

...OUT OF CIRCLE – VOJVODINA

Organization for the support of women with disability

Veronika Mitro, Dajana Damjanovi , and Svjetlana Timoti

Sexuality of Women with Physical Disability from Vojvodina

Novi Sad, 2014

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## **Publisher's Introduction**

...OUT OF CIRCLE – VOJVODINA, an organization for the support of women with disability, from Novi Sad, has for several years worked in continuity in the field of sexuality of women with disability. This has been done in various ways and with support from various local and international foundations.

From 2008 ...OUT OF CIRCLE – VOJVODINA, with support from the Reconstruction Women's Fund (2008 – 2010), the Department of Culture of the City of Novi Sad and the Provincial Secretariat for Culture (2011), and the Dutch foundation Mama Cash (2012 – 2014), has organized a series of psychological and artistic workshops on the topic of sexuality. Young women with and without disability participated in these workshops.

Psychological workshops about sexuality are a form of group therapy led by qualified psychotherapists. They are a means of encouraging participants to accept their body and their sexuality as an important aspect of any person's identity, and therefore of the identity of women with disability as well. On psychological workshops, women – in mixed groups of women with and without disability – discuss important topics related to sexuality: role of parents and society in development of one's self-perception, relation to one's own body and especially to women's body parts – breasts, vagina..., sexual orientation, sexual relations, masturbation, relation to motherhood...

Artistic workshops “Women’s Sexuality Through Art”, accompanying the psychological workshops, are based on efforts and accomplishments of feminists across the world to create art which reflects women's lives and experiences and raises visibility of women in art, art history and art activism. Experiences of women pertaining to sexuality, and especially women with disability, are taboo. Art opens up the possibility for them to recognize their own experiences, define, and accept them, put them in context and share them with the public, redefine their opinions and decrease their prejudices. The art workshops are lead by two feminist, socially-engaged artists, and are conducted through several cycles. At the outset women with disability are introduced to works of famous artists and art groups (Frida Kahlo, Judith Chicago, Linda Vallejo, Virginia Woolf, Marina Abramovic... , Project of Feminist Art, Artistic Labor Performance Group, Guerrilla Girls work...). Next, they learn about the women's status in general and especially about the status of women with disability, they share their experiences and analyze how sexuality develops, how it is expressed, understood and portrayed in the family, in public institutions, theoretical texts, the media and artwork. Lastly, they transform their experiences into an

artistic form: drawing, painting, photography, video, performance or play. The most visible result of psychological and artistic workshops that have been organized by the ...OUT OF CIRCLE – VOJVODINA has thus far been achieved by the theater performance “My Name is Unsaid”, which was performed by the applied theater for women's sexuality. The play was directed by a feminist activist – Ivana Indjin, and it premiered on February 3<sup>rd</sup> 2011 before a packed Youth Center (*Omladinski Centar*) CK13, in Novi Sad.

Aside from this, the organization for the support of women with disability ...OUT OF CIRCLE – VOJVODINA in 2010 began an online publication “Portal on Disability” ([www.invalidnost.net](http://www.invalidnost.net)). Here, as part of the “Women and Disability” ([www.zena.invalidnost.net](http://www.zena.invalidnost.net)) magazine, within the section “Sexuality and Disability”, we publish articles pertaining to said subject matter. Just some of the many articles that can be found in this magazine are: Laura Hershey “Women With Disability: Health, Reproduction and Sexuality”, or Kit Lun “Enjoying Your Own Body” which explores the experiences of women with disability related to sexuality. For women with disability living in these regions, as well as for all others interested in the subject of sexuality of women with disability, the “Portal” represents a useful source of information. Often it is the only source.

With the support from the Department of Culture of the City of Novi Sad, ...OUT OF CIRCLE – VOJVODINA in 2009 translated and published the book “... All Things Are Possible” by Yvonne Duffy. Even though it was published in English for the first time over thirty years ago (1981), our publication of it represents the first of its kind in Serbian – a publication where we could read about sexuality and experiences of women with disability and their attitudes on various subjects pertaining to sexuality. Because the Serbian translation of this publication inspired so much interest we decided to do our own research of experiences and attitudes on sexuality of women with physical disability in Vojvodina.

This publication represents the results of our research, with a *Review* written by esteemed professor Svenka Savic, an expert in the field of psychological-linguistics, gender studies and someone who is very knowledgeable on issues related to unprivileged groups. Also, there is an *Afterword from a Sex Positive Point of View*, written by an expert on issues of women's sexuality, Marijana Canak.

## **REVIEW**

Veronika Mitro, Dajana Damjanovi and Svjetlana Timoti, “Sexuality of Women with Physical Disability from Vojvodina”, ...OUT OF CIRCLE – VOJVODINA, organization for the support of women with disability, Novi Sad, 2014.

When women's equality is discussed in modern society this discussion is lacking sensitivity regarding the fact that there are various groups of women. So in practice it might lead to one group of women being less equal than another – for instance, women with disability in comparison to all others.

Unlike countries where there is a higher degree of consciousness regarding gender equality and all other equality, where one may find a relatively wide array of literature pertaining to research about equality, especially when it comes to women with disability, in our country such literature is still lacking. While the literature that is available to the public (magazines and other media publications), is to a great degree peppered with various forms of implicit and explicit prejudice and stereotypes.

It seems that there is a lack of motivation for research in Serbia – for comprehensive researching of the disability phenomenon. Partly it is because such research demands various theoretical and, firstly,

methodological knowledge, which cannot be gained at a single place in existing educational programs at higher education institutions in Serbia. This is especially true when it comes to issues of disability and gender. Within that specific problematic, the issue of sexuality of women with disability represent a distinct question (more specifically, it is a taboo). This issue is of importance to young women, especially for women with different types of disability, and this publication focuses on women with physical disability.

It is widely accepted that these issues should be dealt with by institutions, while practice shows that institutions mostly ignore it. Women's non-governmental organizations are the ones who successfully deal with this issue, and focus on various aspects of it. One such organization is ...OUT OF CIRCLE – VOJVODINA, from Novi Sad, which has been working for almost two decades and has continuously been publishing books, booklets and/or translations.

When it comes to institutions of higher education which disseminate knowledge regarding disabilities, it must be noted that there are no specific undergraduate or post-graduate programs (master or doctorate) that could supply the base for gaining this type of knowledge in the goal of spreading information against prejudice and stereotypes regarding women with disability. These same higher education institutions do not offer systematic solutions for state scholarships for students with disability who choose specialized gender and disability studies at the Novi Sad University. Therefore, the publishing of this publication on sexuality of women with disability in Vojvodina, as part of the work of a women's non-governmental organization, is not only a rarity but also a watershed moment in regards to how we conceptualize the future of gender and disability studies. In that respect this endeavor by ...OUT OF CIRCLE - VOJVODINA is highly significant.

The Sexuality of Women with Disability in Vojvodina, by Veronika Mitro, Dajana Damjanovi and Svyetlana Timoti, is a new product of activities whose goal is to show the experiences and points of view of women with disability in Vojvodina pertaining to sexuality, so as to produce empirical data and make it available for educational practice with students in schools and with women at universities. Most of all, this is important because these days we are witness to public discussions about whether to introduce sex education in elementary and high schools – especially considering that this discussion is not taking into account the diversity of women, of female students (those with disability, members of national or religious minorities, and such), in regards to whom it would be better to research and analyze sexuality in a more specific manner. Sexuality of Women with Disability in Vojvodina is one such contribution to public discussion in Serbia when it comes to sex education in elementary and high schools – a contribution void of prejudice and stereotypes, with excellent argumentation on the importance of discussing these issues.

The text is conceptualized in such a way that it analyzes sexuality through several basic phenomena (physical changes during puberty, menstruation, masturbation, pregnancy, giving birth and raising children, intimate personal hygiene, going out, dating, first sexual experiences and, of course, sources of information and gaining knowledge about sexuality). These phenomena are reviewed in certain forms: 1. the phenomenon as such is generally explained; 2. they are documented with numerous examples from the experiences of women with disability; 3. conclusions are made regarding practical application. Women's experiences have been gathered from conversations and focus groups with women who acquired disability at different stages in life, or who have had a disability their whole life – in all, 45 women from various places in Vojvodina, aged 19 to 65.

The authors decided not place a complicated methodological construct between their text about women and the women's voices, but rather they decided to have women talk directly to the readers about their

experiences so as to inspire emotion – which will lead to insights regarding the need to change the status quo. This is a method affording the most space for hearing women's voices, allowing them to freely talk about phenomena which isn't well known, even among women with disability (however, some are not specific to this group of women, while others are), as well as serving as a convincing tool for educating the public. The choice of statements is basically the only methodological framework used, and in that regard the authors have shown a high of understanding for the problematic women addressed. The statements are the result of research, since they prove that when it comes to sexuality, women with disability are in many ways, implicitly and explicitly, discriminated by institutions, but equally also by individuals, and also that the media in particular – who inform the public about them - exhibit a lack of understanding.

Data proves that creating new programs is a necessity – programs covering various issues pertaining to women with disability. Such programs are especially needed in gender studies because in they would produce theoretically justified argumentation which may be applied for practical use, and not just within educational institutions but also the public in general.

With this study the authors have supplied justification for using a good methodological approach – one which ensures that the status of women with disability is entrusted to women with disability themselves, and only then to the public in general. By opening this question the authors reintroduced this topic within the women's movement, so as to redefine the hierarchy of issues which need to be discussed in the contemporary academic community.

Because of the pioneering role this text has, because of the abundance of empirical data which can be used as convincing argumentation for changing the status quo in our society, I give my recommendations for publishing “The Sexuality of Women with Disability in Vojvodina” by Veronika Mitro, Dajana Damjanovi and Svjetlana Timoti in 2014, as a valuable contribution to the overall literature (which is rather lacking) on sexuality of women with disability (not just in Serbia), and because the empirical data present here will decrease prejudice about women with disability.

Review by Professor Dr. Svenka Savi , emerita  
Novi Sad  
May 26<sup>th</sup> 2014

## **SEXUALITY OF WOMEN WITH PHYSICAL DISABILITY IN VOJVODINA**

Veronika Mitro, Dajana Damjanovi and Svjetlana Timoti

### **Introduction**

Sexuality is the “central aspect of a human being during his/her whole life and it encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. Sexuality is experienced and expressed in thoughts, fantasies, wishes, beliefs, attitudes, values, behavior, practice, roles and relations. While sexuality may encompass all these dimensions, not all are always experienced or expressed. Sexuality is influenced by the interaction of biological, psychological, social, economic, political, cultural, legal, historical, religious and spiritual factors” (World Health Organization, 2006). Sexual health is “a state of physical, emotional, mental and social wellbeing in relation to sexuality, it is not just an absence of disease, dysfunction or inability. Sexual health demands a positive and responsible approach to sexuality and sexual relations, as well as the possibility to accomplish an enjoyable and safe sexual experience, without coercion, discrimination and violence.

In order to achieve and maintain sexual health, sexual rights of all must be respected, protected and fulfilled” (World Health Organization, 2006).

Sexuality and reproductive rights represent fundamental human rights and are guaranteed by the Convention on the Rights of Persons with Disability, which has been ratified by the Republic of Serbia (Official Gazette of the Republic of Serbia – International Contracts, no. 42/2009). Sexual and reproductive rights include: right to autonomy and self-determination without discrimination, stigma, coercion or violence – right to freedom of choice and full control over one's body, sexuality, health, relations, choice of partner with whom the person will create a union or have children; right to enjoy and express their sexuality, right to make decisions regarding sexuality and reproductive issues without instruction from others, free access to information, services and support regarding sexual and reproductive health; right to freedom from torture, cruel and inhuman or humiliating treatment or punishment, violence, abuse, neglect and exploitation (Frohmader and Ortoleva, 2013, pg. 2).

Women and girls with disability all over the world are not realizing their sexual and reproductive rights. Sexuality has practically been reduced to reproduction, while “reproductive rights are being violated to the extreme through practices such as: compulsory sterilization and contraception, unprofessional monitoring of pregnancy and childbirth, violent or forced abortion, deprivation of parental rights, denial of marriage or forced marriage, exclusion from access to sexual and reproductive services, and other forms of torture and violence, including gender based violence. These practices are based on traditional social attitudes which characterize disability as personal tragedy, burden and/or a problem that must be addressed by the medical staff” (Frohmader and Ortoleva, 2013, pg. 2).

“Measures and activities of states are geared toward treating, rehabilitating and adapting the individual in relation to their current state, so as to enable them to adapt to the environment they live in, an environment tailored for people who do not have a *defect*. Disability must be *rectified* as much as possible so that people who have disability differ from *healthy* people as little as possible. These people are treated as being less valuable, they must be taken care of, they need help and care, they can't see, can't hear, can't walk, can't understand. They are mostly referred to as having *special needs*, where the focus is on special and needs” ( arevi -Mitranovski and Jankovi , 2007, pg. 6). Dominant social fears and stereotypes about disability and reproduction are precisely where we find the reason why medicine controls and prevents pregnancy and sexual expression of women with disability through institutionalization, compulsory sterilization and disinformation about contraception (Waxman Fiduccia, 1994).

A woman is expected to be attractive and sexually desirable, a good wife and mother and someone who takes care of other family members. Traditional values stipulating a woman is successful if she finds a man, gets married and has children, have major impact on the lives of women with disability. If she is restricted by her disability to realize herself in relation to her gender role, a woman with disability will be seen as being less valuable. She is sexually unattractive, and there is uncertainty regarding her capacity to be a good wife and mother. *Will she be able to take care of the child?* - That is the first question asked. “The degree of disability of a woman in a patriarchal society, such as ours, is measured in relation to the extent that disability will prevent her from realizing her traditional role: exemplary wife, good mother, housewife, sexually desirable, someone who *takes care* of all family members and fits the social role she's been assigned. A woman's disability is considered to be *severe* if it impacts her appearance, her ability to do house chores, have and raise children. It is no wonder that women with disability are denied the right to love, sexuality, marriage, motherhood and self affirmation, especially when we take into account the stereotype of women with disability as most often not being able to accomplish their socially assigned roles in an expected and socially acceptable way, while no

alternative means of support are afforded to them (Ilk and arevi -Mitanovski, 2008, pg.11). The perception of women with disability as children who are dependent on their parents and who need protection, of whom it is never expected to have sexual relations, to get married and have kids, has resulted in many women with disability living their lives in isolation, invisibility and dependence (Grobois, 2001). It is important to note that young women with disability frequently receive this message within their families, and this in turn affects their self-esteem and self-perception. “Frequently the mother destroys her daughter's self-esteem, fearing that she will not be able to lead a *normal life* because she has a disability. The mother transfers onto the daughter the messages she herself was told: *a woman is worth nothing if she isn't a good housewife, mother, wife!* And women with disability grows up listening to these messages... looking at themselves through the eyes of others... Overwhelmed by prejudice and stereotypes, they forget they are women, start believing themselves to be asexual and that they don't have the right to love and be loved (Ilki and arevic-Mitanovski, 2008, pg. 14). Barbara Waxman Fiduccia claims that “underneath the stereotype of asexuality there is the belief that that reproductive capability of women with disability is a biological, moral and economic danger” (1994, pg. 155, according to Prilleltensky, 2003, pg. 22). Due to their *reproductive irrelevance* women with disability constitute a sexual minority (Waxman, 2000). Living in a society that constantly keeps reminding her that she's different and reminding her about everything she'll have to worry about if she, *being as she is*, decides on being a mother, is very stressful, fills her with fear and puts her in a dilemma. “Women with disability are frequently less self-confident and wonder if they can be good mothers” (Thorne, 1991, according to Prilleltensky, 2003, pg. 24), even though there is no evidence suggesting that parents with disability are any less competent than parents without disability (Frohmade et al, 2013).

There are many myths and stereotypes regarding the sexuality of women with disability. “The most characteristic, perhaps, are the contradictory presumptions that young women with disability are, on the one hand, asexual, with little or no interest or capability to be sexual, and on the other, that they are obsessed with sex and/or out of control when it comes to their sexual interests and wants. Both myths are detrimental and serve the purpose of preventing women with disability from getting information about sexuality and social and sexual possibilities – two significant components of healthy social and sexual development” (Russo, 2001, pg. 35). Aside from that, focusing exclusively on the sexual function can lead to ignoring other important issues pertaining to sexuality of women with disability – such as meeting others, going out and socializing, dating, realizing emotional, sexual, partner relationships, self-esteem, self-perception and such (Howland et al, 2001).

Social, architectonic, communicational and other barriers prevent young women and women with disability to accomplish intimate contact, intimacy and acquire sexual experiences (Rousso, 2001). Research conducted in the 80s indicate that adolescent girls and young women with disability experience their first kiss, dating and sexual relations, much later and are less frequently sexually active compared to their peers (Howland et al, 2001). Walter and associates (Walter et al, 2001) note that their research shows that women with disability have sexual experiences later than their female peers without disability (pg. 174) and that those differences can be prescribed to other factors but not the means and timing of when knowledge about sexuality was gained. Sexual experience may be postponed by the influence of a society which affords less opportunity for social interaction or activities that lead to sexual experience, as do stereotypes – such as that women with disability are asexual (pg. 175). Results of a quality study done in Croatia (Bartolac, 2004) also show that sexual needs and sexual expression of persons with cerebral palsy are constrained by negative attitudes pervasive in their social surrounding, and that further research is needed regarding psychological, social and spatial limitations.

The fact that they are confronted by social barriers and that they begin having sexual relations later in life and/or have less sexual experience does not, however, protect women with disability from unwanted pregnancy, sexually transmitted infections, abuse and violence in relationships (Rouso, 2001). It is wrong to assume that women with disability are asexual and hence don't have to be informed about sexuality and that they don't have to take care of their reproductive health.

### **The goal of the study and justification of the goal**

The goal this study wanted to accomplish was to describe and analyze the experiences and understandings women with physical disability in Vojvodina have in relation to sexuality.

