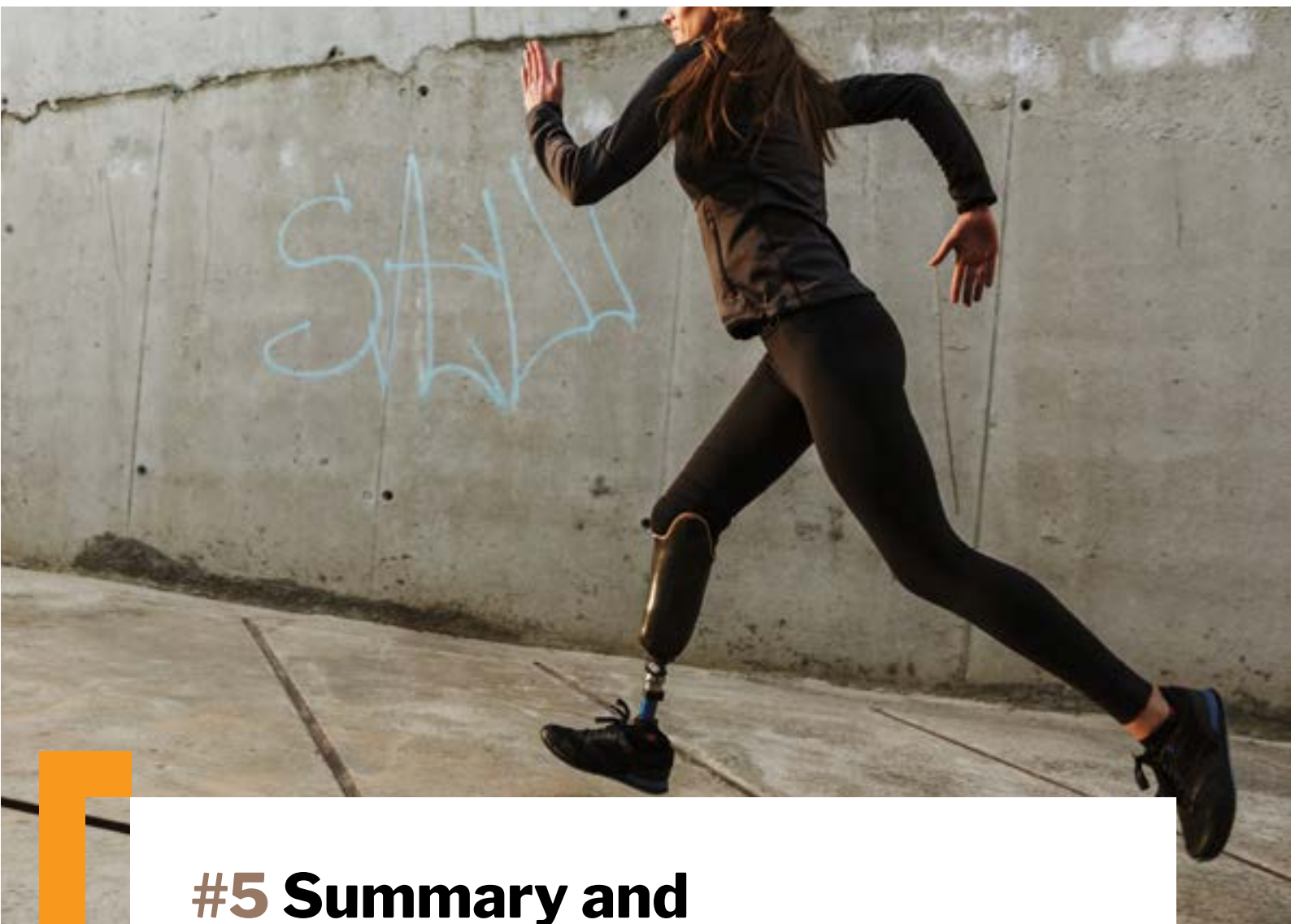
#FIGURE 26

How is your life? Which of the above answers best describes your life circumstances?

According to their own assessment, that is, subjective perception of the life's circumstances, most of the respondents (57%) live well. One in seven declare that they live very well. Interestingly, the share of women who say they live well (43%) is higher than the share of women who say they live "neither well nor badly" (28%). The share of women living badly is relatively small (5%). Only one in a hundred state that they live very badly (1%)³⁵.

