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Disabled Women Everyday Citizenship Rights in East Europe: Examples from Slovenia

Darja Zviršek

Introduction

In post-socialist societies, political subjecthood has been increased for some people but not all, many people are still subjected to the traditional understanding of citizenship, that is, they are denied full participation in economic, social, and political life. Women and men with disabilities are among those for whom this is true. After 1991, socialist ideology was replaced with an economic ideology and the dictates of free market. Many people internalized the neo-liberal belief, that the “happy hours” of history, when everyone had the right to a flat and paid work, were over, and now “real life began.” Neo-liberalism exploited the idea that there was no alternative to the economic organization of the new world order. One consequence of this has been that after 1991, in Slovenia many women and men with disabilities lost paid employment (Zviršek 2000). In 1999, the Employment Service of Slovenia registered 14,787 disabled job seekers and in the year 2000, the number increased to 16,141 (Slovenia has 2 million population). Currently, out of all people who are registered as unemployed, about 10% are people with various disabilities.¹ Additionally, people labeled as moderately, severely, and profoundly intellectually disabled (the exception are those that are labeled as borderline or mild), are still, according to an old communist law from 1983, completely excluded from paid employment, because this law defined them as

being “unemployable” and “incapable for independent living.”² Regardless of the fact that Slovenia, in its accession into the European Union in May 2004, adopted several new laws that promoted inclusion and equal treatment, there are still many burning issues which could at least be partly resolved with some formal guidelines for change. However, neither the EU social policy officers nor the national politicians seem to have any interest to promote such guidelines.³ A limited concept of citizenship, which in the socialist period included able bodied proletariat and privileged disabled war veterans (predominantly men), has today been replaced with another type of exclusionary version of citizenship, which only includes those people who can respond to the demands of the new neo-liberal market. For many minorities (especially people with intellectual disabilities and ethnic and sex minorities) the end of the communist regime did not bring the basic everyday citizenship rights and in some case did not even bring them formal rights.⁴

Disabled people in the post-socialist countries of Eastern Europe are still called “*invalids*” (based on the Latin word, *invalidus* which means, weak; powerless). In Slovenia, a disabled woman is called an *invalidka*.⁵ To categorize someone by such a name produces a certain response from the person who is objectified with the injurious name and fashions a power relationship between the agent who calls and the one who is interpellated. The act of naming, calling someone an injurious name (*invalid*), is rationalized as “caring for the other”, and hides the fact that it assures a long term subordinate place for the person being defined as invalid. Even more, it seeks to assign a social site or locus to the one who labels, who has the power of naming.

Since women with disabilities have historically been silenced and have remained invisible even within the core feminist writing in both the west as well as the east, this article brings forward not only a gender aspect of disabled people’s rights, but also women’s personal testimonies and narratives. These narratives and testimonies will demonstrate that public care is also a form of the violation of citizenship rights because it continues the physical segregation of disabled women as well as their experiences of sexual violence, which not only happen at home but also in public care.

In both cases women experience the abuse of their citizenship rights. The following ethnographic data is derived from a study that was carried out between 2001 and 2002, and was focused on different aspects of exclusion against disabled people, particularly on violence against disabled women in Slovenia. The study consists of twenty-five narratives of women living either at home or in public care. The bulk of each interview was devoted to the re-collection of both violence against self-determination as well as sexual violence. This ethnographic research aimed to de-individualize the debate about sexual violence against disabled women and to show its contexts, which is very often the context of living a segregated life instead of one of independent community living. This research collected individual women's narratives as given by the women themselves, rather than being based on the censored, non-disruptive professional stories, which patronize and do not re-call their personal experiences. During the socialist government, professionals and institutions controlled public knowledge and decided which stories were allowed to become a part of the public memory. When disabled women talk about their experiences, which previously did not have the right to be heard, or to exist, the personal testimonies of women with disabilities also have a political connotation and form some parts of their citizenship status. This article focuses on women with physical and sensory impairments, intellectual disabilities, and mental health problems who have spent most of their lives in a variety of institutional settings. As the deinstitutionalization processes in central and east Europe have only hardly begun, most of the women who were interviewed still have not entered everyday civic life and still live in public care (Pečarič 2001; Smirnova Iarskaia 2005).

State Care Institutions: Inclusion as a Form of Exclusion

Personal testimonies of people with disabilities who lived in public care (asylums, boarding schools, and nursing homes) in the former communist countries are almost nonexistent (McCagg and Siegelbaum 1989; Buda and Gondos 1998; Zaviršek 2000). An extended comparative research about the enforcement of rights in psychiatry in Eastern European countries showed that those who

used psychiatric services had no rights to provide informed consent, received no personal respect, experience no regards to their personal safety, had no privacy, and no advocacy support system (Buda and Gondos 1998). People with disabilities who have lived in public care institutions have often been treated as if they did not share the same humanity and personhood as their guards and professional staff did.