Women with physical disability are confronted by the problem of limited movement, disturbances in coordination, muscle tone imbalance (frequently increase – spasm), they often need some sort of walking aid (walker or wheelchair) and help of another person for performing various activities in everyday life. Aside from this, the appearance of the body itself seems different than those of women without disability due to the contractions, spasms, hypertrophy. Women who were born or acquired physical disability in early childhood or while growing up, are frequently surrounded by medical staff, people who have similar problems (in hospitals and rehabilitation centers) and their immediate family. Additionally, architectonic barriers, problems related to schools, employment, autonomous living arrangements (especially after parents had deceased) and organizing one's life in accordance to the needs and wishes – all this complicates their everyday life. Due to all of these factors, sexuality as an important part of identity of women with disability, mostly gets neglected.

“Sexuality is still a taboo topic in many societies, our included, and especially so when it comes to women with disability. The theater play “Whispering Girls”, performed in Belgrade in 2002, caused a revolution at the moment the women on the stage, both in wheelchairs, publicly opened the topic of sexuality and love and portrayed persons with disability in a very different light” (Bracic, Ruzicic-Novkovic, Savic, 2009, pg. 16). In 2009 the organization for support of women with disability ...OUT OF CIRCLE – VOJVODINA translated into Serbian and published Yvonne Duffy's book “... All Things Are Possible”- a book about sexuality of women with physical disability. This book has had three different editions in the United States (1981, 1983, 1989). We believed that by publishing this book and making it available to our audience we can contribute to the “decrease of far reaching stereotypes about women with disability as asexual beings, who cannot be good mothers or good partners” (\*\*\* 2012, pg. 3), but also to inform women with disability about topics related to sexuality. In this regard we have been mostly successful – one woman with disability who participated in our research said: “You ...OUT OF CIRCLE – VOJVODINA published that book about the sexuality of women with disability, and before you no one had done something like that! And who is supposed to inform you about sexuality of women with disability? Many persons with disability are completely inexperienced sexually, I mean – sexually inactive – and they're around 35 years of age”. Additionally, ...OUT OF CIRCLE – VOJVODINA started the electronic Portal on Disability ([www.invalidnost.net](http://www.invalidnost.net)), and as part of that, within the Women and Disability magazine, we publish our texts. For women with disability living in these regions the Portal represents a valuable source of information, sometimes the only source. A woman with physical disability from Zrenjanin who participated in our research said: “And now, as of lately, I've been giving sex a lot of thought, but I'm concerned whether or not he can hurt me at all, because I don't feel any pain. I can feel that something is uncomfortable, when it's pinching me, I sweat or get goosebumps or I have some similar feeling. And I don't even know if I would feel anything during sexual intercourse and I have no one to ask about this. I talked to my friends and for them all of this is normal and when I ask them questions which interest me they have no

idea how to answer me. The only idea I came up with is to look online, of course, but I haven't found anything there either. I only found your web site ...OUT OF CIRCLE – VOJVODINA.

With this study we wanted to shed more light on sexual development and sexual experiences of women with physical disability in Vojvodina and contribute to them being better informed about sexuality, but also raise public awareness – especially that of medical workers at gynecological and obstetrician centers – about the importance of issues pertaining to sexuality for women with disability.

## **Method**

Studies of sexuality, reproductive health and rights done so far have focused mostly on attitudes others have about women with disability, and comparisons of women with and without disability. With this study we wanted to give women with disability a voice to talk about their sexuality and, to a certain extent, be actively involved in the research. Therefore, we opted for qualitative methodology. The empirical data has been collected by means of focus groups and interviews. We used both techniques so as to create optimal conditions for getting a wide array of information. A benefit of conducting focus groups is in the interaction of participants, mutual encouragement to discussion, as well as providing possibility that out of those discussions a topic may emerge which we had not foreseen. Interviews, on the other hand, enabled women to talk about their experiences and attitudes at length. By monitoring group processes we gained insights regarding what topics are easier to talk about in front of other people, and which topics are taboo within the women with disability group in general.

In her book, Yvonne Duffy (2009, pg. 15) notes that while researching sexuality of women with disability it is “important to gather data on the attitudes of parents, sexual education, cultural tendencies, self-perception, attitudes about child raising, as well as data from relevant fields pertaining to sexual function – menstruation, birth control and marriage, masturbation, homosexuality”. Guided by her insights we included the following questions in our focus groups and interviews:

- sources of information and knowledge about sexuality;
- physical changes during puberty;
- menstruation;
- intimate personal hygiene;
- going out, dating, first kiss, first sexual intercourse;
- gynecological exams and contraception;
- masturbation;
- relationships and marriage;
- pregnancy, giving birth and raising children;

### *Information about women with physical disability who participated in the study*

A total of 45 women with physical disability from various places in Vojvodina, ages 19 to 65, took part in this study. Most members belong to the Serbian national group, while a minority (13.33%) are members of members of the Hungarian minority. Members of other national minorities which live in Vojvodina did not participate.

The focus group encompassed 33 women with physical disability (induced by cerebral palsy and child paralysis, quadriplegia and paraplegia, muscle and nerve disease, various injuries caused by accident and stroke). Out of those 69.69% of women have acquired disability, while 30.31% have it since birth,

The women with acquired disability had acquired it in various stages of life – some have had it since birth (34.61%), others from their first year (19.23%), or elementary school (11.54%), early youth (19.23%) or early (11.54%) or later adulthood (3.84%). Women's ages vary from 19 to 65, and they have varying degrees of education: most have high school degrees (45.16%) and college/university (22.59%), followed by elementary school (16.13%), two year post high school degree (9.68%) and four grades of elementary school (3.22%), and no education (3.22%). Their occupations vary as well: students, biologist, Serbian language professor, economist, economy technician, engineer, librarian, book keeper, trade, nurse, professional nurse. Most are unemployed (46.67%), or retired (40%), only a few are employed part time (13.33%) and none are employed full time.

We used the form of interviews also and they covered in total 12 women with physical disability (induced by cerebral palsy and child paralysis, Friedreich ataxia, various injuries caused by accidents). Out of those 66.67% of women have acquired disability, while 33.33% have had it since birth. All women interviewed have had a disability before their 15<sup>th</sup> year (one from birth, one in her first year, two in their seventh/eighth year, and four from 12 to 16 years of age). Their ages vary from 20 to 57 years old. Also varying educational backgrounds: college/university (41.67%), high school (41.67%), and elementary school (16.66%). Occupations are: student, biologist, economist, economic technician, engineer, ethnologist, psychologist. The majority is unemployed (83.33%), while only some are employed (16.67%). Most are heterosexual (83.67%), while two are homosexually oriented (16.67%).

## **Results**

### *Sources of information and knowledge about sexuality*

Lack of social awareness about physical aspects of identity and sexual development and needs of young people with disability may cause multiple unfavorable consequences and risks for this population. It is therefore important to encourage young people with disability and their parents, but also experts, to contribute with their experience and knowledge to spreading information about this issue (Swain and Lawrence 1994, according to Laklija 2007, pg. 580). Physical changes in puberty and the first menstruation represent an important stage in the life of girls and its important that they be well informed about the processes taking place in their bodies (Kapamdžija, 2013, pg. 63).

Based on research about sexuality conducted on women with disability in the United States, Yvonne Duffy concludes that our parents and guardians probably informed as just as well as they did our sisters who do not have disability – about physiological functions not directly related to sexuality, such as menstruation and physical changes in puberty. Only 10 (11%) of the American women with disability who were interviewed did not know about menstruation before they got their first period (2009, pg.23). This conclusion is, more or less, applicable to women with physical disability in Vojvodina. Two women aged 45 (4.44%) stated that they were given absolutely no information about it, while seven (15.5%) stated that they did not know what menstruation is when they got their first period.

*Neither at the hospital, nor at home, I did not get any information about femininity and such things (50 years old, disability since birth).*

*I started going through puberty when I was fourteen, that's when I got my first period. I didn't know what it was. (57 years old, disability since 12 years of age).*

*That day I was alone at home. I go to the bathroom and see blood on my underwear. I had no idea what it was, I didn't know anything. I was thirteen. So I took some of my mom's absorbent cotton and placed it in my underwear. My mom called from work to see what I'm doing, and I tell her: I have a*

*problem, I'm bleeding. And she didn't tell me at all what to do. Only when she got home did she explain how I'm supposed to use the absorbent cotton, that its not supposed to be disposed of into the toilet and that I will receive my period every month. She didn't say more than that. (37 years old, disability since birth).*

*I got my period when I was in the seventh grade. We were at a friend's cottage and I wanted to go to the bathroom and that's when I saw it. Actually, I did experience some pain prior to it, I remember I was hurting all over and feeling weak. And among people we were with was my former teacher and she told me: It must be that you have to get your period! And she gave me some aspirin, I remember that. (46 years old, disability since 7 years of age).*

*I didn't notice when puberty began. I had already heard from my friends that some had gotten their periods in the sixth grade, but I just barely paid attention to this. I didn't talk to my mother about this at all, because I mostly didn't even know about it. And then when I did get it our physical education teacher explained to us in more detail what it was. (49 years old, disability since birth).*

Most women (84%) were informed about physical changes in puberty and knew about menstruation before they got it, even though that information was frequently lacking. Women told us that their mothers told them merely that *it will happen*, but that they got no information about the cycle, hygiene during menstruation, individual differences, nor were they advised to see a gynecologist.

*My mother simply prepared me for the life women lead, it wasn't any special preparation, rather... She just told me: you're a woman, and you'll experience these types of changes. (50 years old, disability since 10 months old).*

*When it comes to knowing my body, my mom defined it all for me – this is this, and that is that. What I still remember is that my mother was, perhaps, too open when it came to my body and she would mention my private parts in front of my father – her little girly bits! It bothered me a bit. (27 years old, disability since birth).*

*I was sort of aware of it, I had heard about it from friends, but it was different when I got my first period. I wasn't really prepared. (23 years old, disability since birth).*

Our participants listed their sources of information about menstruation and physical change, mostly they mentioned female family members: mothers (8), sisters (4), grandmothers (1) or both parents (1).

*My older sister who told me my breasts will grow, that I'll have a monthly menstrual cycle... (31 years old, disability since birth).*

*Menstruation was the only thing I was ready for and which I discussed with my mother. (49 years old, disability since birth).*

*My sister helped me a lot in this regard. She had finished medical school and she advised me on everything. (50 years old, disability since 12 years of age).*

Citing other sources of information about menstruation and physical change, women in Vojvodina noted their friends (5), Internet (2), hospital staff (2), teachers (3), books (2), magazines (1), media (1).

*My mother didn't tell me what menstruation is, nor did she tell me what to expect in life, not how babies are made, nothing... My first experience with this issue was when we had physical education class and the teacher took us girls aside and dedicated one whole class to explain certain things to us. At that time I still hadn't gotten my first period, so this was the first time I ever heard about it. (54 years old, disability since 1 year old).*

*My mother didn't teach me what menstruation is, but I learned about it at the hospital. And I learned a lot from books. (52 years old, disability since 1 year old).*

*Doctors told me about it and I looked online for information, so I knew what was to come. (28 years old, disability since 8 months old).*

*My mother prepared me well, and magazines and media. (45 years old, disability since 6 years of age). In the fourth grade our teacher talked about the body and development, but at that point I already knew more than most girls did. I had read a lot and gotten my information that way, more than what I learned from my mother – both when it comes to developing school crushes and physical development. (46 years old, disability since 7 years of age).*

When compared to American women with disability, women in Vojvodina also mostly cite mothers and sisters as main sources of information about menstruation and physical changes, but unlike them they do not cite studies, commercials for hygiene products, special programs and movies at elementary school. Internet does not show up as a source of information among American women, but the reason behind this lies in the fact that the research was conducted in 1979, when the Internet didn't exist.

When it comes to information about sexual relations, childbirth, contraception, these topics mostly are not discussed within the family. Only a few women (four) cite family members as sources of information on these topics, especially when those family members were from medical profession.

*My mother helped me, and so did my sister. She basically explained everything to me, because she had gone to medical school. (55 years old, disability since 10 years of age).*

*In the first grade I talked to my mom and she explained what menstruation is and what sexual intercourse means, so at the age of seven I was already theoretically prepared for all those physical processes which I would go through later. (26 years old, disability since birth).*

*In my immediate and extended family there are a lot of nurses and we talked about all of this openly. (40 years old, disability since 6 years of age).*

*I had a very good and nice stepmother. She loved us a lot and took care of us and told us about everything. So I knew everything, about men and everything. (57 years old, disability since 12 years of age).*

Based on qualitative research conducted on four women and six men living with cerebral palsy in Croatia, Andreja Bartolac (2004, pg. 190) states that her interviewees note that “family ignores and marginalizes their sexual needs and they also note a lack of education (*that is a taboo subject; the healthy go to school, we don't; it's not mentioned in the media; there is no opportunity to study*)”. One study conducted on about one thousand women with and without disability from the United States also concludes that sexuality was not a topic of family discussion, not even in one group. For both groups, the most usual sources of information on sexuality and sexual functioning cited were books and other printed material, sexual experience, partners, friends and teachers in elementary school. More women with disability got their information from other women with disability and counselors in rehabilitation centers (Walter, Nosek, Langdon, 2001, 175). In Yvonne Duffy's study (2009, pg. 30), “friends (55) and books (52) are cited as the most frequent source of information about sex, while for Americans an important source of information were their parents as well (41). Twenty four women gained knowledge about sex from their sisters or brothers or at school classes. Six women learned about sex by watching animals, while three learned by eavesdropping on other's conversations”.

For women with physical disability in Vojvodina the main source of information about sexual relations was through exchange of information with female peers, while some got information from books, movies, the Internet and media, from their gynecologist and through educational programs.

*It was definitely only when I became a teenager that I had the first open discussions with my parents.*

*But when it comes to sexuality I mostly shared information with my female peers. (27 years old, disability since birth).*

*I learned about sexual relations mostly from female friends at university, while I got information about contraception from my gynecologist. (31 years old, disability since 15 years of age).*

*Well, in my case, we never openly discussed these things at home. I mostly got information from books. (36 years old, disability since birth).*

*I got some of the first, basic information from TV. There were always some movies. My parents also talked to me, not really in detail, but the basic stuff, and friends also. Then later, when I could go online, it all became much easier. (20 years old, disability since 16 years of age).*

*Mostly from female peers, and media. (27 years old, disability since birth).*

*During puberty, mostly from my mom or my sister and female friends, later the Internet – I could find a lot of information about sex, so I wasn't confused. (28 years old, disability since 5 months old).*

*I went to workshops intended for educating youth for peer to peer education, and there we learned about sexually transmitted infections and how to place a condom and all other things about sex, protection from unwanted pregnancy or sexually transmitted infections. I knew a lot about sex from that medical point of view and I passed that knowledge to others. I went to schools, held workshops where I talked a lot about how we all have the same needs and rights to sexual relations, so I accepted all of that. But that was just talk. I accept all of that, it's all true, but it is something I just cannot apply in my life. (23 years old, disability since birth).*

Some women in our research didn't know a thing about sexual relations, childbirth and contraception until they started engaging in sexual activities. Some of them felt uneasy talking about sexual relations with others, even their female peers.

*My mother never sat down to talk to me about sex. Everything I know about sex I learned through direct experience. I still say that had I known any of this earlier maybe I wouldn't have become pregnant the first time I had sex... (37 years old, disability since birth).*

*I know my grandmother always said: you can let a man touch you from the waist up, but not underneath the waist! You'll become pregnant and what will you do then, where will you go then? My husband informed me about everything, how it's done, what goes where, what happens, everything. (60 years old, disability since 15 years of age).*

*Others had already had some crushes at school, they had some success and I didn't, and I somehow felt ashamed, especially since I would solve my sexual frustrations by masturbating, while they had someone for that. And I, of course, didn't talk to anyone about this. I felt uncomfortable just thinking about it in company. For instance, when some of my friends would talk about it I would usually leave their company and wouldn't express my opinions, because, simply put, I didn't think I had similar experiences like them and I was somehow hurt by this, I don't know... (23 years old, disability since birth).*

Women were mostly not informed about sexuality by medical staff, and only one focus group participant said she was informed about the possibility of becoming pregnant (but no other aspect of sexuality and reproductive health).

*While I was in hospital, about a week after I was injured, they told me: you can give birth, just not in the usual way, but by C-Section, since you didn't sustain any female related problems from the injury. (27 years old, disability since 18 years of age).*

Our research participants recognize that parents can be a limiting factor and that working with whole families is important, especially when it comes to accepting their children's sexuality.

*The parent is the one who knows best, whether you should have a boyfriend or not... and this represents a major obstacle and this is how a person with disability will grow up. (48 years old, disability since 6 months old).*

Participants also note that it is necessary to organize education about sexuality for women with disability, especially the young and those living in rural areas, but also for men with or without disability.

*Some lectures have to be organized for youth. From a psychological aspect they would benefit from getting some encouragement, because who knows what kind of family they live in and how willing their parents are to prepare them for everything. Many parents hide their child who has a disability, they are ashamed of him or her. There must be a way to signal to them that people with disability can be equal to others, with healthy people. They should be advised about this so that they can accept it first and foremost, because they live in their own world where they're pretty much isolated. (60 years old, disability since 20 years of age).*

*In larger cities you can find panels and lectures and a whole lot of stuff. So, who wants to be informed can find information – if it's located in an accessible space. In rural areas the situation is much worse, there women don't dare talk about it and they are uninformed. Ok, so today there is TV and the Internet, they can see much more, but... (54 years old, disability since 1 year old).*

*Education must be organized for men, so they aren't so afraid of hurting their partner and so that they can relax a bit in this sense (23 years old, disability since birth).*

### *Physical changes during puberty*

Girls enter puberty between eight and thirteen years of age. Changes experienced in puberty vary from person to person. Usually changes occur in the following sequence: breasts begin to grow; pubic hair grows; walls of the vagina become harder; the uterus and ovaries enlarge; first menstruation; hair in the armpits begins to grow and the smell of sweat changes; the cervix begins producing a mucus coming from the vagina. Young women grow, their pelvis expands, their fat percentage increases, skin becomes oily and frequently acne appears. Interests and feelings usually change as well (Kapamdžija, 2013).

Many participants mention breast growth and the need for a brassiere as an important change which occurred in their process of becoming women. Some also mention leg hair growth and growing taller.

