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"What the Future Will Bring I Do Not Know": Mothering Children with Disabilities in Russia and the Politics of Exclusion

> "Hard" is not the word. . . .When I was working, I built an apartment, but now it is so expensive, you have to pay around 60,000 rubles a month. It is very hard, I do not know how I will manage. I cannot afford to lose this flat because T. [her son] needs it; it gives him the environment he needs. I do not know how I will pay for it. On the whole, we get by. What the future will bring I do not know. . . . Once we started talking about it, and I told him things would get difficult for him. He said, "It won't be difficult for me because if you die, it means I will die, too. Your death will be my death." He understands it quite clearly. "I will go to our neighbor and ask her to cook a pail of gruel. . . . For the whole week I will eat the gruel. When it's finished, I will knock on her door again." And that's how it is, both jokes and sorrow."
>
> —parent of a Russian child with a disability

Russian mothers of children with disabilities face a complex crisis, and there is not yet an accepted institutional framework in Russia from which to examine that crisis as a women's issue. The reasons for this lack of framework are two-fold. First, research on women's issues was rare during the Soviet period.[1] Recent changes in Russia have contributed to more openness, plurality, individuation, and reflexivity in society, and gender studies and women initiatives are gradually spreading across the entire country. However, most resources for gender studies and support for women's initiatives in Russia today are offered by international foundations such as Ford and Soros, and, judging from the content of contemporary journals and curricula, it is clear that official mainstream attitudes do not encourage an open forum for the discussion of gender problems.

The second factor is that issues surrounding disabilities are even less discussed than gender issues. Although a few institutions caring for children have a lot of experience and provide exemplary care, many have compromised themselves and have come under scrutiny for their methods of diagnosis and treatment by Russian journalists in the 1980s and now by human rights organizations.[2] The 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." These institutionalized "orphans," once diagnosed as uneducable at age four, have been routinely confined to inadequate, understaffed facilities, are frequently bedridden, and sentenced to a life of neglect, if not abuse. In addition, parents who desire to care for their children have been warned that they and their children will be outcasts in society because of deep cultural beliefs that even minor physical or mental disabilities misfit children for useful life and citizenship.[3] This article shows how the personal experience of women struggling to care for their children with disabilities at home demonstrates a need for gendered critiques of entrenched exclusionary policies that affect such families.

This article addresses the contemporary politics of social exclusion and its institutionalization through an analysis of interviews with twelve Russian mothers whose children have disabilities. The women resided in Saratov, a town that has borne the consequences of social and economic change sweeping Russia. Through the interviews, it is possible to see how defined gender stereotypes, insufficient services, and discriminatory social attitudes toward children with disabilities frustrate efforts to develop social tolerance, inclusion, and participation of disabled children and their families in contemporary Russian society. Institutionalized aspects of motherhood with their associated social taboos compound the problems created by the scarcity of resources available to caregivers. The women's narratives are indicators of the socially constructed nature of exclusion within Russian culture and the strain it places on the women's sense of autonomy and identity. I use narrative analysis to interpret the women's stories, which were recorded and analyzed in Saratov, Russia, from 1995 to 1997.

Saratov, a city of about one million people, is a provincial capital and industrial city located on the Volga River about one thousand kilometers southeast of Moscow. Saratov is typical among other similarly sized industrial Russian cities that have suffered extreme socioeconomic difficulties during the ongoing transitionary period. In addition, Saratov depended upon the defense industry and, unlike other Volga cities of the same size, it was a closed community until 1991. After plant closures and massive layoffs from weapon factories during the 1990s, Saratov's population faced unemployment and poverty. In December 1993 the official unemployment rate in Saratov (10 percent) was comparable to the average in Russia as a whole (11 percent) and several other Volga cities (Ulianovsk at 8 percent and Astrahan at 13 percent), but higher than in two large neighboring cities in the Volga (Samara at 3 percent and Volgograd at 3 percent). By 1994, Saratov industrial production levels had sunk to among the lowest in the Volga region. Women comprised 71.8 percent of the registered unemployed in 1995.[4] The economic decline not only influenced family budgets, but also decreased public spending on child care, health care, education, and the family support social network.[5] Despite Saratov's specific economic history, the consequences of the socioeconomic shift for parents and children with disabilities nevertheless compare closely with those experienced across Russia as a whole, as parents and children face scarcity of services and support.[6]