State care institutions symbolized the “good father” who cares for his children and can always take the place of other people close to the person. The remains of this welfare regime still can be found in the legislation that continues to exist across Eastern Europe. In Slovenia, the court can make the decision to restrict or remove an individual’s civil capacity, and appoint a guardian for a person with disabilities. The guardianship can be carried out by parents or, if the parents cannot or will not be legal guardians, by a social worker from the local center for social work. In the latter cases, since the removal of full capacity (plenary guardianship) means that the obligation of the guardian are the same as in the case of a juvenile under the age of 18 years old, the institution replaces the will of the person and therefore represents the person under the law, and makes decisions for them in regards to finance as well as in all other issues. In 2002, there were 4,837 adults under guardianship, however no gender specific statistics are available (EU Monitoring and Advocacy Program 2005, 34). In Bulgaria, the dominant status of state care institutions is even more obvious, since the staff member from an institution where the person is placed, can be the guardian for the disabled person. One of the ethnographic reports even states that “the director or a staff member was appointed as a guardian to 41 per cent of the residents in all homes for adults with intellectual disabilities” (EU Monitoring and Advocacy Program 2005, 32). Here the paternalistic nature of a public care institution is obvious, the guardian is responsible for the person’s life, health, property, and financial interests, or as one of the early state socialist documents from Slovenia pointed out, “from conception till the grave” (Zaviršek 2005, 251). When a director of an institution is appointed as a guardian, the actual and invisible dependency

becomes legitimized. The person cannot leave the institution if the director does not agree to it, and has no independent person outside of the institutional system who can speak for his or her rights in cases of abuse or maltreatment. The social care institution not only symbolically, but also legally becomes a family type placement where the director as a “good father” can allow or forbid the requests of the disabled “resident children.”

A Slovene woman in her early forties, who was born with a muscle dystrophy and has had to use a wheelchair since childhood, described how the communist regime subjugated her to a normative identity, which is, at the same time, an oppressed identity. From an early age she was told, that she was a “child of the state,” which meant that she lived on state money while being sent to different state institutions for disabled children and youth. When she was 19 years old, she was sent to an old people’s home in the capital, Ljubljana, where she lived until her death in 2004. Her memories about the past showed that the internalized identity of a “child of the state” prevented her from complaining, she felt guilty and thankful. She was infantilized and patronized through this system of care, within which she was like a child who never was seen as a political subject. The state defined her personhood through physical segregation and personal silence.

These examples represent many people who are excluded from everyday life through the exclusionary system of public care and who are at the same time included as welfare subjects through the same system that provides them with some social benefits and everyday needs. The dynamic between exclusion and inclusion had been metaphorically described by many authors through the use of the famous “Central European” Franz Kafka story, *Vor dem Gesetz* [*Before the Law*]. This story can also be used for analyzing the social limbo experienced by people with disabilities in central and east Europe today. Kafka’s story describes a man from the country who goes to an open door of the Law in order to enter, but *der Tuerhueter* [the doorkeeper] will not allow him to enter. The man from the country does not give up, he waits there for years, observing and talking to the doorkeeper in order to understand the logic of entering the Law. Time passes, he

becomes very old, and before he dies he asks the doorkeeper his last question: “*If everybody wants to enter the Law why has nobody entered through this door?*” The doorkeeper responds with the words that mark the end of the story: “*No one else could enter here, since this door was destined for you alone. Now I will go and shut it*” (Kafka 2003, 162-63).

The symbolic understanding of Kafka’s story with regard to disabled people shows again the dialectic of inclusion and exclusion. The open door, destined only for the man from the country, includes him as a citizen who spends his life waiting to be allowed to enter the door (living in public care institution and being a recipient of care), at the same time that it excludes him by preventing him from entering the Law (to become an equal citizen). Most of the consumers of social care services encounter the same paradox of the Law, when they are included in the form of an exception (they are called “the different”, in Slovenian, *drugačni*). This pointed out by Giorgio Agamben, “*The exception is what cannot be included in the whole of which it is a member and cannot be a member of the whole in which it is always already included*” (1998, 25). The woman living in an asylum is included through exclusion and is therefore, symbolically speaking, “matter out of place” (Douglas 1994). She is included through her “invalid” category but her inclusion is, at the same time, an exclusion from full citizenship rights as she is spatially, politically, economically, and socially excluded. The concept of citizenship rights remains in this way a flexible category, because the state arbitrarily affords or withdraws citizen rights to different groups and in such a way constructs their identity. This complicated dynamic shows that the rights to different social benefits turns people with disabilities into welfare consumers, and at the same time prevents them from having such basic citizenship rights as the right to vote, work, or make financial decisions, among other things. Further in line with Kafka, the question arises, why didn’t the man from the country break the law and enter the door, anyway? Internalized oppression is one of the constructions of identity created by welfare regimes. When the welfare regime positions people with disabilities as being passive welfare subjects, this in turn can become their “true

identity". This also contains the fear that more active citizen rights might put their current welfare benefits in danger.

According to Michel Foucault, a society's "threshold of biological modernity" is situated at the point where bodies become politicized bodies, constructed by state power. The woman who was called a "child of the state" was not only seen through her impaired body, but her body became politicized through the state apparatuses of care (1981; 1990). Exactly like Kafka's man from the country, the person who is called a "child of the state" is neither free nor un-free, since her identity, as a "child of the state" is an inclusive as well as an exclusive one. Even after the decade of political changes following the change of the regime, the woman who lived in an old people's home remained spatially segregated and still without the right of self-determination. For her, the new democracy, and the new welfare interventions, for example: "inclusion," "independent living," "empowerment," and "self-determination," did not bring any changes. She remained in the past, from which she carried her frozen citizenship identity until she died in her mid forties.