*I was very happy when my breasts began growing, because till then most in my family called me by the nickname of Marko (male name), which really irritated me. I was happy that they'd finally start calling me by my name. And it was right that I've started wearing a brassiere, and since breasts don't grow overnight – where I went, that brassier went with me. It took me about a month to get used to it. (31 years old, disability since birth).*

*I only remember that it was a problem for me that my mom didn't let me buy a brassiere when my breasts started growing. I mean, my breasts started growing early on, somewhere around the fifth-sixth grade. And at that time I remember that I wanted this light blue brassier – this I remember – and she'd be like: No way we're buying that! When my breasts began growing, I had a lot of problems with my spine, it really started to bend under pressure. My therapist insisted that I must increase my exercises and that I should lay flat on my stomach more, which would mean I'd squash my breasts. (46 years old, disability since 7 years of age).*

*I was thin, tall – as if someone had stretched me. Until my twentieth year, I looked more like a man*

*than a woman. (45 years old, disability since 10 months old).*

*My breasts started growing when I was fourteen. And even when I was a kid, when I would see a woman with hairy legs, I liked it, I adored it. When I turned fifteen my legs also started becoming hairy. I was overjoyed. (57 years old, disability since 12 years of age).*

A great number of women cite that breast growth provided a confirmation of equality with their peers without disability, even though their breasts usually began growing a bit later.

*In my case it started later on, due to my disease, because it slowed down my overall growth and development, but I could see that I was becoming more like all other girls, even though I had a disability. When I started developing physically in puberty, I also developed some of those female attributes, even though it was a bit later on... I started realizing that even though I'm shorter, but I'm no longer a child, that I am developing just as everyone else as the years pass, just a bit slower. (28 years old, disability since 5 months old).*

*I started realizing that I'm a woman and that adult women have breasts and that I will soon look like that. I didn't experience these changes as something traumatic. (24 years old, disability since birth).*

Other still were troubled that their breasts hadn't grown already at that time.

*I waited for a while for my breasts to start growing, since I thought they were small, and they just wouldn't budge. Then I realized that what I have is all that's gonna grow, and no more. I was a bit annoyed that my breasts were so small, but I'm fine with it now. (49 years old, disability since birth).*

Other women with physical disability in puberty were more concerned with their disease than physical changes which they were going through.

*In my case, for instance, everything developed simultaneously – disease, development, puberty, breast growth, expansion of hips, everything happened one after the other, so that I basically couldn't pay too much attention to it... I was bedridden, always in hospital and always alone. (49 years old, disability since 12 years of age).*

In adolescence body image becomes increasingly important, and special attention is paid to physical appearance and attractiveness, which may produce different effects on a young person – from an increase in self-esteem, to loss of self-esteem, development of fear and insecurity. Physical impairment encompasses a heterogeneous group where we find impairments of the locomotor apparatus (hip impairments, lack of extremities, muscular dystrophy) and impairments of the central nervous system (cerebral palsy) (Orluki 2006, according to Laklija and Urbanc, 2007). Due to impairments of the locomotor apparatus a person cannot independently conduct actions appropriate for their age – for instance, moving their body (walking, changing position, holding a bat, conducting similar actions). Furthermore, that person may need to use certain orthopedic aids (prosthesis, apparatus, crutches or wheelchair and other), and frequently may not be able to independently take care of their physiological needs and maintain personal hygiene (bathing, dressing, putting on shoes) or to independently prepare and consume food and such. At a time when their identity is forming, young people with physical disability or other type of disability, if they compare themselves with peers who don't have said difficulties, may experience their body as being less valuable, their capabilities inadequate, and themselves as inferior (Laklija and Urbanc, 2007).

Women with physical disability covered in our study talked about various difficulties they had in accepting their body during adolescence.

*I think that how you experience your own body is very important for women with disability. We all want to look perfect, and when I see my ass which is full of scars... I know that my biggest problem at that time was that I had scars on my heels and a large nose – I mean, that's silly, but that's puberty. And I had many stretch marks in my youth, and I developed complexes because of this. And after that came the wheelchair! But I myself didn't see the wheelchair as an impediment, but rather a possibility for me to go to a club, to go for a stroll, to be able to hold hands, and such things... (46 years old, disability since 7 years of age).*

*That whole period was traumatic for me. I was already aware by that time of sexual urges and had experienced excitement and a lot of other things. But when puberty struck me I began realizing that I am different from my peers and that was hard for me. I was so traumatized of wearing short sleeves for instance... this reflected on my style of dress, I would cover my body in wide sleeves, wide pant legs... even in the summer I'd always search out my own designs so as to cover myself up and hide everything. At that time I still hadn't gotten to know my body, but had rather chosen to hide it. (27 years old, disability since birth).*

*Puberty is stressful in and of itself and for a person with disability it is even harder. I wasn't aware of my disability for a very long time, and then when I became aware of it, I needed a lot of strength to accept it in the right way. (48 years old, disability since 6 months old).*

*It bothered me how people would look at me, I'd wonder what they were thinking about, what they thought about me... (54 years old, disability since 1 year old).*

*Oh, he was checking me out, my disability, looking at what I was in – I mean the wheelchair. And sometimes it seems we just imagine these things. (60 years old, disability since birth).*

*I could never accept my body. I can't say that I have accepted it even today. I don't have the ideal body and I personally am bothered by this. Because my whole body is in scars and in the summertime you will never see me wearing something short, and if I'm having guests over at my house, I will dress in long sleeves and long cloths. (37 years old, disability since birth).*

*I had a negative self-image in childhood. I thought I didn't deserve someone who is healthy, someone good looking or attractive and that I must find someone like me. Someone prettier wouldn't want me. (23 years old, disability since birth).*

*At some points it was really difficult. Ok, so it even happens these days, because people think I'm a kid because of my height, and that's how they behave when they meet me, and when they realize I have a disability and that this is the reason why I'm shorter, then they either apologize or are like – I didn't know. (28 years old, disability since 5 months old).*

*At that time I didn't think myself attractive at all, or pretty, that I could attract someone's attention by my physical appearance. I think that resulted in many complexes. I thought I'd never marry, or have children. And I was very withdrawn. (49 years old, disability since birth).*

*I thought that when a boy sees a girl with a crooked leg, that she's limping, that he wouldn't give her a second look, he'd just turn his head. So I didn't think about all of this much, I didn't think there was any*

*chance some guy would pay attention to me in this wheelchair. (57 years old, disability since 12 years of age).*

*I had problems first and foremost because my legs are very infirm, since I don't use my muscles, and so I would just wear sweatpants because I thought this was ugly. I don't even know what I thought, something silly like that. (20 years old, disability since 16 years of age).*

Women with disability who are homosexual talk about accepting their bodies but also other difficulties in relation to accepting themselves – feeling uncomfortable in women's clothes or going out in public with a woman.

*Oh, I wanted to go ahead and get an operation, so that I wouldn't be a woman at all, I couldn't make sense of myself. First, I am the way I am, and then my breasts started growing, sweet lord! Horrible, just horrible. You know what I did... my mother would prepare a skirt for me and some flimsy t-shirt for school – luckily, she'd leave for work before I went to school, and she'd come back home after I returned from school. And so I'd just open up my brother's closet, take his shirt, a man's shirt, a man's vest and I'd put on my jeans and then I'd go to school. I did that until my mother ran into me on the street. I just didn't feel good in skirts, girly t-shirts and with braids. (37 years old, disability since birth).*

*I don't like my legs because they're too muscular from all those exercises, and genetically they're fat, so I was never really fully relaxed. Sometimes I think, even if I were healthy, would I be with me? Would I be with a woman with disability? Maybe I wouldn't, because I know how difficult that is, or maybe I wouldn't be with her because of the shame of being the center of attention, because everybody's looking at me. And then I imagine two women with disability – they'd cause even more attention. (36 years old, disability since birth).*

### *Menstruation*

On average the organism needs three years from the moment breasts begin to grow for menstruation to begin. In our population the average is twelve years of age. The advent of menstruation before 10 years of age is considered to be an early onset of puberty, and if it doesn't happen by age 15 then it is considered that puberty is late. Early onset of puberty and late puberty are both reasons enough to consult a pediatrician-endocrinologist or gynecologist for children. There are numerous reasons why there might be some deviation in timing of the first menstruation, such as slower maturation of the functional axis of the hypothalamus – pituitary gland – ovaries, due to anomalies in development of internal genital organs, numerous diseases which disrupt the organism's development or as result of radiation and certain medications. One reason also is the girl's physical mass. Increased mass may result in early onset, while decreased mass may result in the first menstruation coming on rather late (Stankovi , 2010).

Most women with physical disability from Vojvodina got their first period between ages eleven and

fifteen. Only a few state that they experienced early onset of puberty, or late puberty.

*I was the first in my class in elementary school who got her period, I wasn't even eleven yet. I knew what it was, but I was still afraid when I saw blood on my underwear and I thought it was some sort of punishment, that it was something horrible, and why should it happen to me. That happened to me before my evening bath, my mom was there and she said: oh wonderful, my girl has become a woman! She said something like that and she was really happy, while I was like – oh, horrible. (23 years old, disability since birth).*

*None of it was traumatic for me. Sure, I matured sexually a bit late, it was somehow a slower process in my case. I got my period when I was fifteen, while others got theirs when they were about eleven or twelve. (45 years old, disability since 10 months old).*

*Very late, probably somewhere around my seventeenth or eighteenth year. All my friends got their in fifth or sixth grade, and they have had it for four or five years by then. And then I got it and I was like – ok, I got it as well! What do I know, I was happy. (28 years old, disability since 5 months old).*

*I got my first period when I was fifteen, and then it stopped, and then reappeared again when I was eighteen. That was the only thing I was prepared for, so it wasn't a problem. (49 years old, disability since birth).*

Some women were surprised by their first period, for others it was a nuisance, a frightening thing that produced a feeling as if they were being punished.

*I got my period when I was fourteen. I felt something wet in my underwear so I went to the bathroom, saw the blood and I knew what it was. (57 years old, disability since 12 years of age).*

*I got mine on my eleventh birthday. And I remember being very scared by it. I thought it was something terrible and that I was being punished (23 years old, disability since birth).*

Many had good feelings at the time they got their first period, saw it as a confirmation of their womanhood and that one day they will be able to be mothers and that they are in this regard equal to their female peers without disability.

*I had this perfect feeling when I got my period, I was just happy that one day I will be a mother. (45 years old, disability since 6 years of age).*

*I wasn't ashamed, I just became aware that this is a new phase of my life, that I have to take care what I will wear once a month, what sanitary pads I should use... that I'll have to tell my physical education teacher when I have it and that I can't run around... That part was traumatic because he thought that girls can't get their period till fifth or sixth grade; he thought we were lying because we didn't want to participate in class. (31 years old, disability since birth).*

*I got my period when I was thirteen... and I realized – there, now I am ok as well, everything is normal regardless of the injury (50 years old, disability since 12 years of age).*

Some women experienced difficulties during their menstrual cycle.

*I know I got my period somewhere between sixth and seventh grade. I have a tough menstrual cycle which lasts up to seven days. I have pains when I get my period and before that as well. I don't get pains in my hips when I'm tired, I get pain in my spine. My gynecologist said that all of this is connected, those muscles are connected and that's what hurts me, that whole part, my stomach... (36 years old, disability since birth).*

Most women did not experience any complications regarding their menstrual cycle. Some state though that it worsened in the years prior to menopause.

*I've had a regular cycle all my life, until it stopped. I am now in menopause and I don't get my period any more, it's been exactly a year now. While I did have it, I used sanitary pads and tampons sometimes. That period leading to menopause was really lengthy for me. I experienced major problems for about five years, I had really heavy flows. That's horrible, I would buy those overnight Always pads, the largest pads which are supposed to last for about eight hours, and it would fill up in an hour in my case. I'd bleed all over my trousers. I had extremely heavy flows, so I'd have to put a sanitary pad, absorbent cotton and a tampon at the same time, because otherwise it could happen that I'd return home and be bloody up to my waist. (57 years old, disability since 12 years of age).*

*At this time I don't have it has stopped again, because I'm in menopause, but before it came regularly (52 years old, disability since 24 years of age).*

*I stopped getting my period two years ago... I have smaller problems. Maybe on a psychological level too, I'm not sure, it's a little strange. Because of my menstruation, regardless of how old I am, even today I sometimes get a feeling like I'm gonna get it, I mean it's silly, of course I'll never get it again. But now I can understand those people who talk about being able to feel their legs – and their leg has been cut off. And they can feel pain in their little finger, which isn't there anymore. Just like that, sometimes I have a feeling like I've started bleeding, which is of course impossible. But I guess the mind needs a bit more time to realize that it will never happen again (49 years old, disability since birth).*

### *Intimate personal hygiene*

Many women with physical disability in Vojvodina need assistance with their everyday hygiene (bathing, going to the bathroom), and some women also need assistance with personal hygiene while they have their periods (change of sanitary pads, placing tampons, changing cloths).

*My boyfriend is my assistant and he holds me while I shower. I can change the pads myself. (25 years old, disability since birth).*

*I use the help of an assistant when it comes to personal hygiene, but not when I have my period – I can do that by myself. But when I shower I do use the help of an assistant. And I'm not inhibited in any way, I'm maybe even too upfront. Maybe because I have a good relationship with my assistant and we're both relaxed about it, because we've spent a lot of time together (26 years old, disability since birth).*

*At first I avoided using the help of an assistant when it came to personal hygiene, not because I didn't need it, but because I felt ashamed. This isn't the case anymore, and my assistant said that I behave in a free manner and that it's a bit strange that I don't have any shame. Somehow, all of it just became normal to me – I can walk around naked even though she's there (23 years old, disability since birth). My father was with me non-stop, regardless of the fact that I'm female and that my menstrual cycle was already a reality. I'd stand on one side of the door, while he'd stand on the other and hold it so that I could hold on to the door while I get my business done (51 years old, disability since 8 months old). At first I couldn't do anything, my sister had to do everything for me, or my mother or someone else. In some situations I felt really silly – they'd bathe me when I was little and then I could do it myself, and then again I couldn't do it myself, bathe or anything, and this was problematic until I overcame it (20 years old, disability since 16 years of age).*

When in hospital, bathing and maintaining personal hygiene posed awkward experiences for women with physical disability.

*Bathing and personal hygiene was done in bed and we had one female and one male nurse, and there were some female nurses who refused to do it so they'd send a male nurse. She doesn't care that I'm not even eighteen yet and that I'll be uncomfortable with a man doing it, and if you already have a male and female nurse on the ward this should be an issue which is considered. I fought for my choice of female nurse a couple of time successfully, so that a female nurse would bathe me, and later I just wanted to do it myself. In my case, the male nurses would give me a thorough bath, while female nurses would come, make a move or two and then shower me quickly and then it's over (27 years old, disability since 18 years of age).*

The women participating in our research managed to succeed in their right to conduct personal hygiene themselves despite the difficulties – some earlier, some later in life.

*We had this bathtub which I had to climb into, and this wasn't practical for me, because of my height. When I was seven I asked my mom to just stand next to me and I'd step into the bath myself. I just wanted to fight for myself, for what I wanted, because I did feel a bit of shame – I had talked to my friends at the time and they'd ask me: does your mother still bathe you? And I'd tell them: No, she doesn't bathe me! So I was aware that it's not really normal for your mother to bathe you when you're seven years old (24 years old, disability since birth).*

*Before my mom and my sister bathed me, but for eight years now I've been doing it myself. I shower and wash my hair, all by myself (41 years old, disability since 28 years of age).*

*I couldn't get into the tub by myself in order to bathe, so my sister would carry me from my room through the kitchen and then to the bathroom and to the tub. I lived alone in my apartment and she lived with her husband and children in another apartment, but we were really close. I'd always have to wait for her to come, in order to take a bath. One day I just became sick and tired of waiting so I got out of my chair and locked the door. I came right next to the tub, parked my wheelchair and decided to get into the tub even if it cost me my life. There was a handrail between the tub and the sink and so I*

*could step into the tub and take a shower. I enjoyed it, it was great. My sister knocked on the door, wanting to know what I was doing. I tell her – I'm taking a bath. She tells me I'm not normal, because I locked the door! I tell her – go home, when I finish my bath you can come back. And then I realize I don't know how to step out of the bathtub. I look this way, I look that way, and I raise my legs onto the tub rim, grabbed hold of the arm rail and slowly proceeded out of the tub without any problems... you always have to risk it (57 years old, disability since 12 years of age).*

*I felt uncomfortable having my mother bathe me, that's just the way I am. Later, I had an assistant who'd come to bathe me and, of course, I didn't feel comfortable about that either. Especially when a new assistant would come. Of course, everything becomes routine after a while and becomes less bothersome, but I'd still feel uncomfortable. And I think it's alright if everyone involved finds it a bit weird, for instance, when going to the bathroom – everyone likes to be alone at those times. So I personally find this a rather uncomfortable situation. I just tell myself that this is just the way it must be done – I'm going to be dirty and messy or I'm gonna overcome this awkwardness (65 years old, disability since 6 years of age).*

Some women told us that having assistance from others is precisely the reason why they don't attempt to do some things by themselves, which actually is a deterrent to greater independence.

*Many of us are spoiled, meaning, they could do something but they have the help of others so they don't have to try and they're not aware they're doing a disservice to themselves and that they should try to do everything today so that they could be good at it tomorrow. Because if you don't use your muscles they will atrophy, become weaker and you'll have less power. And then at some point when you will want to become more independent in some way, you won't be able to just because you were lazy when you should have been building those muscles and becoming more independent (53 years old, disability since 33 years of age).*

Women with physical disability who have personal assistants are aware of the difficulty that job entails, and of how little value is attributed to it.

*These personal assistants have to be given much praise, because this is really a tough job to stomach, and it happens too frequently that they don't get the respect they deserve (65 years old, disability since 6 years of age).*

*Going out, dating, first kiss, first sexual relations*

Walter and associates note that their “research shows that women with disability do not differ all that much from their female peers without disability when it comes to gaining knowledge about sexuality, but do trail behind when it comes to sexual experiences” (Walter et al, 2001, pg. 174). The authors speculate that the age difference of first sexual experiences may probably be prescribed to other factors aside from the timing of when knowledge was gained. For instance, the environment in which they live

in affords women with disability less possibilities for social interaction or activities which may lead to sexual experience. Also, stereotypes such as that women with disability are asexual, may delay sexual experiences (pg. 175).

