CHAPTER SIX

"A GIRL WHO LIKED TO DANCE": LIFE EXPERIENCES OF RUSSIAN WOMEN WITH MOTOR IMPAIRMENTS

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The image of a disabled figure in a wheelchair is a generalized symbol of a person with a disability for whom certain adjustments of public space are important. The issue of the adjustment of private space or the experience of daily life rarely arises, since family and intimate relations of people with disabilities are a societal taboo, or absent, prohibited or exotic. However, apart from the public sphere and the norms set by society, the private sphere plays an important role in the lives of the disabled, including the personal experience of disability at a micro level: in their families, everyday routines and romantic relationships.

This chapter begins with short overview of publications relevant to the study of the life experiences of women with disabilities. Next, issues of family structure are considered using a narrative analysis of interviews with women who use wheelchairs. Various cultural, social, economic and political determinants effect the formation of certain types of family structure and attitudes towards family life. At the same time, they interrelate with biographical factors that reinforce or weaken the limits of freedom and private life.

The issues of individual strategies of coping and identity building will be discussed further on, and the possibilities of "moral careers" (Goffman 1959, 123) within the family will be analysed as ways of achieving a positive identity as a person with a disability. Using narrative analysis, I will demonstrate what role family plays in constructing the identity of a person with a disability, and how family members act as coauthors of individual biographies. This can be seen in those dilemmas of family life associated with the feelings, sexuality and emotional stability at the

microlevel of the life experience and identification of women with disabilities.

Women, Family and Disability: the Research Framework

In my earlier research on the issues of disability in Russia, I studied the families of children with disabilities, paying attention to those barriers and limitations which determine the social position of family and children (Smirnova 1997). The study was based on the family stress theory (Hill 1949), and it revealed a low level of stability in the lives of the parents of disabled children and demonstrated the role of such factors as the economic well-being of a family, the level of education and gender of a parent, and the age of the child and accessibility of support resources, including professional help in forming strategies of coping with stressful situations.

When analysing contemporary issues of social exclusion in the lives of women who parent children with disabilities, I tried to understand in what way gender stereotypes, inadequate services and discriminatory social attitudes hinder the development of tolerance in the social environment and prevent the full participation of children with disabilities and their families in today's Russian society (Iarskaia-Smirnova 1999). The study of motherhood as a social institution and a life experience was based on an analysis of narrative interviews with mothers of children with disabilities, which investigated the socio-cultural meanings associated with motherhood, including the responsibility for reproduction and caregiving.

An analysis of the resources and needs of children with disabilities and their families as seen in the medicalized discourse on the hard personal consequences of illness or disability (Thomas 1999) should be complemented by motives of the resistance and success of adults with disabilities, which are considered as a social construct (Oliver 1990). These motives are important in both public and private life, where disability policy is implemented by various social actors, including the people with disabilities themselves, their families, professionals, the community, and the state. A biographical approach and narrative method have been employed in an analysis of the subjective dimension of the life experience of Russian women with disabilities who experienced social transformation in the transition to post-Soviet reality in order to understand the value of their memories in a contemporary definition of disability (Iarskaia-Smirnova 2001).

One of the first collections of scholarly essays on women and disability was the volume edited by Mary Jo Deegan and Nancy A. Brooks (1985),

which challenged welfare policy effects and explored the double handicap effects in terms of discrimination, sexism and social isolation as well as ways to raise awareness and assertiveness in women. Disability policy encompasses the social justice and gender justice issues that have been examined with a focus on the capabilities approach by Amartya Sen (1999). While being in support of his theory, Martha C. Nussbaum (2003) argues that capabilities supply guidance superior to that of utility and resources, but also to that of the social contract tradition and at least some accounts of human rights. She emphasizes the importance of care for people who are dependent as a central element for gender justice because most of the caregiving for such dependents is done by women, often without any public recognition that it is work. The time spent on this caregiving disables women from many other functions of life, even when a society has in other respects opened those functions to them (Nussbaum 2003, 26). To include mobility in the list of capabilities is crucial (see about gendered mobilities in Uteng and Cresswell 2008), especially when talking about female wheelchair users (Reid et al. 2003).