This example shows that political changes do not automatically change the social welfare order or the cultural images attached to stigmatized groups seen as "invalids." Under communism, according to the idea of universal needs and rights, the extensive building of the large institutions during the 60s and 70s, were seen as a form of modernization and progress. Educational training taught the professionals that the "invalids" are "those, who had to be cared for in a socialist society." The cultural images of a woman with disabilities who can be an active citizen, make decisions, and participate in biological and social reproduction, still seems to threaten the knowledge of professionals who were taught that "invalids" should only be treated with respect as welfare subjects, not as equal citizens.

In comparison to the above, some earlier ethnographic research from the Soviet Union showed that during the communist regime people with disabilities were seen not only as dependent but also as powerful and dangerous. Dunn and Dunn, collected examples of the everyday life of

physically impaired persons in the Soviet Union, who were either abandoned, such as one woman who lived in places such as flats for years, despite the fact that she was not able to move and was only brought food once a day; or those who were punished when they demanded rights (1989). An example of this was an almost non-existent civil initiative undertaken by a group of disabled activists who called themselves the “Action Group.” During the 1980s its members soon became demonized, institutionalized by force, and criminalized. Genady Gus’kow, a member of the Action group, and physically impaired himself, became an innovator and entrepreneur, “traveling around on a primitive cart” (Dunn and Dunn 1989). When he became economically successful (he was making and selling prostheses), the local government started to construct him as a “dangerous problem” for the local politicians and the community. His life contrasted with the belief that a person with disabilities cannot remain mobile and active. He disturbed the historically constructed image of the dependent cripple, subjected to the institutional order. On the contrary, he earned his own money, was able to travel, and was quite innovative. Eventually, the local authorities forcibly removed him to an old people’s home that was far away from the community where he was living (Dunn and Dunn 1989). Here the phenomenon called the “hierarchical turn,” when greater power is ascribed to people with less social, symbolic, and economic power, can be observed. The omnipotent communist state ascribed great power to a small group of disabled, disempowered, poor, and often symbolically polluted citizens. These individuals were active and resisted being isolated by a closed state institution, they were well organized, and took social action against the “powerless” state.

In an analysis about mothering children with disabilities in today’s Russia, Iarskaia Smirnova showed how placing children with disabilities in a large institution was a common practice supported and expected by the medical professionals of the time: “Today’s struggle faced primarily by women choosing to raise children with disabilities at home must be understood within the context of decades of professional medical advice to parents that they place their children in state

institutional care and “try again” for a child without ‘defects’” (1999, 69). A female social worker in her seventies from Slovenia recalled something very similar when she talked about her work during the communist era: “I worked very hard to persuade parents to put a child into public care. I said to them, ‘Don’t revolt, this will be good for you and for your child!’” (Zaviršek 2005, 211).

All these examples show that spatial segregation itself contains several elements of violence that were analyzed and identified by Erving Goffman almost fifty years ago (although in a gender neutral manner). The gender aspect of the oppressive caring practices show that, as an environment for “the outcasts”, boarding schools and other public care institutions are places of all sorts of abusive practices, such as violence, sexual abuse, and psychological abandonment. This becomes visible through women’s personal testimonies.

Gendered discrimination

It took a long time for feminists to recognize that the structure of discrimination and violence experienced by disabled women was similar to that experienced by non-disabled women. Feminist researchers have only recently recognized that disabled women, even more than non-disabled women, are vulnerable to different forms of physical and sexual violence. Here I will claim that feminist writing has inherited the same historically constructed stereotypes towards disabled women as can be found within other non-feminist writing. While over-looking and minimizing violence, feminists have reproduced the avoidance, discrimination, and hierarchization of disabled women; and have not challenged the exclusionary welfare regime to any degree in this area. Slovenia for instance, has eight safe houses for women and children who flee domestic violence, but none of them are accessible to women in wheel chairs. According to some of the feminist social workers in those safe houses, women with disabilities are seen as “difficult clients” (especially those with mental health problems), and are often advised to find some other social service to help them. These attitudes show that even professionals who see themselves as feminists, some of whom initiated the first safe houses themselves, have gradually become

medically oriented and dominated by managerial logic (dividing women either as “easy” or “difficult” clients).

When critical writers eventually did use a gender perspective to understand the everyday life of disabled women, it was best done by disabled and non-disabled feminists themselves because they were the first to find the existence of a long historical memory of discrimination towards disabled women (Morris 1992; Rommelspacher 1995; Wendell 1996; Linton 1998; Fawcett 2000). Many feminist disability activists have shown that disability itself reinforces discrimination against women at the structural level as well as on the everyday interpersonal level. Disabled women challenge the idea of a perfect body as part of a constructed women’s identity. Those disabled women who decide to have a child also challenge the naturalized heterosexual matrix, which connects femaleness, heterosexuality, reproduction, and motherhood into a natural, undivided bond (as many women with disabilities can only get pregnant with the assistance of new reproductive technologies). Since ideas about sexuality are strongly connected with reproduction, the prevention of sexual activities also means the protection of a non-disabled world from the “danger” of unwanted pregnancies. Women with impairments might even be seen as productive (when they suffer from physically or sensory impairments, but not with intellectual impairments), but they are not allowed to reproduce. Even if a woman becomes disabled during her lifetime, most professionals in central and east Europe advise her not to have intimate relations or children (Iarskaia Smirnova 2005). In 2000, the Slovene parliament passed a law, which forbid the use of any kind of new reproductive technology by single women, based on the belief that assisted reproduction might expand the rights of single women, including disabled women to have children without necessarily having a partner. Some women with disabilities protested against this decision, claiming that in the times of “perfect bodies” there is almost no chance for them to get married, but rather than being heard they were ridiculed and patronized.