Many women with physical disability, congenital or acquired, talk about not being really accepted by their peers, which, aside from mobility issues, additionally decreased their chances for social interaction that leads to sexual experiences.

*I didn't have friends, maybe that's the way I wanted it, because if they couldn't accept me then I didn't want to hang onto anyone either. I didn't really have female friends. My next door neighbor, she was a bit younger than me, I would just hang out with her. But when it came to kids from my class, with whom I also went to kindergarten and first grade – I didn't hang out with them, I would always stay separate from them. And during recess I'd always stay inside, everyone else would go outside to run around in the yard, and I'd just remain inside. I can't say that I experienced a lot of social interaction or friendship, or for instance, for my birthday – I don't remember anyone ever inviting me over for their birthday, aside from family. And later, around sixth or seventh grade, again there was this difference between me and them, because I didn't go to clubs, or the theater, anywhere, and my peers already went to such places, so again I didn't have anything in common with them (31 years old, disability since birth).*

*I didn't have any special friendships since I lived in a village, and there my situation is largely misunderstood. So, I wasn't really accepted, and I even finished school as an independent student – I went to school only when I had to finish exams, so I wasn't really in contact with my peers (49 years old, disability since birth).*

*I had my two friends, and that was all. I'd go over to their house, and they'd come over to mine. There were thirty one or two of us in first grade and second grade, and no one wanted to be friends with me. While I was in first and second grade we lived in the village, and there at Easter time men would play tricks on women. Only one dared to come to me, the others didn't dare because they feared what others might say, that they may tease them (54 years old, disability since 1 year old).*

*Before I sustained the injury I had friends, and now, of course as well, it's not like time stopped when I got hurt, but then you notice that they treat you differently. After the injury I noticed that when I go to school I don't want to stay too long. Because I could clearly see how they were looking at me – full of pity, different than before, and I know how it was before. On one occasion, and I'll never forget this, one friend told me how she cannot stand looking at me anymore since I am in a wheelchair and that is really depressing for her. I told her: alright, whatever, we don't have to be friends anymore, what can I do (27 years old, disability since 18 years of age).*

*I didn't have friends, not even female friends! Because they thought that if they hang out with me then their other friends, who are physically healthy, will tease them, won't be friends with them any longer. They'd ask me not to get mad because they could be better friends with those others anyway (50 years old, disability since birth).*

*I was always a loner (37 years old, disability since birth).*

*I had about three friends till my twentieth year, and they've known me since birth. And that's it (23*

*years old, disability since birth).*

In rare cases some women with physical disability had more social interaction and activities, aside from hospital stays.

*Even though I have a disability I went to elementary school regularly. I have a physical disability, and when it came to my peers – they all accepted me as an equal. The only thing was that I wasn't really mobile so I couldn't participate in some activities. For instance, in school during recess or physical education class most of my friends would stay behind and talk to me. I didn't feel like they were excluding me, only thing was I couldn't go to some places. But, for example, I went with my class regularly on field trips, to prom and such (28 years old, disability since 5 months old).*

*I am from a small town. I was always the best student in my school. I knew I was different, but others never treated me like I have a disability (36 years old, disability since birth).*

*I had good relations with my peers. I would go out with them at night because I had two neighborhood friends who made it possible. One of them was two years older than me and she'd always take me with her, so I would mostly hang out with the older crowd, her friends. When I'd go out at night I didn't really keep company of my school friends, because school was at one part of the city and I lived in a completely different part of the city (46 years old, disability since 7 years of age).*

*Kids from all over former Yugoslavia were at hospital with me, so that was very interesting. As a child it's easy to find something beautiful in anything. True, we all had casts on our bodies, but we knew how to play (36 years old, disability since birth).*

Many women with physical disability in Vojvodina rarely went out and in adolescence frequently had relationships that remained platonic.

*Those first crushes in the fifth, sixth seventh and eighth grade of elementary school or at the beginning of high school – I knew who I was in love with and there was no qualm about that. All of these stories were unsuccessful though, sad love stories. Absolutely unsuccessful! I mean, I'd chose boys who weren't even slightly interested in me. Sometimes I'd attribute this to my disability, sometimes not... (46 years old, disability since 7 years of age).*

*When I was twelve I really fell in love with a boy and confided in a friend about it, and tomorrow the whole class knew about it. And then everyone teased us both, because... well, what are you supposed to do with that – first off, I'm new in class, and second I have a disability! When it comes to my social life, love life, there wasn't any. I thought of myself as being less valuable, that I didn't deserve it, that no one would want me... And I attributed all of it to disability. Of course, I wanted these things in my life but the most I got was platonic love, unrequited love, because I was always afraid of showing that person my feelings (23 years old, disability since birth).*

*When I was fifteen or sixteen I fell in love with someone, but it was unrequited. It lasted for a long time, about ten years, maybe because I never got an answer about how he felt. He also had a disability and that is why I also felt an immense emotional pain, because, after all, he was a person with a disability. I mean, somehow I understood that healthy people don't want me, but why didn't he want me?! (49*

*years old, disability since birth).*

*There were times when I also fancied them but I never said a word about it, or gave any clue. I waited for someone else to make the first move (54 years old, disability since 1 year old).*

*It was never hard for me to fall in love. As if being a person with disability prevents someone from falling in love. I would always fall head over heels. However, it always turned out that the other person wasn't in love with me, and I'd end up suffering. That lasted for years (23 years old, disability since birth).*

*It was only later in life that I began wanting to be with someone. Disability wasn't the problem in that regard, it was just that I didn't want it before. I much preferred to be on the side as a spectator and create my own notion of what it is that I want or don't want (31 years old, disability since birth).*

*Some people even asked me: how can you expect of me to introduce you to my friends, because of the barriers, stairs? I cannot deny myself something because of you (49 years old, disability since birth). Maybe I was even a bit more, how should I say it – cold, uninterested... I think height is crucial in this respect. Everything came down to physical appearance first and foremost, and second – I lived in a village, enough said. I can't say that my social circles weren't accepting, but I didn't get any chances at romance. I was mostly at home, I couldn't move around too much, or go out too often... There was once this acquaintance of mine who also had an accident and had hurt his spine. He was a bit older, and we lived in the same village and he asked me: maybe we could try and be together. But I wasn't really interested. We'd write to each other online, phone, keep in touch and so on. Maybe this is wrong but I thought, since he is also in a wheelchair – not that I have anything against men with disability – but somehow I think it's easier living together if one partner doesn't have a disability. Maybe this was all a bit too much for me... how were we gonna make it if we both have disabilities?! (28 years old, disability since 5 months old).*

One woman told us how she waited for a long time for her first boyfriend and when he did appear, she thought he would be the only one for her.

*Before, I hadn't had the experience of touching someone, holding hands, I didn't go to parties where naughty things could happen. So I hadn't had any physical contact with boys. In elementary school, in eighth grade, there were about eight girls in my class and all the rest were boys. At that time I didn't like that I didn't have a boyfriend, I wanted to be like everyone else. When I finished eighth grade, I met an acquaintance and he started coming on to me. And since he was the only one, I accepted him right away. But my mom did tell me that because his father drank a lot, that he drank a lot. She said: Don't, don't. There will be other men who will be better. But no, for me he was the first and at that time I thought he would be the only one. I did like him a lot, but I can't say that I was passionately in love, but I was with him because I had all these complexes and he was the first to ask me out to the movies and I liked that, and I couldn't see anything beyond that (49 years old, disability since birth).*

Some women tried to solve their problems by looking for guys online, so as to avoid situations where they exposed themselves to public judgment.

*I didn't go out too much. It was hard for me to accept that I was in a wheelchair, so I didn't go out. I was friends with men, but nothing more. Then I opened up a chat-room, I started meeting people online. I am just more free online, and different, because I am not thinking about how I look. I met a guy online, and that was my first relationship. It lasted for three months but it was very intense. It was a really beautiful experience and influenced me a great deal. Not just in relation to sexuality, but in every way. I changed a lot after that relationship, as a person and in relation to the attitudes I held previously. At first, I talked to him about music, then about cats, and after a month or so I told him I was in a wheelchair. He said: Well, that's ok. I don't know how but we somehow clicked and got to know each other very well, because we chatted for about eight-nine months and I didn't have to pretend to be something I'm not. We saw each other almost every day. He also had a disability, and I think we understood each other better because of it, because for me and for him both this was a first relationship and we both thought about how our peers had all been through this before but for us it was the first time. On one hand we did understand each other, but on the other hand I think I might have pressured him in some areas, I wanted everything, and at the end I got nothing. The first kiss – it was my first kiss but not his... we didn't have sex, but the rest of it... (31 years old, disability since 15 years of age).*

Some women went out and dated actively, but later in life in relation to their peers.

*I didn't have any problems and I went out and lived a full life like all other girls (52 years old, disability since 8 months old).*

*My sister and I were standing and this guy passes by and stares, he didn't take his eyes off me. And then later – he went straight to me, extended his hand and introduced himself. So we sit and talk. He asks me where I live, and I tell him. Then he asks: Can I come over sometimes and keep you company? So I tell him he can. Then we go our separate ways, and tomorrow he came over on his bicycle and brought a full bag of grapes. And then he had to take me down to my wheelchair from the first floor because it was parked down there underneath the stairs. We sat on the bench outside and talked and... we did it day in day out. Then he asked me if I wanted to go out, go to the movies or someplace like that. Of course I want to, I tell him, but how do I do it? Well, I'll drive you, he says. I got ready and we went out. Everybody's looking at us – oh, how pretty she is, how beautiful she is – I was just eighteen. He took me everywhere, to the movies, then to dinner... (60 years old, disability since 15 years of age).*

*When I was at the health resort I saw this guy whom I really liked and I fell in love. We saw each other every day while we were there. I was a child, only fourteen. We didn't even kiss, it was just a crush, just looking at each other and nothing more... A healthy guy won't give a girl who limps a second look, and even less those who are in a wheelchair – this is what I always thought. And I always thought that I'd never be able to find a boyfriend, a healthy boyfriend, I never dreamed about this, never. But this way of thinking is behind me. Yes, I dated, but I always feared having a healthy boyfriend: I'd remain in the room at home, and he'd go outside and walk on the street and find a pretty, attractive woman and he'll leave me for her, and I'll remain alone suffering... (57 years old, disability since 12 years of age).*

*I always wondered what it was about me that men found attractive. I don't know, but I always had the guy I wanted and who was considered to be cool, and this was my success. Like “wow, I was with*

him!'. But I never wanted to pursue a relationship and deepen the contact, precisely because body related fears... (27 years old, disability since birth).

I had crushes and in the first grade of high school I had my first boyfriend, but that was nothing special, just platonic. I was with that boy for a short time, a month or two, and then later I broke it off because it wasn't really interesting anymore (36 years old, disability since birth).

I don't know why, but I always had younger boyfriends. Never ones who were older than me, which would be logical. I rather always met and made personal contact with younger people. This bothered me, the age difference bothered me (50 years old, disability since 12 years of age).

I always had boyfriends who also had disability. I think this was a bit easier for me, I don't have to explain things to them. They share my experience (27 years old, disability since 18 years of age).

Most women also experienced their first kiss somewhat later than their peers.

I remember my first kiss mostly by how ashamed I felt. I was very ashamed because it happened relatively later in life, I thought it was late. I was fourteen and the guy was thirty. I thought he wasn't normal, I mean, if he's attracted to a fourteen year old kid. I was very ashamed and I told a friend about it and she said: Oh my God, he's too old even for your sister! (26 years old, disability since birth).

It was my seventeenth birthday and I felt like – I'm seventeen and I've never been kissed before! And so even that happened. I didn't like my first French kiss, the boy was too forward and intrusive and I was like: c'mon, move away from me... But it was great because I had that wonderful feeling – I had been kissed! Even though I didn't really physically like it, I was like: M-hm, that is it (24 years old, disability since birth).

I was really surprised, because I looked at him as a friend up to that moment. I could see he was approaching me but I was in shock that I was about to be kissed by someone who's my friend. But it was great! And I had drunk a honey brandy and so I remember that first kiss also by the fact that I felt sick, and I didn't know if it was the brandy or the kiss (27 years old, disability since birth).

Well, I remember kissing my pillow. And then I kissed for real when I was, I think, twenty one. I kissed a boy. I really liked him, but as it turns out he was a really bad kisser (31 years old, disability since 15 years of age).

We weren't really friends, or really close, but I came to that first date as his friend because I absolutely didn't find him attractive, I hadn't felt any sparks with him or anything like that. And that first kiss was just weird, how could something like that happen when there was no spark before it, chemistry or anything. It was nice, but I was very surprised – I didn't think it would be like that. And even though it wasn't what I'd imagined it would be, I still enjoyed it and maybe a bit more than I thought I would (23 years old, disability since birth).

One day this guy comes in an electric wheelchair. He's tall, dark, handsome, beautiful. And I liked him at first sight and I could see he liked me too. Since he was at the eighth pavilion, and I was at the first, I'd go to the eighth just so I could see him. And there he is, sitting and playing cards. I'm watching TV but I'd sneak a peek at him every so often and our eyes would meet and then I'd pull my gaze away. Romantic. One day he notices that I'm getting ready to leave and I tell him: Oh, it's so dark, I don't

*dare go alone. So he says: Grab hold of my wheelchair and I'll escort you back. So he's following me back, and we stop in front of this bench and as we stopped he just kissed me. I was really surprised, I'm shocked, and like – what does this mean? He just nodded his head and left. That feeling when you really like someone, when you fall in love, and when you kiss – that is something really, really special, you fly, you feel warmth all over (57 years old, disability since 12 years of age).*

Women with disability who are homosexual also experienced their first kiss later in life, in comparison to their peers without disability.

*The first time I kissed a woman was when I was seventeen years old. Her father caught us at the moment when I was kissing her, so she had some problems after that... (37 years old, disability since birth).*

Seven women who participated in our study have never engaged in sexual relations. Women comprising this group are mostly in early adulthood, between 19 and 28 years of age, and only one is in later adulthood (49 years old). These women name various reasons for not engaging in sexual relations, some of which are and some of which aren't related to disability: awkwardness because of lack of urination control and diapers, living in a village, lack of interest... All had wanted to engage in sexual relations at some point, thought about it and fantasized about it. Some of them had attempted having sexual relations. Some have an uneasy feeling because they haven't had sexual experiences since they know that even women who are younger than them are sexually active. And all believe that it is not too late and that they will also engage in successful sexual relations.

*When it comes to sexual relations, I didn't have them before nor after the accident. Once I did attempt it, and it was really funny, I mean, because I can't move my legs and everything is so much different. We thought about what we could do and then we came up with this solution – we'll put a diaper underneath me, and if it happens, it's ok. I was thinking about whether I'd bleed, whether this, whether that... It was a disaster for him, stupid, like it would be for any man if he wasn't successful in having sex with a woman. But I didn't want to make him feel bad, so I said: Big deal, we didn't do it now, so what! We'll do it next time (20 years old, disability since 16 years of age).*

*He was very interested, but I, however, didn't want to open up to him and explain some things – to talk about diapers and such, even though he was aware of it. Those diapers were my problem. I found out that you can train yourself when and how to empty your bladder. And I taught myself this. But it was always an issue of what man would find diapers attractive (27 years old, disability since 18 years of age).*

*I still haven't had any such experiences. I had one boyfriend, he was interested, but I wasn't at that time. Later, when I was the one in need, he wasn't there anymore. I am satisfied with my looks as is, I don't think that I'm all that different, the only thing is that I live in this village and that's an environment where, for instance, if I were with someone it would really cause a stir. But I hope all of this will come to its own soon. I think that it's never too late and that someone is waiting for me too, somewhere, and that it will happen one day (28 years old, disability since 5 months old).*

*No matter how passionate both of us were and wanted to do everything we couldn't make it happen and we never did it completely. There were offers of oral sex, but I sort of blocked at that moment, I got really scared and felt, how should I say – I was repulsed by it... The idea of it was great but when it was supposed to happen I was repulsed by it. I thought about this often while I was with him: so, I'd like it if he enjoyed himself, I love him, I want to please him. However, when it came to doing it then this fear would rise up in me, repulsion and in general I'd become blocked. He took it all rather well, in the sense that he never reacted negatively to it... (23 years old, disability since birth).*

*By the time they were eighteen or nineteen my peers had already had some sexual experiences, and me, here I am twenty four and I still haven't. I have a rather bad feeling about this: like they are more successful, more worthy in this regard, when it comes to intimate relations and relations with the opposite sex. Of course, I also wanted to have these experiences and fantasized about it and read about it in magazines, got informed about what to do and how, which pills are the best – I know everything – just that I didn't have anyone to try it out with. Of course, I have this image in my head of how it's supposed to be, when I find the right person, how we'll go to the gynecologist to get advice on protection, how everything will be just perfect, how it will be love, how I won't engage in sex outside of a relationship, if I'm drunk or something like that (24 years old, disability since birth).*

*I have tried to make it happen – those man–woman relations. However, because of my height, my stature, I wasn't really successful. What was open to me as an option was a man who hadn't had experience with someone like me so he wanted to try, have a man's experiment. But I didn't want that. Just so he could see what it was like, because he never had sex with someone like that – someone with disability, someone so short. So his fantasy bloomed – how would it look like and how everything would happen. At first I reacted angrily, I was furious and I told him where he can go... and that's it. That happened about six or seven years ago... I mean, I just realized that I'm not going to stoop so low! I want regular relations, love, everything every woman is entitled to, and not to be someone's experiment. I still hope and believe that it will happen one day. Why not, I am still relatively young, and men and women sometimes even marry in their seventies – I'm not saying they have a very active sex life, but they still have it (49 years old, disability since birth).*

Women with physical disability in Vojvodina who participated in our study have varying experiences regarding their first sexual experience. All have engaged in sexual relations later in life, when compared to their peers without disability.