There is a similarity in the distribution of answers regarding healthy and safe sex life (50%) and a good living circumstances, that is, a good life (57%). The contingency index of 0.466 as a measure of the strength and direction of association of those two variables confirms that there is a connection between the subjective experiences of these two phenomena, which certainly reflects the quality of life.

³⁵ We can also take these data to be underestimated because "invisible" women with disabilities did not participate in the survey and women from poor families and the rural areas have not been represented to a good extent.



#5 Summary and recommendations

I. Availability of information

Results of the survey, show that the majority of the respondents consider that they are well informed. Results also show that one in five believe that they are poorly and one in two that they are insufficiently informed, leading to the conclusion that **women with disabilities still do not fully enjoy their right to timely and quality information on sexual and reproductive health.**

Given that women with disabilities are mainly informed in an informal environment (friends, and other women with disabilities) and that they receive only basic information within their family and do not have the opportunity to get information in the counselling centers or specialized facilities and services, **reliable and good quality information and knowledge on sexual and reproductive health and rights is still unavailable to them.**

Insufficient knowledge of basic topics in the field of sexual and reproductive health (family planning, maternity, and child health care services and HIV/AIDS and other sexually transmitted disease prevention) **and various contraception options** indicate that it is necessary to improve education across all stakeholders with aim to allowing access to all.

Recommendations

Thus, in order to improve information and create conditions for enjoying the right to timely and good quality information on sexual and reproductive health and rights, it is necessary to:

- Through continuous education, strengthen the capacities of teachers, pedagogues, educators working with people with disabilities to provide adequate information in order to enable young people, especially girls with disabilities, to understand their own body and the way in which it function, to accept and adopt a positive attitude about their own sexuality
- Through an inclusive educational system, conduct evidence-based training on sexual and reproductive health, adapted to the age, in order to prevent premature and unprotected sexual intercourse, numerous consequences of ignorance and prejudice, different forms of sexual exploitation, abuse and violence, and to contribute to developing tolerant and good quality relationships based on respect between the sexes and among people in general.
- Include public debates and workshops on sexual and reproductive health of young people and the availability of health services and reproductive health counselling services at the local level, and within regular activities of the National and Local Youth Offices, and to ensure that young people with disabilities participate, in cooperation with the health centers, educational institutions, local health councils, and organizations of people with disabilities, and where possible, use an innovative approach to providing information, for example through theatre performances and sporting events.
- Civil society organizations working on issues concerning persons with disabilities should focus their programmes and activities on informing the target group and their families about sexual and reproductive health and rights, including protection from all forms of gender-based violence.

- Develop health education and sexual education curricula in educational and health institutions ensuring adequate access and adherence to the needs of persons with disabilities.
- Women with disabilities who choose to become parents should get timely and adequate information in accordance with their specific needs for support during pregnancy, childbirth and postpartum period.
- Civil society organizations dealing with issues related to persons with disabilities should, as part of their existing activities, enable women and girls to meet regularly to exchange knowledge and information and share concerns and challenges they encounter in exercising their rights to sexual and reproductive health and support them in finding adequate solutions to overcome the difficulties.

II. Access to health care services

According to the results of the research, only one in five women with disabilities easily exercise their right to health services. The majority of them face a variety of obstacles due to which **one in five of them have difficulty accessing the necessary health services.**

Most women with disabilities go for gynecological examinations. The fact is, however, that one in seven women with disabilities have never been to a gynecological examination. If one looks at the intervals between these examinations, it can be said that only **one in two women with disabilities take care of their sexual and reproductive health appropriately. One in three women with disabilities go to a gynecological examination** only when there is a problem or after a long pause.

Research findings show that one in four women with disabilities are not satisfied with health care services related to sexual and reproductive health. In addition to the availability of services, the attitude of health professionals towards women with disabilities affects the quality and satisfaction with the services. Respondents are of the opinion that health professionals lack special training to recognize the specific needs of women with disabilities or that they lack the skills required to provide services in different circumstances, which reflects on the lower quality of the health service received by these groups.



Most women with disabilities cannot use health services as much as women without disabilities. This creates a gap between the needs and the actual conditions that are an obstacle to exercising the right to sexual and reproductive health care. This practically means that due to the inaccessibility of facilities and space, unadjusted equipment and difficult communication with healthcare staff exercising the right to access sexual and reproductive health services is still unavailable.

Recommendations

In order to improve the conditions to exercise the right to health care, it is necessary to **provide accessible and adjusted reproductive health care**. Women with disabilities are expected to regularly go for medical check-ups and thus preserve their reproductive health.