Within the state funded organizations for invalids, established during the socialist era as the privileged sphere of social protection, no awareness of gender can be found. In the majority of post socialist invalid organizations, most of the money today is still spent on sports activities, where men dominate in high numbers. Most of the invalid organizations which grew up on the image of the male “heroic invalid”, have been led by men while the experiences of women are only recognized when western foundations give money explicitly for “disabled women’s activities.” In some central and east European countries, women were able to form women-only groups or, in some cases were only able to become members of disability groups because some foreign funder demanded their participation.⁶

Gender discrimination also remains obvious within the education system. Young people in Slovenia who are categorized as having mild intellectual disabilities and have finished either six years of mainstream elementary school (instead of nine years) or completed a special school (which are mostly spatially segregated and highly stigmatized institutions), are only allowed to continue their education within various lower vocational programs (which consists of two and a half-years of education). Slovenia has, at present, fifteen different lower vocational programs, out of which only one program is explicitly offered for girls (assistant housewife), while the rest of the programs are almost explicitly designed for boys, such as metal or wood worker, assistant glazier, assistant electrician, baker, butcher, pastry cook, amongst others (Urh 2005).

During the inter-war period of the 20th Century, an early Slovenian anthropologist named Božo Šerlj reported a similar gender gap. He himself was a controversial scientist, fascinated with the eugenic movement of the 1920s and 1930s. In his study about the “less-valued children” in Ljubljana auxiliary schools, conducted in 1933, he discovered that parents of disabled boys made more effort to make their sons independent and to teach them special skills than they did for their disabled daughters. He found that most of the parents preferred to send disabled girls to special institutions for disabled youth while preferring to keep their disabled sons at home:

It is not uncommon that parents, in hope of having some use of the child, decide first to give an auxiliary school the care of a girl. The number of differences between the sexes is so great that it cannot be merely coincidental ... It is necessary to prepare a son for independent work, this does not seem for many parents to be so important for a girl and therefore perhaps they leave them to repeat a class two or three times. (Škerlj 1933)

His report also showed that the common knowledge from that period viewed public care institutions as places that did not increase the social and vocational skills of the children who were sent to them. In order to strengthen those skills, the parents were more interested in keeping the child outside of closed and segregated places. In the post-war period, this knowledge was replaced with another welfare ideology. The institutionalization of children and young people with disabilities was seen as a form of modernization of state social protection. It was also seen as a form of completing the socialist vision of the just society in which the state cares for the “needy” (Haney 2002, Zaviršek 2005). In the same study Škerlj drew attention to another type of gender difference, that was obvious in the different levels of material care for male and female children: “In relation to being well-nourished, girls provide a much worse picture than boys, since at least 75% of them are below normal” (Škerlj 1933).

In recent times, sheltered workplaces have been developed for people with moderate intellectual disabilities and even for some with milder disabilities. These people could easily work in paid employment if they would get additional support and assistance. Here, another form of gender discrimination can be interpreted from the number of women and men who work in sheltered workplaces across Slovenia, since most of them are men aged between 26 and 36 years (EU Monitoring and Advocacy Program 2005, 103). The numbers show that men more often than women have the chance to spend half a day in sheltered workplaces, while women usually stay at

home and help with the family's household. Regardless of the fact that the labor in sheltered workplaces does not bring the workers any economic independence, it does offer friendships, exchange, symbolic payment, and, for some people, an important sphere of personal freedom, which can increase their self-respect and personal dignity.⁷ Once again, however, women with disabilities have fewer possibilities for activities and networking outside of the private household domain than men do.

All of these examples show that women with disabilities have even less citizenship rights than men, are more dependent on the existing system of care, and as will be shown below, experience different types of violence. Being disabled reinforces the discrimination against women from an early age.

Safety from Abuse as an Element of Citizenship Rights

The comparative research as well as the testimonies of women living in public care in Slovenia, has shown that experiences of neglect and abuse are, for many of these women, a central part of everyday life. These experiences influence their everyday citizenship rights. Many of them are not able to live in a space of safety and respect. Therefore, the issues of abuse and violence also have to be part of the citizenship debates, especially because women with disabilities do not have the same rights to share their sexual desires with other people as non-disabled people do. The same is true about the disclosure of their personal stories of abuse. Both double standards regarding the right to sexuality and the public silence about the abuse, do not give disabled people the symbolic permission to recall and voice their personal stories. There are no public spaces where the stories could be easily told without a running risk that nobody would want to bear witness. Not having an outside witness, as Dori Laub has pointed out, prevents the victim from bearing witness for oneself. Thus, personal memories remain silent (1992).

It is not only women with disabilities, but also female children with disabilities who are more often objects of sexual abuse and neglect than non-disabled children (Pugh 1997). Several studies

show that among disabled people there are more girls who are abused than boys, and when they disclose abuse girls are less often believed than boys (Brown and Craft 1989; Sinason 1992; Sobsey 1994; Pugh 1997; Cross 1998; Brown 2001; Završek 2000). In a study conducted in 2000 by Michelle McCarthy, 32% of the cases of the abuse of women with intellectual disabilities were not even taken seriously enough to be reported to service managers, whereas this was only the case for 7% of men who reported abuse. McCarthy speaks about the “different thresholds of belief and intervention” connected to the pre-conceptions of a gendered hierarchy (it is not unusual that a Slovene teacher reacts to sexual harassment of a girl with the words: “Don’t make a fuss out of that, these are boys!”).