*I was ready for it, but I was afraid of someone taking advantage of me, I was looking for security. I had sex with him for the first time when I was twenty six. Oh, it is most likely that I was wanting it very much, I know it hurt just a little bit. Maybe I didn't know how to relax, maybe it took me a while longer to start enjoying it, but I wasn't afraid. We used a condom (31 years old, disability since 15 years of age).*

*I didn't have my first sexual experience till a bit later in life, because for me it was tied into finding the right person. So I had my first sexual experience when I was thirty, with someone who was eight years younger than me. I never thought someone could be so gentle (50 years old, disability since 12 years of age).*

*When I met my first husband I didn't want to have sex right away because I was afraid, I didn't know what I was supposed to do. I heard it hurts a little the first time, some say it's nothing but then they tell you that you'll bleed a little. I found it frightening – because if you bleed how could it possibly not hurt, it must hurt horribly! These half-truths just confused me completely. After, when it happened for the first time, it did really hurt in several instances and there were a few drops of blood, but nothing too horrible. After, it was even good, when he caressed me, and kissed me in that way... then I can feel my blood pumping, I can hardly wait for what's coming, but I'm also a bit scared of it. But, whether it was really good or if it could have been better, well, I have nothing to compare it with (49 years old, disability since birth).*

Many found their first sexual experience to be rather enjoyable, and it reflected on their self-perception.

*He accepted me just as I was and what's more he expressed his strong need for me and just generally showed me that he thought I was attractive. This had a very good influence on me, because I finally proved to myself that I can achieve more and better, and that regardless of disability I can have someone who looks good and who is better physically than I am (27 years old, disability since birth). My first sexual experience was funny. It was, of course, something I wanted but it came rather late in comparison to today's standards. I was twenty one years old (31 years old, disability since birth). I didn't have any doubts at all, I was in love and it happened because we both wanted it. Nothing about it was premature. It wasn't just sex for the sake of sex, everything was connected to emotions, wanting it honestly... (45 years old, disability since 10 months old).*

For others, even though the sexual experience was enjoyable they felt fear and disappointment, that is, they were under the influence of alcohol in order not to feel so awkward.

*The experience itself was enjoyable but that's because it was out of love, but I also had this fear, not shame, because I felt absolutely free, but really fear. It wasn't bad, but it wasn't what I expected. I mean, everything was great – I love him, he loves me – but what's the point!? (24 years old, disability since birth).*

*I was horribly afraid! That's why I chose a partner who was much, much older than me... but I felt really awkward (26 years old, disability since birth).*

*When it came to sex I was like – ok, how am I supposed to do this?! However, by that time I had already heard numerous stories: how to do what, where, who. So I felt, not really afraid, but... I can't explain... For instance, I didn't know if I'd feel anything or not. Since my bodily sensations are damaged and I have practical problems when it comes to urination, I was worried whether there'd be an accident or something like that. And, unfortunately, that's what happened – I literally didn't feel a thing. He just kept saying that everything is alright, that there is a problem, but that it's totally normal. I felt uncomfortable because it happened and after that I refrained from having sexual relations (27 years old, disability since 18 years of age).*

*I was drunk when I lost my virginity. Maybe I never would have done it had I not been drunk. I lost my virginity, became pregnant and that was that for me. But, it was ok I guess (37 years old, disability*

since birth).

Many women say that they planned their first sexual experience because they already considered themselves too old not have had sex by that age.

*I decided to find a boyfriend during summer vacation when I was at the seaside. My summer vacations didn't last for ten days, but for two months so I had plenty of time to find a boyfriend. And I found him – a guy from Montenegro who was a soccer player and he had hurt his knee. He was also at that resort for rehabilitation. I thought he was cute, pretty and funny, but a bit dumb. So, I debated with myself whether to pick him or not for my first sexual experience. One night I faked that I was feeling sick, that I feel really weak and nauseous, so that he would come to my room. So that's how that first sexual experience happened and it was very successful – to my great surprise. I thought it would be a disaster, because I lack regular sensation. Meaning, I don't feel if he is inside me, it's just that that type of orgasm is unknown to me even today, but another kind of pleasure – while I'm being kissed, my breasts and some other erogenous zones... He was really experienced – you know, the typical Montenegrin womanizer who knows how to drive a woman mad. He said: Oh, you'll feel something, there's no way you won't! When we went our separate ways we made a deal that we'd meet every year here at the seaside on the date when we first made love... So ok, it's a cheesy agreement, which, of course, never came true (46 years old, disability since 7 years of age).*

*In 1980, or there about – that's when it happened. I was with a married man. We met at the health resort. He approached me, we began hanging out and we fell in love. He was really jealous, I couldn't even look at anyone else. I decided to make love with him because he's married and he wouldn't tell anyone about it, and it would be our secret. And why else – because I didn't want to remain a sort of “old maid” when it came to sex! That's why I wanted to do it. As if, today, someone would know whether I'm experienced or not, but this is what I was concerned with at the time. We agreed that he'd come over and we'd do it. Since I was at the health resort he came over and we went to a motel together. I didn't know what to expect, I didn't know if I had feelings for him or not. And of course, we went to the room and it happened but I didn't feel a thing, my body is blocked and there are no sensations. I pleased him though, well – I felt warmth in the upper part of the body... But while the act itself was taking place I just shuddered, just like when I would get shots to my leg, like when something is pinching me, I have that sense of shuddering and the sex act itself – it's just a sense of shuddering and nothing else. And so that's how I finished that. I was with him just that one time, even though he wanted to do it again in the morning, but I didn't want to, since I knew that I wasn't getting anything out of it (57 years old, disability since 12 years of age).*

Homosexual women also describe their first sexual experience as something they waited on but that came later in life, in comparison with their peers without disability.

*It was during my first year at University, I was still a virgin, and then she appeared. I mean, the first girl I was ever with, since I had never been with a man, so... Somehow it seems that until I had that first experience it was like I didn't know and wasn't aware – that I'm a lesbian. We didn't get to sex quickly,*

*everything went slowly. I wanted to lose my virginity no matter what, because all my friends had lost theirs and I was still a virgin. And when penetration happened for the first time, and I'm talking about hands here, I felt pain, but not much. I didn't bleed, there was a bit of blood but... and then I wondered if I had lost my virginity at all (36 years old, disability since birth).*

One woman described her first sexual experience as rape which indirectly resulted in disability.

*While I was a girl I'd go to other people's houses and work, helped where it was necessary. My grandmother washed laundry for rich people, and I'd carry the water for her since the well was far away. This man called me up to his room, and I went and he raped me. I came home crying and crying... My mother asked me what happened and I told her what he did: look, I'm still bleeding. And my mother told me: You mustn't tell anyone, that is shameful. So I decided to commit suicide and I threw myself in front of a train – the train cut my legs off. Such was my fate (60 years old, disability since 15 years of age).*

### *Gynecological exams and contraception*

Even though one can find a lot of literature analyzing whether women with disability can have children, almost nothing has been written about their means of birth control (Duffy 2009, pg. 113). The research conducted by ...OUT OF CIRCLE – VOJVODINA in 2011, that covered 137 women with disability in Vojvodina, shows that nearly half of them go to the gynecologist only when they notice a certain problem. Women with disability (primarily those with a physical disability) note the following reasons for not going to the gynecologist regularly: lack of architectonic accessibility of hospitals, negative experiences with medical staff and lack of adequate transport and assistance (\*\*\*) 2012a, pg. 29). The Network ...OUT OF CIRCLE – Serbia also shows similar results: women with disability go to visit a doctor only when a disease is already very obvious and they rarely use preventive measures of health protection in comparison to women without disability. Health services and information is still inaccessible (most community health centers and hospitals in Serbia aren't accessible, hydraulic gynecological tables – only 9 out of 152 medical centers have them), while prejudice remains strong among medical staff (\*\*\*)2012b, pg. 27).

Women with physical disability of all ages, heterosexual and homosexual, most often had their first gynecological exams in adulthood (immediately before or after their first sexual experience, as part of systematic exams at University, or when they became pregnant). They are however aware of the importance of regular gynecological exams but in most cases do not visit the gynecologist regularly, rather only when a problem occurs. Only a few women with physical disability visit the gynecologist regularly.

*Well no, I didn't go to the gynecologist. But I think it's important that you go to someone who's been recommended to you, someone who knows what they're doing (27 years old, disability since 18 years of*

age).

*I went and had exams for some sexually transmitted diseases and everything is ok (27 years old, disability since birth).*

*I never went to the gynecologist while I was a virgin. I always thought that he could figure out if I've been sleeping with a man or a woman, which is crazy. The first time I went for an exam was when I had a problem, and it turned out that I have an ovarian cyst (36 years old, disability since birth).*

*The first time I went to a gynecologist was when I became pregnant with my first child. Later, I went when I was pregnant with my second, and because it was a high-risk pregnancy I spent several months maintaining my pregnancy. After my second child was born I only went to the gynecologist nine years later because ...OUT OF CIRCLE bought a gynecological table for women with disability so I went for a check up (37 years old, disability since birth).*

*Usually several years pass from one check up and ultrasound to the next. The last time I went was twelve years ago (45 years old, disability since 10 months old).*

*When I became pregnant, at the point I noticed that I was not getting my period, that's the first time I went to a gynecologist. Before that I didn't have any problems and there was no need to go. Because of the pregnancy I went for the first time, and I went for check ups for a time even after giving birth, and then later I'd go just to get pills. After that, when I divorced my second husband I had stopped being on the pill and I didn't go for check ups for a long time. I went after ten years, for prevention. Now I go every two years (49 years old, disability since birth).*

*I went to the gynecologist for the first time a week after my first sexual experience. I try to go at least twice a year, as is advisable for regular check ups, and I don't have this feeling of shame. If I feel the need to go more often then I go more often. And if something is not clear to me I don't feel ashamed to go and ask – regarding contraception, for men and women both. I prefer to protect myself from unwanted pregnancy, disease and anything else (31 years old, disability since birth),*

*I go to the gynecologist regularly. I think that women should go for check ups, especially after the age of forty or fifty. I regularly go for ultrasounds of my ovaries and breasts, colposcopy and everything (57 years old, disability since 12 years of age).*

Women with disability name the following reasons for not going to gynecological exams: lack of architectonic accessibility, feeling awkward and ashamed because they wear diapers and not being able to undress themselves, inadequate approach of medical staff and the fact that they focus on the disability even though it has nothing to do with why they are there.

*The women's clinic has many steps and this is a problem, there is also no ramp, the ultrasound is on the second floor and there is no elevator. So, my husband and kids, at least my daughter, always have to come along with me, so that someone can carry me and the wheelchair up to the second floor. My husband carries me up and my daughter takes the wheelchair – that's how we manage (57 years old, disability since 12 years of age).*

*I was there once and I felt a bit uncomfortable. There were these stairs and I didn't know how I was going to go up them? Then they dragged me up... then when you have to take your clothes off... I have to wear diapers, and I felt ashamed because everyone was watching (52 years old, disability since 24*

years of age).

*A few years back I had this very problematic exam because the table was all wrong. A woman without disability can go by herself, relax, lay down or whatever, while for me it's excruciating that someone else has to take my clothes off and place me in the right position. And now the table has been bought but I still have troubles reaching the second floor from the ground floor (65 years old, disability since 6 years of age).*

*I don't go for check ups regularly because the medical staff is not educated and I don't want to be looked at as if I were the seventh world wonder. When I was to give birth to my first child I didn't have any unpleasant experiences, they were nice but still they were like – oh, poor her. That is disgusting, that pity! And I don't want to go because the doctor is a man, I don't want that! I requested a female doctor... I feel more at ease if it's a female doctor, she'll understand me better. I had this lump and I went to the gynecologist and he tells me: It's because of your jeans! Is he normal?! The lump was the size of a marble, full of puss, and he tells me: That's because you wear jeans, wear a skirt! That's sexist. Now, maybe I was just unlucky and got such a doctor... but that's a different issue (37 years old, disability since birth).*

*Gynecologist make me laugh a lot, because I can expect any sort of question from a common man, and I don't consider any of those questions stupid, but when a woman gynecologist looks at me and says: traffic accident? I tell her: cerebral palsy. And she puts me on the table four times and spreads my legs and intrudes on my intimacy and then she asks: Can you spread your legs? And I tell her: Depends who's asking... And she's like: You are rude! (31 years old, disability since birth)*

*We went to the gynecologist, into the room for check ups, my mother's standing behind my wheelchair, the doctor's leaning on his table, and the nurse is sitting and scribbling something. I see she's finished her scribbling so I say: well alright now, will you come and lift me to the table? The doctor says: Well, you don't have to keep holding on to that wheelchair, its not going to go anywhere. I become mad and I say: No, it won't run away, but it's also not going to lift me up to the table – you are here, the nurse is here, and you can just raise me up to the table. Only then did he get up and lift me up to the table (49 years old, disability since birth).*

During a systematic gynecological exams, one woman with physical disabilities was not even checked over during her exam even though her peers without disability were given regular exams.

*I felt a bit uncomfortable because this was a systematic exam and the first quest the gynecologist asked was: Do you get your period? And I said: I do. And then it was like: Goodbye, have a nice day (25 years old, disability since birth).*

Most women with physical disability never used contraception.

*I never used anything (57 years old, disability since 12 years of age).*

*I never used contraception in my life. There was never a need for it, my menstrual cycle was regular, I always knew to the day when my fertile days were (49 years old, disability since birth).*

*No, I never used contraception. We didn't use condoms, rather I paid attention to when my fertile days*

were because I have a really regular monthly cycle and I consulted with a gynecologist and he made a calendar for me, explained how to count the days, and I haven't been mistaken once (50 years old, disability since 12 years of age).

Among women with disability who do use some form of protection the most common means are condoms, less frequently the pill or spiral.

*I have to admit I don't use anything, but I am very careful. At first I used condoms, when I engaged in hook ups of some sort, but now that I am in a long and committed relationship, now I don't use them anymore (27 years old, disability since birth).*

*I took contraceptive pills (46 years old, disability since 7 years of age).*

*Well, condoms (56 years old, disability since 33 years of age).*

*For ten years I used the spiral... and I took the pill (60 years old, disability since 15 years of age).*

Most women usually started using contraception during marriage, and only after giving birth to their first child.

*In youth I didn't use anything and then, when my son was born, the doctor who was in charge of my pregnancy suggested I go on the pill for a while because I had a C-Section and I was told that I could have one more but that it would be dangerous to have three C-Sections. Then I thought about whether I even wanted to have a second child and I talked to my husband whether to have another or not, and I just kept delaying it when I saw that he wouldn't quit drinking and I decided not to have a second child, regardless of whether we would remain together or not. I was on the pill, while still married and afterwards because I didn't want to have an accidental pregnancy with someone whom I wasn't planning on staying with (49 years old, disability since birth).*

Women with physical disability who are homosexual usually don't use protection even though they have information about it, but there's also a lot of disinformation, about the various means of protection.

*There are ways of having safe sex. For instance, for oral sex you can use latex foil. For me it's like getting ready for surgery or something, so I haven't used it. And oral sex is nothing special for me so I don't know. When it comes to what others do, I had this one partner who insisted I use latex gloves – that constitutes protection for lesbians. And I, since I was the active one, put on the gloves... But when it comes to protection I just basically take care of myself... I bathe before and after sex... I didn't take any precautions for oral sex when I was in a relationship, but I insisted on learning about her sexual past, because today every other woman has candidiasis, it's impossible to avoid... Now, when we talk about lesbian sex – it's mostly done with hands. I didn't use gloves every time, but I was cautious, for instance, I don't bite my fingernails, I don't have cuts, I wash my hands before and after, and so I take care as much as I can (36 years old, disability since birth).*

*Yogurt is good protection for oral sex. You just spread some yogurt on your partner, because yogurt contains bacteria which is ok (37 years old, disability since birth).*

## *Masturbation*

“A necessary step toward developing one’s own sexuality is intimate knowledge of one’s body – what it likes, what it doesn't like, which parts of the body are sensitive to touch... It's important for women to be aware that they have to learn about what feels good to their bodies, and what doesn't. Also, once we can understand our body and what stimulation it is most responsive to we are better equipped to explain to our partner how to better satisfy us in bed. Basically, if we ourselves don't know what's the easiest way to reach orgasms, we can't expect our partners to know either (Duffy, 2009, pg. 137 – 138).

Women with physical disability who participated in our research talked about masturbation as a regular activity leading one to better know their body and reach certain physical pleasure, especially when they don't have a partner. Most women with physical disability from Vojvodina see masturbation as a means of partner replacement, while not one American woman with disability stated that they see masturbation as a partner replacement, but rather as an additional dimension of sexuality (Duffy 2009, pg. 138).

*That's a good thing, because in that way you can explore your sensations. That's how I explored my sensations... (27 years old, disability since 18 years of age).*

*I was already masturbating in puberty, you know – hormones and everything, that's the time you're discovering your own body... I saw it as something normal. Now, there are periods when you have a partner and periods when you don't... Sometimes I'd be alone for two-three years, I can't say I masturbated all the time. Sometimes maybe I didn't do it for months, but it is still a good way to deal with that situation. A woman can get to know herself and make things easier for herself (36 years old, disability since birth).*

*Oh, masturbation isn't unknown to me! I had lots of that in my life. Well how do you think I managed all those periods of not having sex with a partner? (37 years old, disability since birth).*

*If there is no other way – like there isn't in my case – then... It's not like I think it's healthy, it's different when you have a partner, but just to calm yourself down, your nature, hormones, but this works when there's nothing else... Otherwise you'll have problems: headaches, irritability, nervousness... So if you can, calm yourself down. That's what it is – a necessary evil, there, that's how I'll define masturbation.*

*If you have nothing else, than do it for yourself, for your own peace – physical and psychological.*

*Because it's the same for everybody, but it's a taboo among women. It's considered to be shameful, and it shouldn't be. Even when a woman has a partner, the partner may work hard and be tired, and the woman is in need at that very moment, so what then? If he's not capable or willing at that moment, then it makes sense to pleasure herself, right? And I believe this is the case with men as well (49 years old, disability since birth).*

Some women with physical disability experience a certain degree of shame related to masturbation, but they also talk about being unhappy because masturbation makes them more aware of the reality where they don't have a sex partner.