Women with disabilities share their dreams and disappointments with other women in a society that persists in viewing disability as an emblem of passivity and incompetence, and as a consequence, disabled women occupy a devalued status in the social hierarchy (cf. Fine and Asch 1988). Therefore, it is important to study the life experiences of women with disabilities who strive for an identity against societal prejudices that deny women the capability for many important relations and roles (e.g. Prilleltansky 2003). The stories of "intimate citizenship" (Plummer 1995), family life, gender and sexuality are not only private, but they also become political when they help to redefine normality and to achieve the recognition of those who usually are silent and ignored by the powerful majority. These stories help to reveal the forces that push disabled women towards the margins of social life and the resources that enable these women to resist the stereotype (Fine and Asch 1988). Among such forces, researchers have emphasized the relationships (Fisher and Galler 1988; Shakespeare 1996) that sometimes become violent gendered and disabling experiences (see Mays 1996; Smith 2008).

Six interviews with women who use wheelchairs were conducted in 2002–2003 in Samara with the help of Irina Dvorianchikova, a postgraduate student at Samara State University. Participants of our study included Yulia, 30 years old, who has been disabled since she was 22 (multiple sclerosis), she lives with her parents and works at home; Evgeniia, 35 years old, who has been disabled since she was 10 (a vascular disease), she lives with her husband and mother and works in an

organization of people in wheelchairs; Marina, 24 years old, who has been disabled since she was 15 (miopathy), she lives with a non-disabled partner and works at home; Tamara, 49 years old, who has been disabled from birth (cerebral palsy), is divorced and lives with her son and works at home; Liubov, 33 years old, who has been disabled since she was 21 (multiple sclerosis), she lives with her husband and 9-year-old son and does not work; Liudmila, 22 years old, who has been disabled since early childhood (a complication of meningitis), she lives with her mother, brother and grandmother, and works at home.[1]

The peculiarities of individual biographies are determined by unique opportunities of choice that exist in the life of each human being. Individual choice and self-determination are heard in the personal stories of people with disabilities that are told in the interviews. In these stories, we hear the voices of people who feel restricted "inside the category of disability" (Mairs 1996), i.e. in the frames of an identity defined by a diagnosis and defect. At the same time, disability plays an important role in the lives of these people and therefore becomes a starting point in a personal or collective redefinition of one's identity and of social relations.

Family Structure as the Focus of Study

Choosing the family life of people with a disability as a focus of this study does not mean that such families have fixed and presumed qualities that distinguish them from all other families. Rather, the idea is to see how typical family problems are affected by the disability of a family member and in turn influence the life opportunities of the disabled person.

Some of the women in our study emphasized their similarity with the majority of other people in all respects except in mobility. The size and composition of a household or a family were not the main criteria in our analysis. Rather, the analysis addressed the emotional qualities of family relations and the forms of intimacy between the spouses, parents and children, which constitute a focus of interest for a social scientist, according to French historian Philippe Ariès (1962). In his view, the family structure is considered as the types of connections between the family members, influenced by the special needs of one family member. In such a context, the gender peculiarities of the family structure should be considered as well.

[1] All the interviews were recorded and then transcribed. I use pseudonyms instead of real names in the analysis.

According to a leader of a local organization of people in wheelchairs, as a rule, disabled people want to live independently; however, their wish to be independent is not always realized, especially for those who became disabled in childhood and are living with parents. And for financial, emotional and physical support, the families of those who become disabled as an adult invite the parents to help them. Unfortunately, quite often, when a family member–especially a woman–becomes disabled, her spouse leaves the family, as I was told:

> There is a risk that a family will dissolve in such a case… But there are also good examples, when they stay, when the husbands take very good care of their wives in a wheelchair (Aleksei, a leader of the organization of people in wheelchairs)

For example, Liubov said that she is fortunate that her husband did not leave her when she became ill; he takes care of the whole household. Some interviewees noticed that it is easier for disabled men to arrange their lives, referring to gender-specific social rules:

> If a man has a disability, he usually is more successful in building a relationship with a "healthy" person than if a woman is a disabled. This is because society dictates that the woman should clean, wash, cook and perform certain functions at home, while from a man, our Russian, Soviet society may only demand that he earns money and not necessarily knows how to wash his plate after a meal. He thinks it is permitted by society. (Marina)

These attitudes reflect stereotypes existing in society. It is true that people in wheelchairs have difficulties finding a marriage partner and that marriages and families do sometimes fall apart, but our research shows that the family experience of the disabled is very far from being completely shaped by the dogmatic prescriptions of the "normal" majority.