There are four major reasons why neither feminist social workers nor professionals dealing with different types of violence against women have been able to recognize the vulnerability of disabled women to sexual violence. All four reasons are linked with the explanatory systems used for understanding interpersonal violence and with the long historical legacy of prejudices against disabled persons. These reasons include:

- 1.) The sexualization of abuse: The debate about sexual violence remained for a long time an explanation system that was framed by a naturalized gender-coded. It was believed that violence was caused by the strong sexual drive of men. Sexual violence was therefore explained either as the result of female sexual resistance, or as the social incapacity of lonely male persons to find a sexual partner. In juxtaposition to those opinions stood the belief that disabled people and especially disabled women did not have any sexual drive and no sexual life. Since disabled persons were not seen as sexual beings, it was widely believed that sexual violence could not happen to them. The more they were perceived as children or as child-like adults, the more it was believed that disability itself prevented them from becoming objects of sexual abuse.

In cases of reversed stereotypes, as in the case of disabled persons who have over-sexualized behavior, the victims were seen as the initiators or as triggers of sexual abuse. Similarly, Merry Cross

states: “Already we have touched on the classic stereotype of people with physical and sensory impairments as asexual, and people with learning difficulties as sex-mad monsters” (Cross 1998, 81). In this case, disability does not prevent the person from abuse but on the contrary, causes the abuse. The labeling of the abuse covers it in the language of disease and pathology.

2.) The de-sexualization of abuse: After the broader influence of feminist explanatory models, the debate about sexual abuse moved towards the idea that sexual violence was simply another form of violence, most commonly used by men to control women. Juxtaposed to this idea, common attitudes towards disabled people were dominated by the notion that they were powerless, “innocent cripples” towards whom nobody would react violently. In this view, again, disability itself was believed to protect disabled persons against sexual violence. The substantial vulnerability of disabled children to be sexually abused was turned around and reinterpreted as the protection of disabled children and adults against violence.

3.) Abuse as a shared activity: Another common idea regarding sexual abuse was that abuse always involves “two sides” where every side “plays” a specific part in the drama of sexual violence. This view assumes two equally powerful and active agents who share the responsibility for the sexual violence acted upon them. In juxtaposition to this view is the belief that disabled persons are passive human beings without personal autonomy who are not able to enter the “violent drama.” If disabled persons do not have their own sexuality and agency, or even any knowledge about sex, they are not able, it was believed, to share the responsibility for sexual violence. Their not knowing prevents them from becoming actively involved in an activity that demands two “actors.” For most professional helpers in Slovenia sexual abuse is still an individual matter, connected to the deviance and illness of the perpetrator as well as, to a “certain degree,” to the deviance and illness of a passive victim. The models of “shared responsibility” and a “pathological family” (that sexual abuse demonstrates a pathology of all family members) prevails.

4.) The romantization of sexuality: Another view, which obscured the high rate of sexual abuse against disabled people, was the common belief that sexuality and sexual abuse do not have anything in common. Sexuality was connected to love, innocence, and beauty, whereas abuse was dirty, immoral, and removed from everyday life. In opposition to this view, many researchers have shown that violence and sexuality are not at all *a priori* distinct from each other, they are very strongly connected.⁸

In public care, the romanticization of sexuality manifests itself in cases where the institutional relationships start to be seen as personal relationships (between the inmates and the paid caregivers), which in turn justify the sexual acts. This erases the aspects of coercion and intimidation involved in the sexual act and hides the fact that sexuality accumulates a great deal of power. Sexual acts in public care as well as in the domestic sphere cannot be distinct from the question of control: the person who controls the space (the house, the rooms of the disabled persons, the keys from the bathrooms) also controls the everyday life of a disabled person (the food, timetable, other contacts etc.). Consequently, those who care and protect the person, also control the bodily space of the disabled individual under their care. Because of the strong romantization of sexuality, sexual relationships, which are in fact an institutional relationship of dominance and control, fail to be recognized as an instrument of the administrative apparatuses of closed or semi-closed institutions.

Personal Memory

Women with physical disabilities, such as impairments of hearing and vision, have fewer chances to avoid abuse because they cannot see or hear the perpetrator, and therefore cannot scream or run away. Some people with intellectual disabilities might not be aware of what is going on. In addition, in most cases, relatives and other unpaid caregivers as well as professionals, as was already discussed, do not believe the children or adults when they report abuse or pay attention when they show signs of “unusual” behavior, which is often a symptom of the abuse. Most often, they individualize the personal stories (a disabled person is “unstable,” she made up “the story” because she desires intimate

contact etc.), pathologizes them (she or he needs more drugs), or educates them (with punishment, more control, or physically moving them to another peer group or another building). Most people are convinced that in hospitals, schools, residential homes, and boarding schools abuse happens only among peers.

Much of the research conducted so far has shown that the perpetrator enjoys having the feeling of power and control over someone who is weak and prefers people who cannot defend himself/herself. Therefore, it is not surprising that people with more severe mental disabilities are more often sexually abused than those with milder impairments (Sobsey 1994). The wider and more disparate the social status between the able and the impaired, the more likely the disabled persons will be subjugated to abuse and victimization. This gap in the social status between two individuals will assure that the abuse and victimization will have less social consequences and condemnation for the abuser.