*I started masturbating pretty early on and for a while I did it quiet frequently. It was ok up to a point and it wasn't a problem, I wasn't really ashamed of it. Of course, I never talked about it with anyone. Then at one point I started feeling that it's very bad, that it's horrible, that it's a sin, how I would love to have something real, and it seemed that masturbation just pushed me further into depression. For a short time it is a source of enjoyment and then it starts creating some sort of emotional vacuum. But I got to know myself better, what I like, what I don't like (23 years old, disability since birth).*

Many women with disability who participated in our research about masturbation only thought about it, and only rarely, if ever, masturbated.

*I thought about it a lot but masturbation was completely forbidden to me, something that I personally didn't know if I'm allowed to do, didn't know if it's good or bad... I didn't experiment much with my body, touching and such... I had a wish to experiment with a vibrator, but that's something that just remained an idea... (46 years old, disability since 7 years of age).*

*I have never done that! I have honestly never done it! (50 years old, disability since 12 years of age). Well this is a bit difficult, because usually when I'm alone I'm fully dressed, so... But, I don't know, somehow I haven't felt a need for touching myself or anything like that (20 years old, disability since 16 years of age).*

### *Partner relationship and marriage*

A little less than half (48.89%) of participants of our study are in a committed relationship. 40.91% of them are married, 36.36% have partners (partners live apart), and 22.73% are in a common law marriage (partners living together).

Women with physical disability married men whom they previously had a long relationship with, or they married their first suitor. Some have had several marriages.

*I dated for eleven years, and now I've been married for seven years (45 years old, disability since 10 months old).*

*I married when the first opportunity to do so arose. I was married for eleven months, then we had the accident – he died at the scene, and I remained... I remarried after two years (60 years old, disability since 19 years of age).*

*I rushed into my first marriage. And after I divorced my first husband, I met my second husband quickly. We worked in the same factory. He was also divorced. There was a party at the factory and he approached me then. Out of all the women at the factory, some divorced and some young and single, he chose me. This raised my moral. We were married for six years. Now I am with my third husband (54 years old, disability since 1 year old).*

When discussing marriage and family, women talk about how their husband proposed, about the wedding, and how others reacted to their wedding.

*My folks went to their company' office for the New Year's party, so I was home alone, sitting on the couch and crying. And then the door opens and it's my sweetheart! Dressed nicely in a new suit and tie, and he always went around dressed as a mess. He says: Where are your parents? I tell him: They are at the company's New Year's party. He says: I've come to tell you that I don't want to come here anymore. I ask him: Who's been asking you to come so far? Me? I know I didn't. He sits next to me and says: What do you think about us getting married after New Year? - What?! He asks me then: Would you marry me? And I just answered immediately: Yep! I'll do it right away! And he stayed there with me till my folks returned – so that he could tell them as well. My mom said: Where she goes, so will you... He didn't kiss me or anything, everything was just talk. And when my mom said that he could move in, he went to his apartment, got his things and moved in (60 years old, disability since 15 years of age).*

*When I got married it was a real classic wedding, everything was done by the book – the dress, everything. Believe me, two thousand people came to see my wedding because it was like: Oh my, who would have thought – a woman like her is marrying a healthy man, a good man! It was crazy (52 years old, disability since 3 years of age).*

They also talk about their dedication to their husband and family, but also about the support they've had and still have from their husbands.

*Something has to happen for two people to get together, there must be attraction. For instance, I have a husband and he wasn't attracted to my disability, but he was attracted by my – how should I say – strength, the fact that I'm a fighter. He knew exactly what my situation was... He met me when I was in a wheelchair, he didn't see me standing... While I was married to him I had a lot of medical problems. Had he minded, he would have left... Which I would have maybe understood. But he stayed with me, meaning that he didn't see me just as a woman with disability (45 years old, disability since 6 years of age).*

*I married when I was eighteen, and I've not been able to use my legs since I was fifteen. I married being the way I am now, while my husband is healthy. Me, my husband, two plastic bags, my suit and his suit and – an apartment. We slept on those plastic bags for a month. He worked, I didn't. He'd come home, spread his legs, I'd lean on him between his legs, and that's how we slept. We literally started from nothing. Then my husband got an apartment from his company on my behalf and because we got a child. And so we moved our asses and our child in a trailer to the new apartment. We came there, the apartment had running water, there was a bathroom... I did my best so he wouldn't notice my disability – I could do anything: cook, wash, iron, clean, paint the walls and the furniture. I would go around on my hands, not in the wheelchair – the wheelchair would remain outside and I'd be moving around on my hands. I'd go up and down. We eventually had people renting a room, and I went to competitions – I went everywhere. There wasn't a thing someone could do that I also couldn't do... It's been fifty years since I got married and I can say that I have a life aside from my husband and children. Now I can say*

*that he loves me, takes care of me, tends to me, takes me everywhere, approves of me, as do my children – a daughter and a son (60 years old, disability since 15 years of age).*

*A woman is frail, weak, cannot help a man, to carry him somewhere for instance. My husband can carry me. When I go to the doctor's, and there are stairs he raises me up easily – takes me up the stairs, and it isn't a problem. It's different for a man to be in a wheelchair and for a woman to be in a wheelchair (53 years old, disability since 33 years of age).*

On the other hand, some women talk about becoming tired of the relationship after several years of marriage.

*Now after fifteen years of marriage, we're together only on paper. He sleeps in one room, I sleep in the other. I cook, wash, iron, he goes to work, eats and goes to his room. That's how we live (52 years old, disability since 24 years of age).*

Women who are in common law marriages or in stable relationships, maintain long-term quality relationships with their partners.

*We've just celebrated five years together (20 years old, disability since 16 years of age).*

*I'm satisfied and happy, I'm in a relationship and it's great. He's good, a serious man, honest, gentle, everything, everything, and I like that (41 years old, disability since 28 years of age).*

*He didn't have any doubts, he saw me as healthy both physically and psychologically, even though I wasn't physically. Like everything is normal. I don't mind anything, he helps me a lot, and gives me full support (40 years old, disability since 6 years of age).*

Women with physical disability talk about sex in committed relationships, marriage and common law marriage, exposing good experiences but also various difficulties and stresses regarding sex.

*For me, it was just something that I owed my husband. I married when I was eighteen and at the time I thought that's just the way things have to be, that that's the way things are done, and that's how it was. And now, it's been two years since my husband's operation and we don't even think about it at all. We hold hands and we have sex with our hands (60 years old, disability since 15 years of age).*

*I have complete sensation, meaning that everything is normal in my case when it comes to sex – the same as for someone who doesn't have a disability. I can feel everything so everything is fine and normal (53 years old, disability since 33 years of age).*

*Well, now that I'm fifty I think this relationship has become less important. I always considered myself to be just about healthy and I had regular sexual relations and orgasms. Meaning, I have also experienced that physical aspect in a normal manner, that's what I think. I mean, there is also that physical part, but it isn't so important, now I value a good movie or dinner more... (54 years old, disability since 1 year old).*

*My husband and I had problems regarding this issue. He wants sex, I don't. I turn to face the wall and he'd pull me by my hair, when I pull back really strongly he lets go and I hit my head in the wall. I*

*didn't want to do it, my mother told me I'd become pregnant – so there was no way I was doing it! He finally managed to succeed. For three nights he'd go out drinking, come home and kneel at the side of the bed and say: I want her, I love her, I want to live with her, and she doesn't love me. First night, second night, third night and then he couldn't do it anymore... Then he started massaging me, and when he put his hands across my throat something came alive in my body... He kissed me, I kissed him, I even kissed him on his chest... Oh, and then I straddled him and rode him. I really liked screwing. I even had sex with my husband on the kitchen table (60 years old, disability since 15 years of age).*

“Open and honest communication is the key to good sex for everyone, but for persons with disability, who have to overcome additional difficulties, it is a necessity” (Duffy 2009, pg. 105).

*The injury I have is tightly connected to sex and you just have to work on creating a situation where he becomes aware of that injury, just so he doesn't hurt you (34 years old, disability since 23 years of age).*

*Actually, he should express it in a different manner. He can't do it physically because that physical aspect of the act isn't something I miss. My sensations are partially damaged. I have to explain to him what I feel depending on the situation, what I don't feel, what hurts and what doesn't... I do have some sensation, but I am one hundred percent sure that I'm not feeling the full specter of the sensation, as it should be, but – how should I say this – I can still enjoy it in some way... I am aware that I am maybe not able to satisfy him as well as would someone who's healthy, because I don't have sensation and because I lack experience. I have to explain what suits me and what doesn't, but then again, if he's pleasuring me, I don't know how to reciprocate. When he asks me: is it good for you, or isn't it? What's good? I have no idea what to say when I can't feel it. Something yes, something no (27 years old, disability since 18 years of age).*

More than half of the women with physical disability in Vojvodina who participated in our study are not in a relationship (51.11%).

Some of them talk about how important it is for a woman to be *healthy* in order to have a committed relationship or marriage, and about the difficulties in establishing a long-term relationship due to issues pertaining to accepting their body. In this aspect it is evident that the “notion of disability covers ideological categories such as: those who are sick, who are deformed, crazy, ugly, old, crippled, hurt, maniacal, abnormal or mentally damaged – and this violates human rights and devalues bodies which are not in accordance with cultural standards. The system of disability has the function of maintaining and justifying privileges such as: pretty, healthy, normal, handsome, competent, intelligent – which secure cultural capital for those who poses them” (Garland-Thomson 2004, pg. 77). The stated opinions are widely common among persons without disability and deeply internalized among persons with disability.

*Men always expect that women should take care of them, nurture them. That is intrinsic in society. For a woman it is important that she be healthy and strong (55 years old, disability since 30 years of age).*

*I remember when I had this boyfriend, he was healthy. He came to visit his father. He was cute – blond, thin and short. He would always sit alone on a park bench, and looked lonely. My friend and I approached him and wanted to keep him company. I think I won him over with my words, because I talked freely. So love blossomed and we started dating. Out from the start I told him: While you're here we can date and love each other, but when I leave and you leave it's over. Maybe I was wrong, I don't know. He said he wanted to live with me, and I told him: You can't get anything from me, you have to get married, have a family, you need someone healthy, someone who can move around. And so it ended. I kept thinking that if I marry a healthy man I'll remain at home in the room, and he'll go out into the street for a walk, run into a good looking, attractive young woman, he'll turn to look at her, and he'll end up being with her. And when I find out, what then? Suffering, torture, crying. And I didn't want that (57 years old, disability since 12 years of age).*

*When I'd start a relationship with someone, and when it would come to the part that I'm supposed to undress in front of him for the first time, I'd always have some doubts: how will he react when he sees my leg, how thin it is, that it's all in scars from the operation, on my back also I have a big scar, scars all over. But I don't think they minded, I was the one who minded. I didn't even notice that they looked at it weird. When I was to take my clothes off and my undershirt I just wouldn't do it. Then he'd ask: why won't you do it? So I'd say: I don't want to, I'm cold. I needed time to relax and undress. I've had relationships where I'd only seen the guy a couple of times, and when it came to having sex I'd just tell him: I'm not taking my top off. If he would persist, then I wouldn't see him anymore, but I wouldn't say it's because of that reason, rather that I didn't like him anymore or I'd come up with some other reason (49 years old, disability since birth).*

Some women maintain online relationships.

*I have this guy on Facebook and we write to each other and talk on the phone. Of course, on Facebook he talks about having sex with me – from start to finish. He writes how he would come over to my place, come into my room, we kiss, move to the bed, we make love, just like real life. And I reply the same to him. As soon as I tell him I've taken my shirt and brassier off, he's already excited, but I'm still not feeling anything, no excitement, no warmth – nothing. I tell him lies: I'm feeling hot, I have to open the window, I have to take my clothes off. I lie to him a lot, and he's really honest. Actually, we write to each other about a whole lot of things, and at the end it comes to sex, then good night and sweet dreams. And I'm happy and content, and we're in like a relationship (57 years old, disability since 12 years of age).*

Some women have broken up their long-term relationships and are now living alone, or have divorced and are living with their kids.

*I think it's great to come to this age, somewhere after fifty, when a woman knows what she wants, and regardless of her disability can say: this guy is no good for me. I think that means you're becoming mature and it makes a woman – a woman... It wasn't until I was much older that I experienced a great love with a healthy man, who unfortunately died. But I think this experience really strengthened me...*

*and now I can freely say that love is reeeeeeally beautiful (65 years old, disability since 6 years of age). I dated for three years and was married for twenty three years. While it lasted I really did receive endless love from him. It was great while it lasted and I remember that which was beautiful, as I remember everything that was beautiful in life. The divorce wasn't my choice, it was a sort of betrayal, which I took rather badly. Even today, four years later, I still prepare coffee for two people, and then I cry. Oh well, even women without disability get divorced, and go through scandals, and are left, and cheated on, but also loved (48 years old, disability since 6 months old).*

*I divorced because I realized that just because I'm a person with a disability does not mean I have to tolerate someone who's disrespectful of me. For instance, I didn't have any problems until my daughter was born and he was just plain jealous of her. It's normal when you give birth to a child and the child is little that you dedicate more time and attention to it. Knowing how men can experience this period, I tried to teach and include my husband into everything, but that wasn't enough... Since I've divorced I've heard people say: Can you imagine, she dared to leave him! I divorced when I was twenty five or six. My mother says: You're a young woman, you should find yourself a partner, don't go interfering in anyone's marriage, blah blah blah, but find yourself a partner. Just then I did become aware that I do miss having a partner. That I miss having someone for a life that has enough sex... (52 years old, disability since 3 years of age).*

*I divorced when my daughter was a year and a half old, after seven years of marriage. We got caught up in that seventh year, which everyone says is critical. Nothing was any good... Even though I divorced, I'm still good with my ex husband, and we're on good terms: we take care of our daughter together. My divorce made the rumor mills: She has a disability, she could barely find that one husband, and now she dares to divorce (45 years old, disability since 10 months old).*

Younger women with physical disability talk about their committed relationships and difficulties they faced.

*That relationship lasted for about a year and a half... even though we had some breakups in between, with periods of undefined relations, and then in time it became obvious that it was something much more, but it was never defined in words. I immediately wanted the whole world to know, but he wasn't ok with that... I introduced him to my family right away, after a month a introduced him as my boyfriend, while he was till hiding being with me at the time. Saying I was his friend, I'm a hook up or whatever, and so it went on. We were a hook up for quite some time, even when it wasn't a hook up any more and when we knew it was more serious (23 years old, disability since birth).*

One woman talked about the relationships she has had, gave her reasons for not being in a relationship now, that is, she explained why she opted against marriage, and told us about the advantages and disadvantages of being in a relationship with a man with disability compared to a relationship with a man without disability.

*I fall in love easily and I can't be with someone unless I'm in love with him. There were many men whom I really loved, but I never thought about marriage. There was this one guy in a wheelchair who*

*fancied me but initially I rejected him. Eventually, though, we started going out and there was something interesting and beautiful about it, but he bored me fast. And what was the problem? We would be together non-stop and he suffocated me, he was always next to me, so I couldn't go out for a stroll, or be alone. I left him and he cried and suffered because of me. Another guy showed up, a healthy guy, he was divorced and had a son. He adored women in wheelchairs. He started writing to me. And one day he calls me up and says: I'm coming over to see you and meet you. I panic. He came to the door, knocked – he's large, tall, handsome, a beautiful man. He started kissing me right away, and I said: No, stop! You can't do it like that. I was with him for a month, he would visit me almost every day, worshiped me. I explained everything to him: what I can do, what I can't, what I use, I told him everything so he understands. He wasn't bothered by any of it, he liked me a lot and I really enjoyed myself, but he had to go back and I advised him and told him I don't want to get married: Find yourself a girlfriend, a woman, get married, make a family, that's the way it must be. ...A guy in a wheelchair can give you love, gentleness, caressing, kissing, dating. A guy who can walk can help you out a lot, push the wheelchair, he can sleep with you, have sex, everything. While those who are in a wheelchair can't. Then again, I don't know... the guy in the wheelchair also gave me a lot of love, just as the one who could walk, so I don't see much difference there now (57 years old, disability since 12 years of age).*

#### *Pregnancy, childbirth and raising children*

Most women who participated in the study don't have children (27 = 60%), some have two (12 = 26.67%) and some one child (6 = 13.33%). Women with acquired disability have more support to become mothers than those with congenital disability or disability acquired early in life. Among those who are mothers there are more with acquired disability, while no participants who acquired disability early in life are mothers.

*I don't want to and I've had my tubes tied (25 years old, disability since birth).*

*As a teenager I was told and convinced that I'll never be able to have children and I made my peace with that (27 years old, disability since birth).*

*It all depends on the level of disability. I think having a child is totally ok, why not? Or maybe adopting, or becoming a, what do you call it? - a foster parent. I think it's stupid when they say an adopted child isn't like your own! It's a small child, it loves you, if your brother's or sister's child can love you, so can this child (28 years old, disability since 5 months old).*

*I spent a lot of time in therapy, and when therapy stopped and life reached a level of normalcy, that's when I started thinking that it might be too late to take that step. It's always better if you become a mother at twenty five, or thirty (49 years old, disability since 10 years of age).*

*I've never wanted kids, actually, I've never wanted to get married. I feared that he would leave me. I feared this because I've had a hard life, I've suffered, I lost my mother, my father was a drunk, he beat my mother and a lot of other things happened. So there was that fear (57 years old, disability since 12 years of age).*

*I wanted to. However, they found that tumor on my uterus and, thank God, it was operated on time so it wouldn't spread, but now I can't have kids (40 years old, disability since 6 years of age).*

Many women with acquired or congenital physical disability have had children and have positive experiences in relation to pregnancy and giving birth.