The twelve mothers of children with disabilities whose narratives are examined here were interviewed by a colleague of mine, a psychologist at a rehabilitation center. Interviews were voluntary and generally unstructured, although the interviewer was provided with a list of important questions to cover. Women between the ages of twenty-eight and fifty-four agreed to be interviewed. Their children were between the ages of five and fifteen. Four of the mothers were single. Seven women reported that they were unemployed. I decoded and analyzed the taped interviews as texts, using an approach that asks how meaning is being constructed and how it might be constructed differently—in other words, analyzing the contextual basis of motives.[7]

The women constructed their lives as they talked about themselves. Each woman narrated her past selectively, based upon her values and interests, as interviewees do, especially in telling about complex and troubling events.[8] However, the historical truth of an individual's account is not the primary issue; rather, in the words of Anthony Kerby, "The narrative is the meaning of prenarrative experience."[9] Such acts of self-narration are fundamental to the emergence and reality of that subject.[10] While analyzing the experience of mothering as a socially constructed phenomenon, it is possible to consider women's identities in terms of exclusion, autonomy, and dependency. What kind of identities do Russian mothers of children with disabilities construct for themselves in their narratives? Do they seek autonomy or dependence? Do they live in solitude, or do they feel supported, helped, included? At the same time, institutional context must be taken into account, particularly in regard to gendered cultural stereotypes, which can be obstacles for families coping with stress.

The Politics of Exclusion

Motherhood becomes institutionalized when a set of cultural practices and representations are selected as qualifications. The selecting process reduces the variety of motherhoods to that particular matrix of meanings and simultaneously identifies and excludes differences and exceptions. The intolerance of nontraditional mothering roles is reproduced in the social environment when mothers of children with disabilities are identified as different and cast out of society, an example of the phenomenon defined as the "autonomy of the environment" by Emmanuel Levinas.[11] In this process, the social environment neither permits diversity nor recognizes the special needs of individuals with disabilities and their families. Because consumer goods and services, leisure activities, and almost all aspects of public life are usually designed with the able-bodied person in mind, people with disabilities and their families find themselves consistently requiring the exceptional.[12] The exceptional is more expensive than standard issue, and there is usually insufficient money to allow a Russian family to pay for goods and services that would make life easier. The family generally finds itself excluded because of its special needs and forced to rely only on the energy and muscle power of its members. The "autonomous environment" that provides insufficient and low quality services for children and families overburdens women, forcing them to leave their jobs and depriving them of time to recover their physical and psychological strength. Additionally, the lack of social tolerance toward "otherness"—that is, toward the atypical appearance or behavior of a child manifested in everyday interaction—denies the mother any chance of emotional support or acceptance from those around her. Social attitudes in Russia often blame women for their children's illnesses.

Although a variety of family forms existed in Soviet Russia, tradition dictated that the woman was the caregiver in the family until 1991, when new family rights laws were introduced to allow shared parental leave between fathers and mothers. Women were encouraged to become workers in the public sphere during the soviet period, and economic conditions also made it necessary for the majority of families to have dual incomes. At the same time, because social networks and support systems were insufficient for caring for the elderly, those with health impairments and disabilities, and children with behavior problems, caring for these individuals became the responsibility of the family. A contradictory message was sent to families when they were expected to take responsibility for extraordinary family demands while still responding to the social norm for both partners to work away from the home.[13]

Helping families to rear a child who is disabled is a rather new idea for postsoviet society. A child with a disability in Soviet Russia was more likely to be placed in an institution than cared for and brought up within the family due to the perception that such a child would not become a contributing member of society as a worker.[14] These prejudices persist in postsoviet Russia, despite pressure for reform both from within Russia and from international groups to end the practice of state institutionalization and encourage alternatives to state institutional care. When parents are willing to keep their children at home, their efforts are frustrated by the inadequate allocation of resources, such as for additional expenses, schools, and other facilities.