Many people with physical, sensory, and intellectual impairments in Slovenia spend most of their childhood in various institutions (hospitals, rehabilitation centers, special institutions, boarding, or special schools) where they internalize the message that they are not the same as “normal children,” even more so, that they are of a lesser value because they are “invalids.” They are reduced to a disabled body that is controlled by others. Some of them experience different types of institutional violence, which make them more vulnerable to other types of abuse. Veronika, a woman in her late 20s with a physical disability testified about her sexual abuse at rehabilitation centers and physiotherapy:

I had very bad experience with the staff at the health spa. The first year after my attack of sclerosis multiplex I had massages and physiotherapy by male staff. I hated verbal contacts with them because they use such expressions that they abuse you just by talking to you. They often said, “You will never have a boyfriend because you are different, you should use what you have here, now, because you will never have a chance for anything else!” I tolerated that and decided to go to

someone else next year. Then came the following year, and then another year and I found out, that it would be the same also the fourth year. So I decided not to go to the spa again although I have everything paid for. /silence/ They wanted me to sleep with them. It was terrible to come to the spa because I am a local girl and I knew they were talking about me outside of the rehabilitation center. I isolated myself from local people, I was ashamed /silence/.

Her experiences of a continuous hate speech and verbal abuse were followed by sexual abuse:

At first, it was verbal. Since I was able to move around, I was having the massage done at the hotel. Because I am communicative and I was talking with them, they thought that they could do whatever they wanted with me. I can tolerate one wrong move on my body, but then they start touching you, and I made quite a fuss about it. At first, they massaged me in a normal way. I know well that my prescribed massage includes legs, arms, and back. But then they came to my breasts. Although I did not want that, which I told them clearly, it was getting worse and worse. I don't know what would have been the reaction of the manager if I had told him, I didn't know how to tell. It was the same with physiotherapy. In Ljubljana, at physiotherapy they treat every group of muscles: arms, legs, and then they slowly came to the parts where I felt that it was not what it was supposed to be. I told them that I did not want that. But the reaction was the same: "You will always be like that, who would take responsibility for you, who would want you for a girlfriend?"

A disabled body is an imaginary locus of sexual activities, which does not necessarily include any kind of emotional relationship or consent from the disabled person. There are "other" rules connected to the relationship with a disabled person, than with a non-disabled person. The totality of the disabled body deprives the person of the right to an ordinary intimate relationship ("*You will never have a boyfriend, use the opportunity which you have it now, you will not have another one*").

Hate speech did not only affect the interpersonal relationship between Veronika and the staff, but it also affected her social network and her social well being in a close community. Her first reaction to the hate speech and sexual harassment was silence, adopted in the hope and as part of a strategy that would make the event disappear. The repetition of abuse increased her terror and powerlessness, which not only silenced her but also caused her withdrawal from the therapy that she had the right to receive. The public silence made her more powerless and less capable of disclosing the events. Since there was nobody who would bear witness, she was not able to bear witness on behalf of herself, therefore her personal memory did not become part of the public knowledge.

In Veronika's testimony, the abuser presented himself as "her opportunity," as someone who was giving her a chance, which she would otherwise not get. Here the manipulative element of an abusive situation can be observed: an abuser presents himself as someone who is doing something for the benefit of the disabled person. Sexual abuse becomes therapeutic and is normalized by being medicalized.

Traumatic events thus do not only produce thick silence as a form of narrating what should not be disclosed and re-called, but these events can also be a reason why disabled people often talk about their wish for their bodies to physically disappear. Miriam, a 37-year-old woman diagnosed as mentally disabled, who has experienced recurrent sexual abuse, spoke about her wish to disappear from the world:

You know, when it happened to me I was in the special primary school. And he said to me: "Oh, you damn bitch, why can't you give it to me, tell me, why can't you give it to me? Come on!" And I said: "Here I am so take me," you know. He was persuading me that much, so I said: "Here I am so take me!" He persuaded me ... I thought about suicide, it was so hard for me. I wanted to cut my veins, but so nobody would know, my mother mustn't know, and father mustn't know, nobody at home must know, and none of the teachers. All the time I had in my mind that I

should kill myself, how do I kill myself, how do I do it so that no one would know.

How, how am I to “vanish,” how do I get out of this world, how to pack myself out of it.

This testimony shows a specific dynamic of abuse where Miriam unwillingly consented after verbal victimization (“*damn bitch, why can’t you give it to me, tell me, why can’t you give it to me? Come on!*”). In traditional conceptions of sexual violence, dominant in post-communist countries, similar events are not defined as sexual violence. The consequences are that most victims of rape report sexual violence only when they can prove the “unproblematic dynamic” of an assault in which they had physically defended themselves. Women’s consent for sexual activity is also linked with the socially constructed images of a woman and female sexuality, where girls and women often consent because they were told that this is the way to be accepted and loved. McCarthy showed that within public care women sometimes consent in order to get some rare privileges within the closed institution or in order not to lose these privileges (2000).