*I gave birth at thirty five. When I gave birth I said: If I had known it was this easy I would have done it when I was thirty (60 years old, disability since 20 years of age).*

*I wanted a child even before marriage. I talked to my mom and said: If I don't find a suitable partner in life, I'll have a child out of wedlock. At that time that was considered scandalous, but I was prepared to do it. Later, when I started thinking about marriage, I went to the hospital at Banjica and told my doctor that I plan on having a child. He tells me: You know what, be prepared to be in bed for nine months. Many women, healthy and those with disability both, have to be in bed and there's no problem with that. I had an exceptionally good pregnancy, the sort you wish all women would have – I didn't experience any nausea, or have any problems. Ten days before my due date I was climbing the sofa to hang the curtains. By mistake they performed a C-Section, it wasn't necessary though (52 years old, disability since 3 years of age).*

*After I was married for one year I got pregnant. I went to the doctor's and he told me I'm a month and a half pregnant – I felt like kissing him out of sheer joy! How happy I was – I'll be a mother, I'll have a child! When I went to the hospital, I gave birth as no one else did, and everyone was saying: Look at this woman with no legs, she didn't make a sound while giving birth. The newspapers reported on it too, in Ekspres Politika there was an article: Woman without both legs becomes a mother. The mailman came over and delivered packages, little dresses, blankets, little pants, everything, and the check! (60 years old, disability since 15 years of age).*

Some younger women, who haven't had children yet, want to become mothers in the future.

*I don't want to have kids right now, but of course I want it in the future. I think that's normal (20 years old, disability since 16 years of age).*

When debating whether to have children, women with physical disability consider three issues: is the disability hereditary, will they be able to carry full term, and will they be able to take care of the child? Most troubles arise due to the attitude that women will not be able to take adequate care of the child because of the disability, and tend to it properly.

*First I think about whether I'll be able to carry full term. Till recently I had this fear because I know that I want to become pregnant one day, but I wasn't sure whether my body could manage it or if I'll come away from pregnancy even worse off physically. Since I have really narrow hips, and we all know what happens during pregnancy and childbirth, the body prepares for its natural state in pregnancy: the hips widen. On the other hand, I did talk about it with my boyfriend and he's like: I'm here, we'll do it all together. He's very optimistic: You can do anything, you have convinced me of that, we'll handle*

*it... But I'm still somewhat blocked regarding this issue, so to say (24 years old, disability since birth). I've had some exams done because I have some questions regarding my disability – whether it's hereditary? I don't want to have kids just yet, but I just wanted now to prepare for the future – will my kids be physically and psychologically healthy? That's what interests me (27 years old, disability since birth).*

*I was more interested in whether I could get a spasm, because I've had it happen and take hold of my whole spine and legs, and I was wondering whether this can effect my ability to carry full term, and on the fetus itself – would it damage the fetus? They say it won't (27 years old, disability since 18 years of age).*

*My husband and I talked about it – if by chance I'm not able to have children, that we'll adopt, and if I can, then I will have children. I knew it would be by C-Section, that I can't do it the natural way, but that's not that big of a deal these days. I mean, first I inquired with the doctor if it's contagious, since I knew it wasn't hereditary, and it is actually viral. But I asked just the same and was told that it wasn't. And while I was pregnant I worried about something happening and the child not being healthy or who knows what, but, thank God, everything was fine (54 years old, disability since 1 year old).*

There is no evidence supporting the belief that the quality of parents is directly tied to the degree of disability, or that parents with disabilities when compared to parents without disability are less competent (Frohman et al, 2013). However, many women with physical disability think they wouldn't be good mothers precisely because of their disability, and that because of physical barriers they cannot satisfy social criteria of good motherhood.

*I am not physically independent. I don't think I can take care of myself, let alone a child, because of that physical dependence. I need long-term assistance and I really think I wouldn't be up to the task of being a mother, of fulfilling that role, as I think it should be done (28 years old, disability since birth). There is a difference between wanting a child and being able to raise that child, so I wouldn't want to become pregnant. I wouldn't be a good parent, and that's not something I want to happen. Do I want to have a child? Yes, of course. But if I'm realistic: I couldn't be that selfish and make my wish come true and have my child be denied a thousand other things. It's not just a thing, like – today I want this pencil, and tomorrow I don't and so I'll get rid of it (31 years old, disability since birth).*

*In this state I'd never be a mother. Do any of us think about what will happen when that child grows up and will he/she want to have a mother with disability? I personally would never want a mother who has a disability. I always think of my mother, who always knew where everything was in the house, she cooked and made cookies, strolled and played with us, went to PTA meetings. How would go to a PTA meeting, how could I... ? (55 years old, disability since birth).*

Some participants noted that women who don't want to have children are not supported in that decision by their communities and that women with disability are also expected to fulfill gender role criteria so that they can prove themselves as women. This issue is especially important to us because it not only indicates the status of women with disability but also the fact that women with disability also have to confront gender stereotypes, and therefore are confronted by double discrimination.

*That is, I guess, the most beautiful thing in life, but in our culture, and I mean this generally, there is a lack of support for women who do not want to have children. I said I didn't want to and, simply, the years are passing and I don't think I'll have any. I don't think this is something that makes me unhappy. My doctor told me: You should have an operation, because you should have kids! I was deeply offended by this. I mean, what am I – some sort of baby making machine? This is all culturally induced, it's a general pressure, and then on top of it the issue of disability, so it's like I should be proving to everyone that I am like everyone else (40 years old, disability since 6 years of age).*

*When everyone was saying that I couldn't have children, I thought that I could and God blessed me with one. I didn't care what people said because I desperately wanted that child. My husband supported me and I knew if there was something I couldn't physically do he'd jump in and help out. Of course, I had doubts, I wondered how my disability will influence her while she was growing up. The process of giving birth itself, I knew it would be a C-Section, I knew it would be very complicated and difficult considering my physical constitution. And it was really horrible, I could only do it because of my youth and because I wanted it so much. I really had a wonderful husband, he was an endless source of support, I certainly couldn't have done it without him, and the decision was, of course, mutual. And I'm not sorry, I'd go through those same physical problems again in a second (48 years old, disability since 6 months old).*

By analyzing life stories of women with disability authors (Braci , Ruži i -Novkovi , and Savi 2009, pg. 18) concluded that children have various reactions to their mother's disability. "They mutually accept one another despite frequent temptations which society places on children of women with disability". In their life stories, women with disability note examples when their communities, consciously or unconsciously, decreased their possibilities in life: "...I don't want to go through the same thing all over again – that for every PTA meeting I have to beg someone to carry me up and then someone else to take me down. That was a nightmare". Parents of children without disability don't want their children being friends with children with disability: "she asked that I be removed, since her daughter had to do everything for me" (pg. 23).

Mothers with physical disability who participated in our study have varying attitudes and experiences regarding raising children, but most of them are positive.

*It all depends on the degree of disability, but they invest more effort than other mothers, more care. There are so many mothers without disability who abandon their child after birth... so I think that women with disability try harder, as much as their degree of disability allows them (28 years old, disability since birth).*

*I was prepared to raise the child as a single parent from the moment I learned I was pregnant. With a partner or without one, with a husband or without one. So, I was aware that this was something I could do. And my daughter also accepted everything as being pretty normal. I came to the first PTA meeting and my daughter was beaming with joy, there was no shame in her: See, this is my mom! Meaning, she didn't see my disability as any sort of handicap, as something she should be ashamed of (52 years old,*

*disability since 3 years of age).*

*I divorced and was left alone with my daughter, so I took on a part time job, aside from the pension I have. I always exceeded the limitations placed upon me. I was “mother Ruza” to everyone: What did mother Ruza cook today, what did she bake... Everyone would come over, my door was open as it is today, so I was never burdened by this and there was never a problem regarding my disability, but those kids looked at me rather through the prism of what I could give them and how I behaved, which is most important (48 years old, disability since 6 months old).*

*We lived alone. I would get up early, leave my room, take her from her bed and into my arms, come to the wheelchair and then go outside. I'd hold her in my teeth, I'd go out and hold my child (60 years old, disability since 15 years of age).*

## **Conclusion**

Myths and stereotypes about the sexuality of women with disability still exist in various cultures (Grabois, 2001; Howland et al, 2001; Nosek et al, 2001; Rousso, 2001; Walter et al, 2001; Bartolac, 2004; arevi -Mitanovski and Jankovi , 2007; Laklija et al, 2007; Miljenovi , 2010). The messages patriarchal society, such as ours, sends suggest that a woman is only a woman if she accomplishes the task of being a wife and mother, while simultaneously sending the message that she is sexually unattractive because of her disability, probably even asexual (Ilki and arevi -Mitanovski, 2008), thus rendering women with disability invisible in society.

With this study we wanted to give women with disability a possibility to talk about their sexuality and be actively involved in the research, unlike in previous studies on sexuality and reproductive health and rights which mostly dealt with attitudes other women have regarding women with disability and comparisons of women with and without disability.

The goal of this study was to describe and analyze the experiences of women with physical disability in Vojvodina regarding sexuality: sources of information; physical changes during puberty; menstruation; intimate personal hygiene; going out, dating, first kiss, first sexual experience; gynecological exams and contraception; masturbation; relationships and marriage, pregnancy, giving birth and raising children.

We chose women with physical disability because they often need a walking aide and need assistance for different activities in everyday life. Aside from this, the appearance of that woman's body is different than that of – what is referred to as – *physically healthy people*. Architectonic barriers, school related problems, employment, independent living, these factors all complicate their everyday lives. Because of all these factors their sexuality usually gets neglected as an important part of their identity – sexuality being an important part of any person's identity.

Data has shown most women with disability whom we have talked to were informed about puberty

related physical changes and they knew about menstruation before they got their first period. The information received was often lacking, while sources of information on these matters were most often their mothers and sisters. Myths about women with disability also form the attitudes parents have regarding their children with disability, and they may cause parents to think there is no need to talk about sexual relations and sexuality with their daughters with disability. It's interesting to note that, unlike information about physical changes and menstruation, contraception and sexual relations were not something that was usually discussed within the family, rather women found out about these topics from friends. When it comes to sexual relations and contraception some women knew nothing until engaging in sexual relations. The attitude a family holds may serve to discourage a woman from seeking information elsewhere, leaving her to learn about sexuality and reproductive health only through exchange of information about personal experience with peers. Therefore, it is important to educate families to accept their children with disabilities as sexual beings, especially the daughters, as was also pointed out by some participants in our study. Only one participant stated she consulted with her gynecologist about contraception. It's possible that other participants failed to do this because, as they stated, medical facilities – and therefore medical services as well – are inaccessible to them. When we take into consideration the experiences our participants have had with medical staff – who exhibit a great degree of prejudice against women with disability – we are left asking whether women with disability can actually be certain that medical staff will see them as women and will focus on their reproductive health as an aspect separate from disability.

Inaccessibility of buildings and rooms in medical facilities, as well as the staff's prejudices and lack of knowledge (\*\*\*2012a; \*\*\*2012b) do not only testify to the fact that the system for reproductive health is not accessible to women with disability, but also to the fact that because of the many barriers, women with disability easily give up on caring for their reproductive health. We could argue that women are aware of the necessity of regular check ups, but that they are discouraged from going to check ups due to the many physical and psychosocial barriers. Results of our study pertaining to experiences of women with physical disability with medical staff indicate that the medical model of disability is still dominant in community health centers, hospitals and rehabilitation centers in Vojvodina, and Serbia.

Results on how women with disability view parenting bring to the forefront their worry that they will not make good parents due to disability. They judge their competence as parents in relation to disability, and fail to take into consideration their other characteristics – which is indicative of prejudice which women with disability have about themselves, as well as low self-esteem. Also, participants noted that physical barriers represent a significant obstacle in accomplishing parental roles. Based on other research as well (Ilki and arevi -Mitanovski, 2008; Tarandek, 2008), we may conclude that establishing a community based service, one which would support women in caring for their child, would be a very meaningful improvement for these women to realize their right to be mothers.

When it comes to women with disability, the quality of life is rarely assessed from the aspect of sexuality. The focus is rather on improving the social and material status of persons with disability and

on creating equal opportunity for active community participation. No legal document deals with the issue of realization of sexual rights of women with disability, nor is there any statistical data about women with disability even though the “National Strategy for Improvement of the Status of Women and Advancement of Gender Equality for the Period from 2007 to 2015” (\*\*\*)2007), recognizes that women with disability suffer multiple discrimination. Also, the Serbian Government had adopted the “Strategy for Improvement of the Status of Persons with Disability for the Period from 2007 to 2015” (\*\*\*)2007), and one of the goals of this strategy is to develop and create equal opportunities for women with disability in order to achieve their equal participation in community life. However, at this moment there are no provisions specifying how this goal will be achieved. The medical model of disability, which evidently manifests in medical staff's attitudes, but also among women with physical disability themselves – when it comes to their own attitude about themselves and their needs – all of this only contributes to the women with disability remaining largely invisible in society. The results of our study point to a conclusion that society's stance on this issue is not changing as quickly as was expected and that changes made thus far have only been declarations not supported by acts. In order to improve the social status of women with disability the movement of women with disability, as well as the feminist movement, need to recognize the gender dimension of disability, and from there start to work on changing reproductive and sexual policies so that they recognize women as a heterogeneous group and women with disability, in all their diversity, as part of it.

## Literature

- Bartolac, Andreja (2004). *Seksualni identitet i iskustvo osoba s cerebralnom paralizom*. [Sexual Identity and Experiences of Persons with Cerebral-Palsy]. *Revija sociologije*, Volume XXXVI, No 3-4: 187-206.
- Braci , Milica, Milica Mima Ruži i -Novakovi and Svenka Savi (2009). Introduction: Braci , Milica, Milica Mima Ruži i -Novakovi and Svenka Savi , *Životne pri e žena sa invaliditetom u Vojvodini*, [Life Stories of Women with Disability in Vojvodina], Futura publikacija and Ženske studije i istraživanja: Novi Sad, 5-34.
- arevi -Mitanovski, Lepojka and Aleksandar Jankovi (2007). *Moje pravo je da budem zdrava: žene sa invaliditetom i zdravstvena zaštita - podsetnik o barijerama, pristupu i pravima* [My Right to Be Healthy: Women with Disability and Health Protection – A Reminder on Barriers, Access and Rights] ...IZ KRUGA, Organizacija za zaštitu prava i podršku ženama sa invaliditetom Srbije: Beograd.
- Dafi, Ivona (2009). *Sve je moguće...* [... All Things Are Possible], ...IZ KRUGA - VOJVODINA: Novi Sad.
- Fiduccia Waxman, Barbara (1994). Up Against Eugenics: Disabled Women's Challenge to Receive Reproductive Services. *Sexuality and Disability*, 12 (2): 151-171.
- Fiduccia Waxman, Barbara (2000). Current Issues in Sexuality & the Disability Movement. *Sexuality and Disability*, 18 (3): 167-174.
- Frohman, Carolyn and Stephanie Ortoleva (2013). The Sexual and Reproductive Rights of Women and Girls with Disabilities. Issue paper. International conference on human rights.
- Garland-Thomson, Rosemarie (2004). Integrating Disability, Transforming Feminist Theory, in;

- Gendering Disability, eds. Bonnie G. Smith and Beth Hutchison, Rutgers University Press: New Brunswick, New Jersey and London: 73-103.
- Grabois, Ellen (2001). Guide to Getting Reproductive Health Care Services for Women with Disabilities Under the Americans with Disabilities Act of 1990. *Sexuality and Disability*, 19 (3): 191-207.
- Howland, A. Carol and Diana H. Rintala (2001). Dating Behaviors of Women with Physical Disabilities. *Sexuality and Disability*, 19(1): 41-70.
- Ilki , Olivera and Lepojka arevi -Mitanovski (2008). *Žene sa invaliditetom nevidljive žrtve nasilja - Studije slu ajeva* [Women with Disability Invisible Victims of Violence – Case Studies]. ...IZ KRUGA - organizacija za zaštitu prava i podršku ženama sa invaliditetom Srbije: Beograd.
- Kapamadžija, Aleksandra ur. (2013). *Zdravstveno vaspitanje o reproduktivnom zdravlju* [Health Education on Reproductive Health], Pokrajinski sekretarijat za sport i omladinu Autonomne pokrajine Vojvodine: Novi Sad.
- Laklija, Maja and Urbanc, Kristina (2007). *Doživljaj vlastitog tijela i seksualnost u adolescenata s motori kim ošte enjem* [Experience of One's Own Body and Sexuality of Adolescents with Physical Disability]. *Ljetopis socijalnog rada*, 14 (3): 579-596.
- Miljenovi , Ana (2010). *Zna aj seksualnih tema u socijalnom radu* [Importance of Sex Related Topics in Social Work]. *Ljetopis socijalnog rada*, 17 (1): 27-48.
- Nosek, A. Margaret et al. (2001). National Study of Women with Physical Disabilities: Final Report. *Sexuality and Disability*, 19(1): 5-39.
- Prilleltensky, Ora (2003). A Ramp to Motherhood: The Experiences of Mothers with Physical Disabilities. *Sexuality and Disability*, 21(1): 21-47.
- Rouso, Harilyn (2001). *Strong Proud Sisters: Girls and Young Women with Disabilities*. Barbara Waxman Fiduccia Papers on Women and Girls with Disabilities, Center for Women Policy Studies: Washington DC.
- Shakespeare, Tom (2000). Disabled Sexuality: Toward Right and Recognition. *Sexuality and Disability*, 18(3):159-166.
- Stankovi , Zoran (2010), *Prva menstruacija, De ija i adolescentna ginekologija Srbije, Beograd* [First Menstruation, Gynecology of Children and Adolescents in Serbia, Belgrade]. Taken from: <http://www.dags.org.rs/files/prva-menstruacija.pdf>, Date of access: March 15<sup>th</sup> 2014.
- Tarandek, Tatjana (2008). *Postoji li povezanost izmedju stupnja motori kog poreme aja i kvalitete obiteljskog života kod žena?* [Is There a Connection Between the Degree of Physical Disability and The Quality of Family Life for Women?] *Hrvatska revija za rehabilitacijska istraživanja*, 44(2): 111-118.
- Walter, J. Laurie, Margaret A. Nosek and Karen Langdon (2001). Understanding of Sexuality and Reproductive Health Among Women With and Without Physical Disabilities. *Sexuality and Disability*, 19(3): 167 -176.
- World Health Organization (2006). *Defining Sexual Health: report on technical consultation on sexual health*, 28-31 January 2002, Geneva. Taken from: [http://www.who.int/reproductivehealth/topics/sexual\\_health/sh\\_definitions/en/](http://www.who.int/reproductivehealth/topics/sexual_health/sh_definitions/en/) Date of access: February 19<sup>th</sup> 2014.
- \*\*\* (2007), *Strategija za unapredjenje položaja osoba sa invaliditetom u Republici Srbiji* [Strategy for Improvement of the Status of Persons with Disability in the Republic of Serbia], Službeni glasnik

Republike Srbije, br. 55/05 and 71/05: Beograd.