According to Baskakova and Baskakov (2000), "the marital status of men and women with disabilities differs significantly by many indicators, including 'married', 'divorced', 'widow/widower' and 'cohabitant'". The share of widows is three times more than that of widowers, which can be explained by general social demographic trends–differences between the life expectancy of men and women and the tradition of the husband being older that the wife. The exception is "not married", for which the proportions of men and women are practically the same, about 6%.

It is important to take specific mechanisms into account, mechanisms that are characteristic only of families of the disabled. For instance, the fact that the share of divorced women is 2.5 times more than that of men is

more probably explained by the "gender differences in the value of marriage and responsibility for a spouse and a family, which are realized in a specific way in the families where a member is disabled. An indirect proof of this hypothesis is the fact that a father often leaves a family when there is a child with a disability" (Baskakova and Baskakov 2000). Yulia thinks that it is the husband's female relatives who contribute to a family breakdown:

> If his wife becomes disabled, they tell him: you should look for another woman, this one is not a blood relative to us, and you may leave her and find another one. Such situations happen and one cannot get away from them.

The prescriptions of the gender roles of people with disabilities that exist in society and culture are contradictory: on the one hand, disability threatens masculinity, while female gender identity is compatible with the qualities of the passivity of the disabled (Iarskaia-Smirnova 2002); on the other hand, women with disabilities acquire a stigma of double inferiority because their reproductive and economic functions are challenged.

Society, through its kinship structures (relatives of the husband, as in the above-mentioned example), through its medical workers, and due to the lack of institutional support, deprives women their right and desire to have a child. Moreover, the unpaid female labour taken for granted as an inevitable part of family economy may be significantly decreased by a woman's disability. Society blames the woman with a disability who has become a wife and has given birth to a child in cases when something goes wrong in the lives of their children. A feeling of guilt and worthlessness may be reinforced by the social surroundings, as shown in this study. Therefore, the issue of social exclusion in regards to women with disabilities becomes very important. Feminist researchers confess that they have experienced new challenges and have encountered a whole range of new questions in studying the problems of women with disabilities (Kelly, Burton and Regan 1994, 31), because the problem of inclusion, which is central to feminism, acquires a new meaning in the context of disability.

To Be or Not to Be Disabled

In spite of the individual nuances of biographical trajectories and the uniqueness of today's life situation of the research participants, all of the interviews are connected by several fundamental themes, including an articulated need for independent choice as well as the recognition of the important but very controversial role of family.

In adjusting to a disability, a person learns to value little moments of everyday life–an opportunity to go to a new place, the freedom of personal choice, even such little pleasures as ice cream, beer or just a walk in pleasant company:

> And you see ice cream–not just an ice cream that somebody has chosen for you–but you drive to this kiosk yourself, choose which ice cream you would like to eat, and something else, well, the feeling of some freedom, at least in the choice of that ice cream. (Yulia)

Lack of space, limited community access and other barriers were reported by the women of this study. However, various tactics of gaining personal autonomy and interpersonal relationships were taken up. By Yulia, the wheelchair was described as what Reid et al. (2003) have labelled as "a liberator and sense of comfort". For Evgeniia, the freedom of choice is combined with her adventurous temperament:

> I am always engaged in some adventure, but it is better than doing nothing. Having understood that the water does not flow under the still rock. I decided to publish an advertisement in a newspaper.

She did not mention in the advertisement that she was disabled, but did describe her "state of mind–and of course I wrote about my height, weight and such, and that I am looking for a friend". Three people answered, and none of them stayed with Evgeniia after learning about her disability. She published the ads once again and found a young man with whom she has now lived for four years "happily, though there are all kinds of days". She says that her husband rarely sees her at home as Evgeniia is very active in an organization of people in wheelchairs.

Marina believes that one should not exclude a disabled person–a child or an adult–from the process of making important family decisions. Her mother's doing so led to a dissolution of family ties:

> I moved in together with my mom. I think, however, that it was only her who moved, and she just took me as a puppet. I had my own life, and it had just become satisfactory–I started going out, making friends, putting down roots, trying to realize myself, earning some money, just living as I liked. I liked my active life. And my mom, she found herself alone; she decided to move and sold the apartment. A week before our departure I learned that we have tickets to Samara–what nonsense, it is just unreal, no one should do this. I was nineteen, and of course I could not imagine my life without my mom and she also thought so, which is why she made the decision without even discussing it with me. I was very hurt!