Miriam’s wish to “pack herself out of the world” could also be understood in connection with her unwilling consent. She was not able to protect herself, but she also did not expect protection from outside. Many researches show that, often, women who have already been victims of sexual or physical abuse are less able to protect themselves from new abusive situations. In this respect, her unwilling consent could be interpreted also as a part of learned behavior. Her powerlessness to protect herself and her experiences of how other people did not protect her, led to her wish to “pack out of the world” in which she is not safe. The idea could be understood also as a desire for her physical body, upon which so much pain was inflicted, to disappear. At the same time, her wish to disappear physically is a metaphor for overcoming the traumatic memory of the event. Her hope that nobody would know about her suicidal thoughts can be understood as an actual fear that somebody would discover her plan and punish her, or interpret her suicidal fantasies as a symptom of mental disability or mental health problems. She was afraid of more pathologization since people might make her

responsible for the abuse. Miriam's fear that somebody should find out about her plans could be understood as a metaphor of shame and guilt for what happened to her. Her hope that nobody would find out that she wanted to hurt herself was also the hope that nobody would know that others had hurt her. This story has also shown that the everyday life of disabled people is a space without privacy, controlled by institutional staff or parents. It is a life of taboos concerning the body and sexuality, which is one of the reasons why disabled peoples are so often sexually abused.

Human Agency: Remembering for Oneself and for the Others

As it has been shown, the right to share personal memories in the public sphere is an important segment of active citizenship rights. Telling what was impossible even to think of shows that the person who tells carries a certain degree of human agency and power. This is especially important because many people with disabilities, especially those diagnosed with moderate, severe, and profound intellectual disabilities, or those who have an "invalid status" under the already mentioned Social Care Act from 1983, are declared completely or partially incapacitated by the courts and placed under guardianship as described earlier. They do not enjoy the rights of an adult and are dependent on their guardian (they have no right to vote, marry, be a witness in a criminal court procedure, or work). The grounds for an order that would in turn restrict or remove an individual's civil capacity were that the individual was deemed "incapable of taking care of himself or his interests" due to "mental illness, intellectual disabilities, addiction to alcohol or illegal drugs, or for other reasons influencing his/her physical or psychological state."⁹

Maja is an adult women diagnosed with an intellectual disability who lives with her parents. In the following paragraph she recalls the traumatic memory of a group rape that she experienced:

I have such a hard life, I had bad luck, I know how it is when you are seventeen, I was young, not even of age. I have this feeling, you know. I'd rather be safe or with some friend so that I feel safe. I know how hard it is to live like that, that you go out and somebody grabs you and takes you somewhere ... /tears/, I know, I had

such life, I'm telling you, if anybody knew how a woman like me suffered, with tied hands and tied legs, that two men took me to a flat, that it was dark in there, and they lubricated my lips when I came there, when we came there. I didn't know what it was, I couldn't speak, you know /silence/, and then they told me what it was, /silence/ they caught one of them but they didn't catch the other. But then the worse thing was, I tell you /silence/, I cannot go alone, I like to have someone to go with me, I can't go by myself, I had a hard life, I tell you, my life sucks. I know how it is when some man grabs you, and drags you to some place where they touched me, they pulled my shirt off /silence/, That's why my parents don't let me go out, or I'm happy just to go to the castle, they let me go there and I'm pleased. Only for me, it is so difficult that it will never be the same again and that's why I have this feeling that /silence/, you have to trust someone, you must trust, don't you? Only I am more quiet you know, and no one has ever felt what I felt, you know /silence/. Yes, and that's why I'm so quiet, but it is all right to tell, isn't it.

Maja speaks about rape as a sudden, unexpected event, a shock, which became a traumatic experience. She tells about her fear, which is a continuous response to the trauma and marks her attitude towards the world (*"only for me it is so difficult that it will never be the same again"*). The world will never be the same as it was before the traumatic experience. What she went through gives her a special knowledge (*"I know how it is..."*), which produces her exceptionality (*"no one has ever felt what I felt"*). However, the knowledge also deepens her loneliness: if there is nobody who experienced what she did, then she cannot share her entire story with anybody (she herself states that she is more "silent"). No one can be her "witness from the inside." During the process of testifying Maja encouraged herself with normative messages (*"you have to trust someone, don't you"; "that's why I'm so quiet, but it's alright to tell, isn't it?"*). She looked for a confirmation from the outside that it is right to talk about the event (*"it's alright to tell, isn't it?"*). She spoke about her own silence, which

formed her narrative (*“only I’m more quiet”*). Her narration, which touched a “deep memory,” an expression used by Holocaust memory researcher L. Langer (1991), has been from time to time switched into the normative knowledge, that it is “alright, to tell.” She needed support that she could testify and touch her “deep memory.”

Because of the rape, she is even more dependent on her parents who “do not let her go out.” The event of rape affected not only her personal attitude towards the world, but also affected her limited social network. Loneliness is the price that Maja has to pay in order to feel protected from the dangers of the outside world. During the interview, she expanded her individualized memories to the outer world which was the moment at which her memory became a testimony, a political act of her awareness that she had to tell the story not only to recall her personal memory, but also to remember it for other people. Maja has told the story also “for others to know,” as a warning, when she said: *“Sex with someone that you don’t like disgusts you and you are afraid of it. I just wish it wouldn’t happen to anyone. I want the others to know.”* Her wounded memory becomes a point of individual action; a means for building a positive identity since her “knowledge” can help others (*“I want the others to know”*). Finally she can do something for others. She took the opportunity to recollect her memories and reciprocate them to someone, a human right that was taken away from her by the institutionalization of her disability: since she was labeled as intellectually impaired, she was seen as “stupid” and unworthy to enter reciprocal relationships. She took the opportunity to share her personal, “special knowledge” to protect others from the same violent event.