\*\*\* (2009), *Zakon o potvrđivanju Konvencije o pravima osoba sa invaliditetom* [Law on Confirmation of the Convention on the Rights of Persons with Disability], Službeni glasnik Republike Srbije i Medjunarodni ugovori, br. 42/2009: Beograd.

\*\*\* (2012a). *Istraživa ki izveštaj o kvalitetu života žena sa invaliditetom u Vojvodini* [Research Report on the Quality of Life of Women with Disabilities in Vojvodina]. ...IZ KRUGA - VOJVODINA, organizacija za podršku ženama sa invaliditetom: Novi Sad.

\*\*\* (2012b). *Izveštaj iz senke za CEDAW komitet: Položaj žena sa invaliditetom u Srbiji* [CEDAW Shadow Report: Status of Women with Disability in Serbia]. Mreža ...IZ KRUGA - Srbija, Savez organizacija za zaštitu prava i podršku žena sa invaliditetom: Beograd.

\*\*\*(2008). *Nacionalna strategija za unaredjenje položaja žena i unapredjivanje ravnopravnosti polova (2009-2015)* [National Strategy for Improvement of the Status of Women and Improvement of Gender Equality (2009-2015)], Ministarstvo rada i socijalne politike, Sektor za rodnu ravnopravnost: Beograd.

## AFTERWORD

### *FROM A SEX POSITIVE PERSPECTIVE*

Marijana anak

*To define freedom is the same as to define sexual health. (Wilhelm Reich)*

Being sex positive means to... a) advocate sexual hedonism; b) latently or openly promote pornography; c) call for sexual revolution in a (dis)organized orgiastic parade. Or none of the above. In order to reach (*sex*)positive answers, first it is important to question our own criteria based on which we declare forms of sexual expression (or non-expression) to be *right* or *wrong*. We also need to ask ourselves how much are our criteria and our *indisputable* truths about sex really *ours*. We know that sex is wrong if it isn't safe and consensual. If it's a hassle it's also wrong. Sex positive thought values sexuality as a source of ultimate pleasure and as a cornerstone of overall health. A sex positive person's consciousness questions sexual norms and patterns of sexual behavior, but not for the sake of a new anarcho-porn hedonistic rebellion, but rather out of a feeling of responsibility for one's self and personal development. Sex positive movements do not call for revolution, but to a meeting with the self, to intimate self-exploratory discussion about sexual values. Some of the issues which may be reflected on are (keep in mind that these should not be valued in terms of how right they are, but rather how open a person is to the answers):

*What emotions and attitudes guide me when it comes to sex? Do I see sexuality as part of my identity? To what degree do the sexual activities I partake in contribute to the quality of my life and health? I react to sexual topics with a certain degree of uneasiness and by withdrawing... or am I ready to speak about it clearly and openly? Am I ashamed of my sexual fantasies (even before myself)? Am I able to express my own sexual values and not judge those of others? I am disturbed by differences in sexual*

*identities? If yes – do I know why? Have I ever engaged in sexual practices because I felt I was obligated to, or was driven by compulsion? Can I promise myself that it will never happen again?*

Searching for all those unspoken answers and opening up a series of other questions about our sexual, authentically female beings – this is the first step in creating a sex positive environment. Instead of being based on clearly specified definitions and a rigid concepts, the sex positive movement is actually based on their deconstruction, and sees sexuality as a pure, powerful creative and life force, the denial of which is equal to fearing life. The sex positive movement sprung up as a reaction to the dominant understanding of sexuality which Western culture constantly interprets as being *potentially dangerous, instinctive-animistic and destructive* force, and justifies taking control of it as a conscious attempt to protect and direct civilizational development. Viewed from a wider perspective, revival and undisturbed development of sexual potential of human beings (complete acceptance of the *homo eroticus* component) really does lead to change in global social structures. But not in a destructive sense. It only means that instead of living in an erotophobic society, it is possible to create an environment suited to the criteria for being a human (individual) – by developing individual sexual consciousness. Out of the centuries old mixture of medical fallacies and religious dogma, sexuality has become associated with risk, unwanted consequences, disturbances, infections, sin and violence. Our mental inheritance burdens sexuality with those secondary meanings and we need to rediscover it under all those remnants of *moral hygiene*. In that context, the sexual movement provides confirmed information on sexuality, without prejudice and judgment, advocating comprehensive sexual education for everyone, out of the medical pathologization of the body. Genitalia is not the exclusive (epi)center of our sexual lives – actually, there isn't a part of the body not receptive to sexual pleasure – our body, what ever it is like, in its entirety is a *sexual instrument*. Nurturing sex positive attitudes shifts the focus from reproductive health to issues of sexual pleasure and the importance of orgasm – especially so when we talk about female sexuality, which has been reduced to its socio-biological function of procreation. Imminent women's sexuality is constrained by the reproductive properties of females / by being the female of the species. This societies we live in, being such as it is, ranks sexual practices on a rigid hierarchical scale on top of which we find heterosexual marital coitus. All deviations from that norm – an innumerable lot of sexual variety – we are prone to classify as *deviant*. On the other hand, sex positive attitudes recognize and accept the whole specter of sexual practice, orientations and preferences, and fluidity of sexual identities. Instead of insisting on uniform rules about the body and compulsory conformity of sexual diversity, sex positive approach accepts diversity of sexual expressions and experiences, respecting each individual's unique sexual code. Being sex positive means being aware of personal sexual truths, decoding and differentiating one's own unique and authentic sexual profile, overcoming shame and coming into the domain of sexual intelligence.

Exploration of the *dark continent* of women's sexuality shows a continuous lack of authentic female voices. As a general rule, it was always the phallogentric branches of medicine, religion or pornography which dealt with our bodies, sexual needs, pleasures, frustrations, lust or lack thereof. While others used female sexuality as a means of talking about themselves, we have had to be content with other's interpretations instead of gaining real insights into the real state of affairs, and we have been

conditioned to not work (enough) on ourselves. The study herein – Sexuality of Women with Physical Disability in Vojvodina – undoubtedly breaks the continuity of women's silence, noting individual sexual histories, coming from credible women's voices. This pioneering endeavor of gathering intimate women's histories from our country is based on sex positive research approach: *being a witness, and not a judge*. However, examination of the final results, all interviews and analysis, through a sex positive approach raises the question – to what extent was it possible to fully succeed in accomplishing the basic intent of the research? So, we are not only questioning the sexual consciousness of women interviewed, but also to what extent were the researchers and chosen literature sex positive? The question of sources of information and accessibility of knowledge pertaining to sex is crucial for establishing a sex positive community. Lack of credible information regarding sex is evident: on one side, sexuality is an ever-present topic which is exploited by the media and in commercial campaigns, trivialized by bad comedy sketches, glamorized in movies... and on the other side, *expert* texts are mostly written as a note of caution, focusing on reproductive health, that is, the risk of sexually transmitted infections. Such a (mis)understanding of sexuality leads to a pretense of sexual freedom. Undoubtedly, women with disability have by far less access to real information about sexuality due to neglect of the sexual aspect of their beings and understanding disability as cause for asexuality. This deep-rooted stance not only denies sexual development of women with disability, but also stigmatizes asexuality as a form of sexual orientation. The notion of asexuality is used as a tool of oppression, it is equated with negation and absence – which violates sex positive values. Repressed sexuality is one thing, and asexuality is another thing; it is a fact that disability itself does not cause asexuality, just as it is true that should not be looking for causes or *cures* for any other sexual orientation. Along with the belief that disability necessarily carries an *absence of sexuality*, there is another, completely opposite myth which hypertrophies sexuality of women with disability to the point of *nymphomania*. We may therefore also deduce that sexual consciousness contains a formula for some sort of optimal degree of female sexual desire, which is not easily maintained on a scale ranging from *frigidity* to *nymphomania*. On one side of the scale there is an absence of lust in an *anesthetic* women's body – *frigidity*, while on the other side there's the state of being devoured by one's own passions – *nymphomania*. In both cases, women's sexual pleasure is (made) (im)possible. Nurturing a positive attitude about one's own sexuality, being synchronized with the needs of one's own body (with both intense desire and the lack of it), perfecting the skill of sexual pleasure (and orgasm) – are imperative to women's health (*nymphomaniacs* are just women who enjoy more sex than we do). Indisputably, sexual diversity is central to the human experience and the sexual profile of each person, including libido, is something that changes during life – what is still open to discussion is to what extent each of us is in sync with those changes.

Women's sexuality has generally been treated as pathology since the earliest medical texts where women were represented as being victims of their own bodies and biology (even to this day woman's reproductive system is referred to as *women's issues*). The pathological determinants of femininity are evidently also easily attributed to women with disability, because the whole body of a woman is an *anatomical echo* of her sex organs, while disability, supposedly, is not *desirable in relation to reproduction*. Is this really so and has it always been so? Since humans started covering up their

genitalia, not only with clothes but with shame as well, other sexual characteristics, and gender differences, have become over-exaggerated so as to take over the role of that (covered) sexual identity. This tendency often gains obsessive proportions and leads to various modifications or even practices of disfiguring the female body – so that it could resemble the *perfectly* sexualized form, which is the exact opposite to all elements of male anatomy. For example, in order for a body to be *completely female*, it is expected to have smaller feet, longer and smooth legs, wider hips, slimmer waist, (incomparably) larger breasts, more exaggerated lips than a male body. In the name of that much desired femininity, parts of women's body are shortened (by binding and constricting feet into miniature shoes), elongated (excessively high heels), (overly) exaggerated (wire cages called crinoline), reduced (laced-up in corsets), enlarged and emphasized (push-up bras and silicone injections) or removed (surgically, without anesthetics) – in a word, it has been altered to fit an established mold. *Worshipping* small female feet, even if it comes at a brutal price (which has a long tradition in China), is explained by erotic attraction to women's fluttery and unstable walk. Not only have miniature feet left the impression (or trace) of correct femininity, but that unstable walk was a symbol of having *stable* status. A woman with bound (broken) feet is considered to be privileged not to have to move around and work, her existence being relegated to her (sexual) service to her husband (and reproductive service to society). The widely accepted obsession with increasingly elongated female legs is fueled by the same mechanism. When she's on high heels, which give the impression of longer legs, a woman is put in a highly sexualized position. The body *spontaneously* adjusts itself to a more appealing position sending signals that she's been prepared for mating which accentuates all female sexual attributes: buttock muscles are tense and firm, hips are raised and protruding, breasts emphasized, legs elongated and feet shortened. Standing in heels indicates sexual accessibility of the unmoving woman/female of the species, a delicate and attractive being on flimsy legs. When modified by wearing high heels women's legs lose their primary function of walking and become a signpost to her vagina.

In the civilized world, the forbidden exposure of sex organs is compensated in more socially acceptable ways – (broken) feet or (constrained) women's legs become an external mark of her hidden intimate parts, an anatomical echo of her (shameful) genitalia. If we look at things from this perspective, based on the evolutionary function of biological properties – which make a woman /the female of the species – what is evident is that the need for beautification, improvement, *feminization* of the body results in its violation, even disfigurement. On the surface this may seem paradoxical – the ideal of women's beauty is often achieved in deforming women (to a greater or lesser extent). It seems that on the cultural-historical map of the female body, sexuality and disability are deeply intertwined. Statuettes such as the Venus of Willendorf, dating from ancient history (around 30 000 years BCE) that have been found around the world, are characterized by a lack of legs, which usually stop at the knees. Legs of the Mother Goddess have been broken so that she could not move. Not only is her power diminished in this way, but her mercy is also kept tied to the ground. The Goddess's devotion, that of woman-mistress-mother, is thus secured by her disfigurement; she has been desecrated in order to be *worshiped* by humans. Some tribal cultures have a common woman-mother with broken legs, who is there to serve for the overall satisfaction of the tribe. A similar manner of restraining the divine-feminine from wandering and running away is still practiced today – cliterodectomy (removal of the clitoris). In

Western civilization cliterodectomy isn't related to religious mystification, but is done in the name of *health* – so as to restrain women's masturbation, which official medicine believed to cause lethal consequences (from paleness to *nymphomania induced death during orgasm*). In books on raising girl children (which weren't published that long ago – mid 20<sup>th</sup> century) parents were advised to scare their daughters from masturbating by telling them it causes disability (from spinal dryness to vaginal hypertrophy). Since masturbation is considered to consist of any pleasurable contact with genitals, even personal hygiene was considered to be a *high risk activity* needing strict monitoring. Genitalia then becomes the *untouchable zone* – even in modern times, prohibition of touching one's genitals is the first prohibition we adopt in childhood. Sexual shame, fear of the body and erotophobia as a conscious state are undoubtedly what actually causes the practices of damaging and deforming the female body. Patriarchal society and phallogocentric consciousness dictate that woman must be incapacitated and/or made weak, and her sexuality subdued.

It isn't our bodies that are the problem, it is the ruling norms and their (re)interpretations. Pagan cultures believed that the properties of female nature – which bleeds without dying (menstrual cycle), creates life (gives birth) and produces food (breast-feeding) – were signs of powerful magic. In the course of civilizational development and Christian demonization of sexuality, the difference posed by the female body and the advantages of female nature were actually equated with weakness. Menstruation became a consequence of *women being cursed*, women's role in the creation of life was degraded to that of an *incubator*, while the apotropaic<sup>1</sup> power of women's breast was debased into vulgarity. The craze for the idealized form of the female body – the hourglass figure – has persisted, and reflected the need for a *fertility goddess* who is subdued here on Earth. It represents the search for a sexually mature *virgin*. Accentuated breasts are a sexual signal and proof that a woman/female of the species is a suitable candidate for raising offspring. The effect of round, firm, raised and protruding breasts, as is created by bras (or silicone implants) simulates ovulation (sexual readiness), to which the male of the species will most certainly react – from the far depths of his consciousness. Unlike protruding breasts, a slender waist signals that the woman is sexually inexperienced – because her body isn't yet *deformed* by childbirth. Wide hips are a sign that the woman/female of the species will be able to *storage* and carry offspring. The effect of the ideal form was achieved by constraining the female body into tight corsets (with built in metal bars) which created *support* for women's posture – physical, but also character wise. A woman who is tightly laced/up in a corset is considered to be sexually desirable and attractive, but her character is not loose; also, she is neither cold nor reserved, rather she is *disciplined* in her own body; upright and rigid body posture is a show of her upstanding and reliable character. (The side effects of this *disciplined method* were fainting, problems with breathing and circulation, and spinal deformity). The story of the corset<sup>2</sup> (body) is intertwined with the Christian version of the pagan fertility goddess, who should guide our behavior as role model. In the *new dogma*, women achieve their social status through reproductive rights, but they must however not be sexually active. It is more likely that this demand for something simultaneously *virgin* and *mother*

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1 Power to avert evil forces. It was believed that by suddenly exposing her breasts a woman could stop natural disasters, weaken a man's will (of her husband, soldier or legislator).

2 Corset – from old French *corps* and Latin *corpus* – meaning body.

creates a tear in the female psyche, rather than making her a more complete being. It results in discord between the reproductive properties which are socially desirable (and in Christian ideology procreation is something that *must* happen) and sexuality itself which has to have its *demonic* nature subdued. According to the traditional value system, women's sexuality is conditioned by marriage and is therefore intended/rationally *justified* by the reproductive function. Other aspects of sexuality – pleasure and (spiritual) freedom – are not part of the female sexual experience. To be *sexually attractive* is not an expression of being sexual fulfilled, nor a synonym for a conscious sexual subject (it's much closer to being objectified), and therefore it is far from being some sort of guaranteed starting point for healthy development of sexual potential. She is *sexually desirable* but still anxious in her own body (as if in an inherited uncomfortable corset), a mother with the mentality of a *virgin*, because she doesn't possess satisfactory sexual experience – just as one of the participants in the study said: (sex is only) *a duty to my husband...* or she has low expectations of sex: *later it was even good.*

Women still pay a high price for actively and openly sexually stepping out. The centuries long moral divide between the *exemplary woman* (wife and mother) and *destructive* temptress (labeled as unfit for emotional partnership) is still ever-present in modern society. However, the situation isn't such that we are being exploited by sexuality – but by its denial and misunderstanding. The process of women's sexual liberalization was such that it strove for attainment of men's sexual privileges – which turned out not to be sufficient (because we are constantly striving to attain the degraded *homo eroticus* in a sex negative concept). In striving to realize their sexual rights, women with disability are guided by existing privileges attained by women without disability. Both groups need to rediscover sexuality anew – an individual evolution instead of sexual revolution. It's a paradox that we receive the propaganda of sexual health as some sort of preparatory training for fighting against disease. When we're informed that we should have regular gynecological exams it is mostly as a warning, something that frightens. The hidden message we receive has not changed since the times of Hippocrates: *having an uterus means having a problem.* Having a woman's body always carries risk, it is attacked with warnings and under strict control. We adopt the message that potential danger is stalking us from the depths of our own body. As if hidden *women's issues* is inherent to our sex organs, and if it manifests then it should be removed (problem or the whole organ). We are preemptively amputated from the *most risky* parts of our body, from our own healthy femininity. Timely discovery of disease and removal of its symptoms cannot be considered true prevention. Instead of exploiting problems (*women's*, of course), we need to come up with permanent solutions – change of sexual consciousness, reconnecting with our bodies and establishing a healthy relationship with our own female core.

## Literature

Mirkovi , Zoran (1999). *Eros – Bol, Žena – Bog* [Eros – Pain, Woman – God]. Rad, Beograd.  
Morris, Desmond (2004). *The Naked Woman: a study of female body*. Thomas Dunne Books, St. Martin's Press, New York.