Perhaps just as the most people who have experienced family life, the women of this study recognized the high value of family, but at the same time they noted contradictory feelings. The formula "family is everything for me" is a *leitmotif* in the interviews. On the basis of their own experiences, as well as from observing other disabled people's lives, the narrators offered their own theories on spousal and parent/child relations. According to Marina, hyper-protection in the relations between parents and their disabled children may become, a reason for the future isolation of an adult with a disability and may decrease his/her chances of having a family life. In Marina's case, the relations between mother and child in her case were characterized by the abuse of power and the ignorance of certain important wishes and priorities of the child. In such a model of family relations, in addition to the formation of a hierarchical age and gender structure, the important ideological role that the family plays in the stability of a social system is also seen.

Indeed, a family as well as a number of other social institutions is a reproduction of the status hierarchy of society. People with disabilities, who have learnt passive and dependant roles in family or at a boarding school, experience difficulties in their adult life.

Personal Agency of Women with Disabilities

United by the same primary feature–limited mobility–the narrators understand their disability in different ways: some of them think it is an unavoidable disadvantage; others believe it is one of their peculiarities, along with the colour of their eyes and hair style; some see it as a resource of change and development. For example, Tamara does not see any possibilities of improving her life situation. Even moving from her apartment on the fourth floor to a similar one the ground floor, which could make the mobility easier for her, seems to be unrealistic for her:

> I cannot even leave my home. I can do it only in the summer time, but not in the winter time. This physical barrier is the most important. And to remove it, to change apartments, I have a lack of finance and possibilities to change anything. [--] Personally, I do not want anything for myself.

However, for others, changes in their life situations are not only possible, but an inevitable part of their existence. For the narrators of this study, the wheelchair is an inevitable part of their everyday life; in addition to the telephone, it is an important means of communication with the outside world, their mediator in exploring and constructing social space. In the narratives, the wheelchair is depicted as a device with many not yet

exhausted resources. The wheelchair transforms and can "turn into an ordinary table", making a situation of interaction with friends a wonderful routine:

> Imagine, we are going, meeting somebody. It is possible to sit down on an ordinary bench, drink beer as normal people do in such a situation, and you never have been drinking like this before… [You feel] such a pleasure, just like normal people, and the wheelchair is like a table, the beer is standing on it, some nuts, something else, and people walking around do not know about you, who it is, what is going on, where it came from. It is funny. And not everyday such things happen… (Yulia)

Yulia perceives her disability as a source of a new knowledge, a way of exploring new qualities in oneself and other people, or even as play: "This situation helps you to discover traits of life which you otherwise never would have seen". The disability itself sometimes becomes a new starting point in a life choice. This transformation adds new sense and sensitivity to the everyday routine and to life as a whole. In some cases, it also helps to develop empathy with others, as Yulia described: "Such a situation helps you to be open such to qualities of life which you could not have seen otherwise".

Disability is not just a load and immobility; it is not merely a condition. It also moves, enlightens, and sharpens the sense of time passing, as Marina's narration shows:

> Well, I understand that it is unlikely that [I] will live until I get grey hair, though who knows what awaits us in life, and one should value the moments of life because of that. I had a period in my life when I became ill, in the beginning, but I felt much better than now. I did not value that; I simply mourned what I had lost–my health. And when I feel as bad as now, I remember: how do you know what will happen tomorrow? Maybe tomorrow I shall lie on a sofa. Why should I not value what I have now? See, the illness taught me to be friendlier; I have developed a different attitude to people… to accept them as they are.

For several women, their disability does not mean collapse, isolation and loneliness or the end of adventure, discoveries and challenges. It is just another type of challenge, through which one may express and strengthen oneself, for example, by loving life, people and oneself. For Evgeniia as for several other women, disability is creative and rational work, a special philosophy and a way of life.