Maja did not only remember the event, but she also spoke about the continuing traumatic responses and about the bodily memory that render her unable to differentiate between “sex” and “rape.” On a rational level, she defines “sex” and “rape” as two separate things, but on the emotional level, they merge into feelings of “disgust.” Her bodily memory is not only present in the case of sexuality but also continuously in the public space, which is for her is not a safe space; instead it is a place where she can become a victim again. Public space reactivates the feeling of fear, which she

herself experiences as a re-emergence of trauma, which lives as a bodily memory. This became obvious when she talked about her boyfriend, who she sees as a protection against violence:

That's why I like to see him, that he is there if I go somewhere, I have the feeling that I'm more safe because when I go somewhere I have the feeling that someone will grab me all the time. /silence/ Because it happened, when I was walking, I have the feeling that those two men grab me, that's why I don't like to walk in the darkness alone.

Maja's memory has continued throughout her life. Instead of having a chance to be protected from abuse, having the right to start a legal court procedure, or to be heard and believed, her traumatic memory became her life itself.

Conclusion

From the perspective of gender, it is not only the right to education, paid employment, independent living, and public access that are important for women with disabilities in order to gain more active citizenship rights, it is also the right to make reproductive decisions (with the help of reproductive technologies and supportive professional network); the right to be safe (from violence and abuse); to be protected (while still living in public care); and for what they have experienced and lived through to be heard. In Slovenia, the liberalization of the market and political access to the EU has yet to bring everyday citizenship rights to the most vulnerable people, particularly those who were, during the socialist regime, seen only as passive welfare recipients. Soon, the power of the old images has to be confronted with updated legislative reflections and actual inclusionary practices of all those spheres that create an important part of everybody's everyday life in today's societies.

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¹ Employment Service of the Republic of Slovenia, 2005.

² The Act Concerning the Social Care of Mentally and Physically Handicapped Persons, passed in 1983, Official Gazette of the Republic of Slovenia, 41/1983.

³ One of the newest laws on the employment of people with disabilities is called the "Vocational Rehabilitation and Employment of Disabled People Act" (adopted in May 2004) which surprisingly includes a variety of employment support schemes and creative, individual based possibilities to

enter the employment market. Although, it is said to open the opportunity for all people with disabilities, it entirely excludes people with intellectual disabilities who are still supposed to be treated according to an old communist law from 1983 that was mentioned above.

⁴ The distinction between “passive” and “active” rights, which was the division that created the traditional concept of citizenship, is still very obvious. Passive rights (or natural civil rights), were defined as those, “for whose preservation the society is formed,” and were given to everyone, while the active rights were denied for women, children, foreigners, and those “who would not at all contribute to the public establishment” (meaning disabled persons and those condemned to a punishment). Since the end of the 18th century the public realm and civil society were the spheres where only “the rational ones” and “men of best quality” were exclusively defined as political subjects. One politician expressed this very clearly: “The people who own the country ought to govern it,” in (Noam Chomsky. 1999. *Profit over People. Neoliberalism and Global Order*. New York: Seven Stories Press). The Marxist concept of civil society included only the male proletariat who were seen as having political subjectivity, as being the privileged subjects of history and thus laying claim to all citizen rights. The post WW2 conceptions of citizenship, which were implemented in communism, was essentialist and overlooked the gender, class, and ethnicity biased concepts of citizenship. In 1999, Plugh and Thompson pointed out, it was based on the idea of universal and undifferentiated citizenship, which *presumed that “all people have the same needs.”*

⁵ This is an example of a very gendered naming, as the suffix *-ka-* (*invalid-ka*) marks the female gender. In spite of the political demands of the disability rights activists to change the oppressive terminology, the new laws adopted in the last few years, have not changed the old terminology. Women invalids are, in the current laws, even subsumed under the male grammatical form “invalid.”

⁶ In Slovenia such an example was the first disability-led activist organization YHD- Association for the Theory and Culture of Handicap, founded and led by a woman, Elena Pecaric. The members started a personal assistance scheme for individual persons with disabilities who wanted to live in their homes and was entirely supported through the help of western foundations such as Soros (USA) and Matra (The Netherlands). This example shows, as Nanette Funk emphasizes in this volume, that the western foundations that funded eastern NGO's didn't only import western ideology, but also contributed to democratic changes and the support of several left and critical oriented not-for-profit organizations in Eastern Europe.

⁷ People who work in sheltered workplaces receive only monthly awards and not salaries. In 2005 the awards are between 5 USD and 180 USD, but on average between 20 USD and 80 USD per month (EU Monitoring and Advocacy Program 2005, 102).

⁸ A large art history exhibition, *Sexual Strategies in the Art of the West*, which was displayed in the Louvre in 1999, showed a close connection between violence and western sexual politics. In the words of curator Regis Michel, the director of the Louvre exhibition, "the art of the West knows sex only through a single word, violence, better to say, rape" (Nochlin and Solomon-Godeau 2000, 93). Visual art demonstrates that sexual drives and desires most often manifest themselves through the symptoms of castration, fetishism, disturbances, and violence. Looking from a gender perspective this is even more true in women's lives and was most wonderfully shown in the exhibition of surrealist art in the Tate Modern in 2001, where "unbound desires" were manifested in the fragmented, violated, and toy-made female bodies. See also Henrietta Moore 1994.

⁹ Non-litigious Civil Procedure Act of the Republic of Slovenia, art. 44.