The extra living expenses of children (or adults) with disabilities and their families are well documented in the West. For example, research shows that individuals with disabilities often require extra clothing, modified furniture, special diets, extraordinary transportation costs, and modified accommodations, all of which place financial strain on families.[15] Although new social policies are being implemented in Russia to support the incomes of disabled individuals and their families with benefits, beneficiaries are nevertheless disproportionately represented among those living in extreme poverty.[16] Economic crisis is blamed for the failure of benefits to adequately relieve the extra cost of living with a disability in Russia, but perhaps more insidious is the impact of inflation. Parents of children with a disability in Russia face incredible financial difficulties because their incomes are rapidly decreasing in spending power. The average real monthly income per capita in Saratov at the beginning of 1995 was 205 thousand rubles, or about 85 dollars—higher than average in Russia and higher than in other Volga cities, but at the low end of Russian regions as measured by standard of living.[17] This downward slide is reflected in women's narrative representations of a future filled with uncertainty for them and for their children. Such families carry a colossal workload and face nearly insurmountable obstacles in obtaining basic services to meet just a few of their needs.

Pressure to Relinquish Children with Disabilities

Women's narratives about their interactions with health care professionals give us a picture of how a situation of exclusion is produced through the relationships between the powerful and powerless. When respondents were asked to tell the story of their child's birth, the distinguishing features of their accounts were lack of effective communication by medical professionals with the parent regarding their child's condition, and, once the diagnosis of mental or physical disability was made, pressure to abandon the child to an institution. Almost all women reported that they were told the child was born healthy, and the diagnosis was made long after:

> Sveta was born a healthy baby. The doctor said, "The baby is healthy, have more babies, you'll be welcome back." Until she was a year old we did not notice any changes in her development. The only thing I paid attention to was that she had difficulty sitting up; she was not like the other children. And when she was one, I mentioned that she had difficulty standing on her feet. We applied for an expert opinion and we had a consultation with a pediatrician at the Clinic of Orthopedics. They gave us a diagnosis and we were put on an assessment program.

Even when deliveries were abnormal, no diagnoses were made at follow-up visits at the maternity hospital during the early stages of the children's development. Later on, when the children were diagnosed and the mothers started visiting clinics, the women report that they often encountered a negative evaluation of their decision to keep the child. Such negative attitudes of the medical staff, relatives, and others laid the foundations of social exclusion:

> The neurologist said that she suspected something was wrong with my boy; she would have to observe and assess him. We began the assessment and had been going for three months without a diagnosis. By the fourth month she made a diagnosis of cerebral palsy. Well . . . I did not know what it was but she told me that it meant he would be handicapped for the rest of life. And the things she said besides, "Do not spend money on him," "He is absolutely hopeless," "I advise you not to take him anywhere." And what's more, just as I was leaving her office I said, and can you imagine this, what it meant for me, I said, "But what can I treat him with, what can I do?" She says, "Well, give him aminolon [a sedative]." Those were literally her very words. That is all I left her office with.

An analysis of the narrative scheme for these stories recalls the three forms of censorship described by historian Michel Foucault: signaling that a thought or statement is not permitted, preventing it from being said, and denying that it exists.[18] All three forms of censorship are present in the above narrative, in the denial that the child can be socialized, in the implication that a child with a disability is a waste of resources, and in the dismissal of the child as a human being entitled to a full life. Such encounters are marked by a narrative closure, a statement that the process is ended, signaling that the act of exclusion is completed. Another women tells of her similar experience:

> After looking at the child, the doctor invited me in and I experienced fifteen very unpleasant minutes. In so many words I was told to give up [my child]. "It is hopeless, he will be an idiot, he will not even be able to move." In other words, he is a prostrate fool. But I just could not do it.