> The history of my life? Once upon a time there was a little girl who liked to dance... I loved everything that is alive, that is moving, twisting, not staying in place, loved to be with people, to have parties, birthdays, celebrations, all this I loved [but] I have to spend more time alone, now– have both, fifty–fifty. Then, when the girl has grown up, a pile of problems has occurred, which she has been solving on the sly, thanks to the people who were near her. [Problems,] which she has understood in due course. In my life, I was surrounded by good people most of all. Well, if somebody would ask [me]: [raising her voice] would you prefer not to be? I was thinking about it recently. I think that sometimes, I would prefer it. What was before this period always was a discomfort, often not pleasant, not good about health. Perhaps, it was necessary to overcome such a period to understand that what is happening now is good and remarkable. (Evgeniia)

One interview partner told that each individual may or may not treat her/himself as disabled. This shows that the life strategy of a person with a disability is to a large extent a matter of choice. Moreover, although in a situation of choice an actor is always opposed to a structure, we may surely say that within the walls that surround a person and his or her disability, within the walls that seem to be unchangeable and insuperable, there is always an exit. The key to this exit can be found if one is understood and accepted as a human being in one's family, including all one's emotions and needs.

Disabling and Enabling Social Environments

Social expectations ascribe a person with a disability a passive position in life, a state of hopelessness and dependant attitudes, which together, paraphrasing Freud's "anatomy is a destiny", meaning that one's sex determines one's main personality traits, could be expressed in the slogan "disability is destiny". At the same time, in their own examples, many of the narrators show that they are creating their own destiny, their biography that they are "writing" with the help of and together with relatives and close friends.

The life experience of families with a disabled member is first of all specific in relation to the needs to adjust the environment. The inconveniences of everyday domestic life are known to the millions of Russian citizens, while those who are disabled perceive these difficulties even in a stronger way. The women of this study emphasized the complexity of organizing a domestic space where many simple things have become difficult. They also shared their ideas on how to overcome or adjust to these complexities. There were no rich people in the sample, and none of the interview participants could afford to buy remote-controlled

expensive equipment. In order to adjust their homes to the special needs of a person in a wheelchair, the family members invent new devices and contraptions, making them from any materials available. The attitude of the narrators to private space was similar to the attitude towards the disability itself, which is perceived as one of the conditions of everyday life that requires certain adjustments from all family members.

Those who have a child or an adult with a disability in their lives continuously make changes in the way in which they work and live. To accept the disability is only the first battle; the second challenge is to change oneself (Spiegle 1993, xiii). These changes help to decrease stress, which is inevitable in the everyday efforts of the families–especially in today's conditions in Russia.

Such processes of adjustment of the family members to each other and to the disability itself require a great deal of energy. As a result of these processes, an atmosphere of friendly support is created.

On the other hand, the disability also tests the strength of social networks, as Yulia described:

> [They] were friends before and then have disappeared… When one finds oneself in such a situation–it is like a sieve, it screens, sieves people, so that you see who stays with you and who are for themselves.

In such cases, rehabilitation is needed not for the disabled and their families, but for those who are close:

> They needed a lot of time, a period of rehabilitation, in order to deal with and understand their own feelings.

Thus, social environments, networks and relations can disable or enable a person to live a full social life. As the United Nations Convention on the rights of persons with disabilities proclaims, "disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others" (Convention… 2006).

The Borders and Freedom of Private Life

It is possible to group different ways of positioning oneself in relation to family into several types of strategies. Obviously, we cannot speak about the pure types of strategies found in the narratives; this is just one of the possible interpretations of the family structure types constructed out of the

analysis of the interviews. The polar strategies are represented in the following cases. The first two cases show the effects of total subjugation of oneself to the family hierarchy, while the third and fourth cases illustrate negotiations of individual freedoms between family members.

Case One. A Public Child: Tamara

To a large extent, Tamara's life was predetermined by the family culture in her childhood family and her formative years in a boarding school. She has contradictory feelings towards her parents. On the one hand, she mentions only biological relations with them:

> They have just given birth to me. I did not love my parents because I was not brought up at home, beginning from a young age–sanatoriums, hospitals, boarding school. I was rarely at home. Somebody joked that I am a public child… as I was mainly on state provision [with tears in voice].