- Establish special programmes for undergraduate studies and continuous medical education to build the capacity of health professionals in gynecology departments and sexual and reproductive health counselling centers for work with women with disabilities.
- Remove architectural, communication and economic barriers to access reproductive health services in health care facilities.
- Make a record of health care facilities that have adequate access to their facilities and gynecology departments, as well as of the status of equipment in surgeries and health care facilities for providing health care services to persons with disabilities, with focus on services related to sexual and reproductive health. It is recommended that adjusting the infrastructure accessibility should be a priority. Patients should be referred from facilities that do not have all the necessary conditions to those which have them.

- Apply a multisector approach (MoH, NHIF, MoLEV-SA) to overcome limits to providing health limiting the provision of care to persons with disabilities by allowing for use of available facilities in other district.
- Include women with disabilities in compulsory screening programmes and provide adequate conditions and access to screenings that allow for early detection of reproductive system cancers.
- Within the framework of Continuous Medical Education (CME) for health professionals, regularly conduct education about prohibition of discrimination and patients' rights when using health care services. Also raise awareness among healthcare professionals about the need for equal treatment, affordable health-care services related to sexual and reproductive health and all other rights that should be ensured towards women with disabilities.,
- Civil society organizations and associations of persons with disabilities should encourage women with disabilities to make a discrimination appeal to the Commissioner for Equality and ensure protection in this way in cases where reproductive health care services are unavailable to them as a consequence of their disability.

III. Awareness and attitude towards sex, marriage and family

Women with disabilities have a liberal attitude towards sex life. Most of the respondents think that it is every woman's right to decide whether she wants to be sexually active or not. Women with disabilities also have a positive

attitude towards marriage and family. The majority disagree with the claim that persons with disabilities should not marry and cannot have children and that they should terminate a pregnancy in case they do get pregnant. According to the assessment of the majority of women with disabilities, **due to the stereotypes and prejudices**, it can be concluded that the social environment is an obstacle to having family and children. However, one in four women with disabilities do not see obstacles in their environment because they are able to decide independently and freely or have the support of their families.

Women with disabilities **confirm their positive attitude towards marriage also through their personal lives**. One in three women with disabilities are married or have a partner, and, together with women who plan to get married and women who have been married before, they make up an absolute majority.

Autonomy in decision making on marriage and family is important in exercising the right to sexual and reproductive health. **One in two with disabilities is completely independent and freely decides about getting married and having a family**. The majority of women are not forced to marry. The fact that one in fourteen women with disabilities are not independent in deciding on marriage and family and that one in seventeen were forced to marry even though they did not want to, is not an insignificant finding.



One in two women with disabilities says that she has a healthy and safe sex life. The right of women to a satisfying and safe sex life and freedom to decide whether to have it, when and how often is threatened by coercion into sexual intercourse against their will. Three out of four women with disabilities do not have unpleasant sexual experiences, that is, they were not a victim of sexual violence due to coercion to sexual intercourse against their will.



The majority of women with disabilities have a very strong personal attitude towards having children and having a family. One in three already has children and one in four wants and plans to have children.

Recommendations

In order to further improve the conditions for autonomy in deciding on the exercising of the rights of women with disabilities to sexual life, marriage, and family, it is necessary to:

- Include the topic of sexual and reproductive health and rights of people with disabilities in all activities and events aimed at combating stereotypes and prejudices related to persons with disabilities. Use every opportunity to publicly promote the right to sexual and reproductive health of persons with disabilities and to present positive examples and good experiences of women with disabilities in exercising that right.
- At the level of local self-government, connect sports organizations and drama societies with associations of people with disabilities and through joint activities promote a healthy lifestyle and strengthen motivation for the active participation of women and girls with disabilities, and reduction of prejudice in society.
- Include women with disabilities in all activities aimed to improve women's position and promotion of gender equality, and activities to prevent and respond to gender-based violence.
- Work on the establishment and improvement of community-based services.
- Include Youth Offices as well as students from relevant faculties in creating innovative approaches to support and promote the right to independent life and autonomy in deciding on sex life, marriage and family.
- Provide systematic data collection and regular monitoring of sexual and reproductive health of the population and analysis of the existing data in relation to particularly vulnerable groups including persons with disabilities.
- Promote the importance of sexual and reproductive health of women with disabilities among socially responsible businesses and encourage their partnerships with disabled people's associations to provide funding for the promotion of an inclusive society.



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