The father, in her words, "just fulfilled his paternal duty by taking me to the school on his back or on a sleigh". And as for her relations with her mother, she told:

> [I] had no such tenderness, as can be between daughters and their mothers, such warmth and attention as can be given to a child who is brought up at home... There were, of course, a child's hurts that I could not express to her, and she did not understand [me], and I was very self-contained. And she was taught by life; she saw the war, she saw the Germans, which is why she had some sort of nervous condition; however, she saw her attitude towards me in her own way.

At the same time, the death of her mother was a strong stress factor for Tamara, which resulted in the worsening of her health condition; also her ability to move by herself significantly decreased. The lack of emotional familial ties in Tamara's life, according to her own words, led to dry and alienated relationships in her own family. While all the other narrators recalled their childhood with a special emphasis on play, which is absent in Tamara's memories:

> We didn't have any games… I was on the skids, what games could I take part in? There were routine study days. I do not remember even."

The lack of family experience and the absence of psychological support and physical help in building a family characterize her life today. She was married to a disabled man; they had a son and later divorced. She lives

with her grown up son, and in her family are no holiday traditions or parties, and no rules or feelings are discussed.

The research showed that not only disability by itself is a mediator determining the mother's opportunities and limiting the available choices for mothers and their children, but that poverty and single parenthood have also a strong influence (Read 2000, 112). Under such conditions, mothers would often ignore many needs of their own in order to satisfy the needs of their children; they would fight for the resources to create such a space where their children and their relationships could flourish. As Tamara's case shows, such a space becomes even more restricted when there are no positive models of motherhood obtained from one's own experience in childhood, the experience of close relatives and friends, or with the help of family therapists and other professionals.

Case Two. Liubov: "A Tiger May Eat a Monkey"

Liubov is 33 years old; she is married and has a 9-year-old son. She decided to carry and give birth to him in spite of doctors' warnings about the risks to her health; she was diagnosed with multiple sclerosis prior to her pregnancy. After the birth of the son the illness progressed, and Liubov has been is in bed since 1999. She considers knowing her husband and the birth of her child as the brightest events in her life.

Previously she cooked, shopped and worked, but now his husband takes care of domestic work:

> He [husband] does everything himself. See, he deserves a monument to himself… He brings up our son, he washes our son's pants, while I... [Decision making] does not happen here. Again, he himself makes all decisions because he is such a person, he is a Tiger according to the [Chinese] horoscope. While I am only a Monkey. And it is said: a Tiger may eat a Monkey.

The behaviour of her spouse became rather authoritarian, but Liubov completely accepted it:

> He can shout, for instance. But he takes such good care of me, very good care. I am not at all judging him, I understand everything, I am grateful to him so much!

At present, she is excluded from the decision-making process, and in her words, this is natural as she "cannot decide anything, while he does

everything better". This indicates that Liubov is deprived of her human rights by the moral violence that she is subject to. A recent analysis revealed that women with disabilities experience almost twice the rate of all forms of abuse compared to other populations. According to Diane Smith (2008), factors that increase the likelihood of becoming abused include being young, female, disabled, unemployed and single.

Liubov developed her own theory that justified her descending place in the family. As her husband was never interested in her opinion, wishes and priorities, she rationalized her own worthlessness in the eyes of her spouse and son. She felt degraded in the depths of her soul: "No, he never asks [her voice breaks]. What sort of opinion can I have?! Here, on the sofa?" Although in her narrative there was some inner protest, it was suppressed and lost in the shadow of the monumental and sacred figure of Liubov's husband: "A family for me is everything. A husband is for me everything, see… Seriozhka, such a man!" Liubov seemed to be dissolved in her family, where she obeyed physical and psychological restrictions that are justified to her by the philosophy of the Chinese horoscope.

Cases Three and Four. Family as a mutual obligation: Marina and Evgeniia

For Marina, family relations seemed to be a type of work: "it is responsibility, relations, which should always be worked with". She has set up and achieved her goal of living independently from her mother: she has an interesting job and lives independently, although her mother often visits her.

In Evgeniia's narrative, family was not only a place, but also an obligation:

> [family is] an obligation that you take on, for yourself and for others. It is an understanding that they do not owe you anything, and if you want something, you should do it yourself.

Evgeniia stressed the proactive, negotiable, reciprocal and rational nature of relationships in addition to caring and warmth. We can see not just psychological attachment but the large and substantial emotional work of family members–both parents and their grown-up children. As Rousso (1988, 139) writes, the parents are "a powerful influence on the degree of social success as culturally defined, of adolescent women with disabilities". But the young adults explore their mutual obligations and support while building reciprocal relations both in their parental families and with their partners.

In the narratives of the women of this study, a model of the universe is constructed. Here external and internal worlds of individuals and families are cemented by a degree of freedom and responsibility, by the opportunity to change and the permeability of the borders. The refrain "Family is everything for me" that was heard in most of the interviews, presents a continuum of meanings ranging from *freedom* to *borders*. Freedom, which is provided by family, is highly valued–this is a space for self-realization under the comfortable conditions of mutual support and understanding, compared to the risky environment outside the family, as in Marina's case.

In other cases, family as the only refuge, as a place of survival, is connected with a bitter reflection on the narrowness of one's own network, which concerned Yulia. For Liubov and Tamara, the word "everything" meant that the worldview of a person is restricted exclusively by the frames of family, while personal choice, needs and wishes are reduced to a minimum.

The personal position of the narrators in relation to the freedom, promoted by the family, and the restrictions set up by the family is located between the poles of subjugation and resistance. This is because human subjects do not always passively internalize the structures of the relations, offered by the family. In the family research, family relations have often been characterized by patterns of domination; however, practices of subjugation often are confronted by various forms of control and resistance (Poster 1988, 165).

Discussion

This research takes part in a long debate about societal norms concerning disabled people's life experiences and the uniqueness of them. It is only an attempt to sketch a rich description of the family practices in which people with disabilities are involved. In order to consider the issue of moral careers inside the family, it was important to learn to what degree family structure reinforces or weakens the hierarchies caused by disability, age and gender.

This study provides a window into the real life of families who are directly involved with disability, who have accepted it and who have experienced a range of changes. I would hope that the voices of these women who live with a disability help us understand that the families of the disabled are similar to other families, but there are certain risk zones that are constructed by social convention and a lack of social support from professionals and the community.

In his critical theory of the family, Mark Poster (1988, 202–204) wrote about a frightening choice that people encounter today–the choice between family and complete loneliness. Family provides a person with disabilities with psychological comfort, a supportive network and freedom from societal control. At the same time, family builds hierarchies of age and gender, which reproduce social inequality within the family as well as in society. In many cases, family is unable to solve the problems formed by the inequalities in society. The organization of contemporary society often contradicts the interests of men and women with disabilities. In the stories discussed above, the choice is made in favour of family. The choice is based on necessity, or on love, respect and attachment.

Families of disabled people are not all alike and should not merely be classified as "risk groups" or "families with problems", but these families encompass a great variety of cases. Families of people with disabilities experience as many ups and downs of spousal and child/parent relationships as other families; they have dreams, plans and realities, just like all the others. The patterns of child/parent and spousal relations in the cases that we have observed nurture the potential of the social mobility of the disabled and help them to be independent and to build positive identities. However, sometimes these relationships develop a mode of possession, authoritarian power and subjugation that can be protected by the familial ideologies of romantic love, domestic chores and a mother's care. Such ideologies deprive people of community resources, make them ignore each other's needs and, as a result, break down the relationships. Many of the problems that people with disabilities and their families experience are caused by prejudices towards the disabled, gender stereotypes and quite typical interpersonal conflicts.

The experience of the narrators and their families shows that they have survived challenges and became stronger. Moreover, allowing children or adults with disabilities to make a choice and to take a risk (usual event for each "typical" human being) raises human dignity and mobilizes each individual with feelings of self-reliance and confidence (Spiegle 1993, xv).

In spite of the differences in the women's experiences, many of them have devoted most of their energy to career and to love. Some of them found establishing romantic and sexual relations difficult. The narratives of some other women were bound with the public narratives and meta-narratives of gender and disabilities (Thomas 1999, 51), where the "disabled" body was constructed as poor, asexual, regulated by public discourse and controlled by the state.

In a society which equates worthiness and beauty to physical strength and health, a woman with a disability feels the physical deficits more than

any other. Although some women discussed their life experience with bitterness or even apathy, many others seem to perceive it as a challenge. Even though their lives cannot be considered perfect from the viewpoint of societal standards and negotiations, these women believe that they live productively and passionately. Their stories are not the "the histories of triumph over tragedy" (although they have had tragedies and triumphs), but, following Nancy Mairs (1996, 145), their stories are adventures as they explore unknown territories and draw their own maps, which they can then use to navigate and to lead others.

The symbolic barriers that are constructed by the Russian society are difficult to overcome; both Soviet and post-Soviet models of disability are medical, in which the most significant feature is the provision of medical help to restore a disabled person's ability to adapt to society and in particular to work. Among the dominant themes in the Soviet approach to disability from the very beginning, the most persistent was "who does not work does not eat". This maxim resurfaced explicitly at several points throughout the 20th century and was implicit in insurance-based healthcare for workers only and in the notion of the "rational management" of disability in relation to a person's capacity to work, which was certified by medical doctors. Paradoxically, the development of the "rational management" of disability ultimately led to the marginalization and exclusion from work of some disabled people, both men and women. Some forms of disability were classified as capable of work; others were excluded. Military disability was prominent after both world wars, and, in theory, disabled soldiers received the largest pensions and privileges, while in reality, these forms of support were not always delivered. However, war-injured men received more respect and attention, while mental impairment, women, children and the elderly were excluded from the war and labour heroics of Soviet disability discourse.

The establishment of nursing homes, advertised as a benefit of socialism, often led to the removal of disabled people to isolated venues. Gradually state control and isolating forms of care provision increased, so that by the 1960s there was little chance that a disabled person could have economic independence. Late Soviet disability policy during the stagnation era cultivated even more medicalization with its emphases on science and technology and the *sobes* (social protection) treatment of disability. These are the two pillars of the contemporary paradigm of disability policy where the disabled are clients and patients. At the same time, in late Soviet society, the shoots of the disability movement started growing but were trampled rather effectively.

Today's disability policy is still paternalistic and medicalized, and gives priority to soldiers and workers over children. This policy manifests itself in inaccessible housing and public buildings, transport and services, as well as in the reproduction of negative stereotypes in social attitudes. Since the early 1990s there have been several important changes in the disability policy, some of them rather contradictory according to the universalistic and liberal principles of the time. In September 2008, Russia signed the UN convention of the rights of persons with disabilities (Convention… 2006), and since then more attention is paid to issues of building an accessible environment and respecting the rights of the disabled.

The assumption that medical professionals are experts on disability is one of the greatest challenges in conducting disability advocacy in post-Soviet Russia. This assumption prevails among ordinary Russians as well as and disabled people themselves. The non-disabled "expert" approach towards disability activism has been less than effective at the local level, where disability issues are more deeply affected by public attitudes and assumptions than by technical expertise. Russian disabled women are actively pursuing their dreams within a system of poverty and great physical inaccessibility, and in spite of a history of ignoring and warehousing disabled women. Current disabled women leaders see an immediate need for service-based systems run by and for women with disabilities. Throughout Russia there are only a handful of experienced disabled women leaders, but more and more women with disabilities are taking new leadership opportunities through training offered to youth by disability organizations, community leadership development programmes and economic support projects (O'Toole 2000).

There are organizations led by women with disabilities and mothers of children with disabilities in Russia. Some of these organizations, for example in Moscow, Novosibirsk, Kazan' and St. Petersburg, offer programmes on business and employment, peer support, and health. They provide job training and placement, operate legal clinics, sponsor wheelchair dancing, vocal and sports groups, and offer counselling and vocational training to women with disabilities. A few such organizations conduct workshops for young women with disabilities on health, sexuality, community integration and rehabilitation, offer medical consultation and peer counselling for disabled women, and participate in international conferences and trainings. Some of their programmes assist women with disabilities who are home-bound, lacking community access, to learn sewing, telephone and other home-based work.

The activity of such organizations focuses on issues of disability which impact women's lives, not only those of women with disabilities but also non-disabled women who are directly impacted by disability, such as mothers of disabled children. A special task is to create resources for disabled women with small children. Advocacy groups help women with disabilities to develop the abilities necessary to actively participate in society, to uphold the interests of women with disabilities on the governmental level and to demand equal opportunities for women with disabilities from other members of society.

Giving voice to women with disabilities through research into their family life experiences can change social attitudes towards the disabled and their families. I would hope that the families and professionals who work with the disabled can gain new resources from these stories for the acceptance and understanding of the problems which they encounter every day and for the development of new forms of support on the side of public and non-governmental organizations.

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