This account is an excellent example of Janet Read's stark observation, "Any encounter between a parent and a service provider is likely to consist of the state's well-paid and prestigious representative (that is, the controller of resources and information, the policy-maker and definer of problems and people) coming face-to-face with a woman on a low income, engaged in domestic labor, bringing up a child for whom a marginalized and largely segregated life has already been mapped out by dominant forces within the social structure."[19]

The Role of Others in the Family's Life

When the child is born, medical professionals and relatives potentially become significant sources of support for the mother. Gradually, the more important role is taken over by other professionals (educators, social workers, psychologists), the informal social network, and the broader social environment (for instance, children in the yard, people in the street). The attitudes of relatives, their positive treatment of the child, help, and support are obviously very strong factors in stress management. As a rule, the main role within the informal support network is given to the child's maternal grandmother, which tends to reproduce the idea of the mother's destiny and mothering/caregiving as destiny:

> The main help comes, of course, from my mother. Granny contributes all she can, which means, if necessary, she will take care of her, sit at home, take her to and from school. When I go to work, Granny stays at home with her. And there is the material support—we put all we earn, all our incomes, together. Of course, most of the upbringing falls on my shoulders. Daddy is a little bit outside it all.

A different situation results when a woman wants to care for her child and have a separate life of her own. What is accepted today by many Russian women as opportunity to recover a sense of individuality and a hard-won feminine identity (sometimes labeled as essentialist thinking in the West) is rejected with hostility as an inappropriate social role by representatives of the old totalitarian culture.[20] Such traditions and stereotypes continue to reduce a woman's identity to one of caregiver without options. When the woman wants not only to take care of her child, but also have time for herself, she often faces misunderstanding and condemnation even from those closest to her:

> It was especially hard that I was blamed and made to feel ashamed for not caring for the child. . . . I don't know, maybe I should have dressed in rags, powdered my head with ash and told everyone how unhappy I was, what a tragedy it was that had happened to my child. But you see, I wanted to be well

> dressed, to look nice, have contacts with friends. . . . So at home we have quarrels all the time.

During the interviews with women, open-ended questions were asked about how people treated mothers of disabled children. Depending upon a woman's experience, encounters with those outside the family are potentially therapeutic or stressful, and might result in the growing isolation of a mother ("I, myself, most of all take care of him") or in the development of a supportive network. Women reported that they sometimes had very important encounters in their lives when a teacher treated their child with respect and integrated the child into a group of peers through individualized teaching and by taking time to explain to the class how to relate to a child with a disability. At the same time, mothers often experienced cool and even hostile attitudes from other people, as the following women's narratives demonstrate. For example, one mother said:

> We were scheduled for a massage—we had to be there at ten to nine. And what a time—the rush hour. . . . He could move a little by that time. Now, we can even walk. But then—I had to take him in the pram—he was heavy. . . . So, in the morning, the traffic . . . [starts crying] they all climb in, although they can see how the child is, no one helps, you know, they nearly push us out: "Get off, where are you going at such a time, can't you stay at home?" . . . And in the bus—if I ask someone to give up a place, it's "Oh, he's such a big boy, he himself can already give up a place." Whether they do not see—that hurts me all the time—such cruelty. . . . But on the whole, [in a low voice] friends, they relate well and try to help.

In another encounter, a mother recalled:

> I went out into the yard and asked, "D., why are you crying?" [starts crying] He says, "Vadik said that I am a monster." "Don't cry," I say, "You are not a monster at all, you just have weak legs and if he says that, it means he is a monster himself, it means his brains aren't in order." I went to that Vadik and knocked on his door. I gave him a talking to, "If I hear that just once more. . . . Don't you see, the boy has weak legs, he needs help." Of course there is cruelty among the kids.

The lack of social tolerance and rude attitudes, which could be defined as uncivil attention (paraphrasing Irving Goffman's idea of civil inattention), contributes to the isolation of mother and child, their exclusion from a heterogeneous, diverse social life, and leads to overdependence of the mother and child on family relationships. Thus, the politics of exclusion at the level of contact with those outside the immediate family flows to the level of personal experience and everyday practice, raising fortresses around the outcasts.

The Kingdom of Outcasts: The Context of Experience

An effort by women to escape from overdependency on others, including the family, might take the shape of escape from reciprocity,[21] that is, escape from the intimacy of shared feelings and relationships, such as that described below by one woman who excluded her husband from sharing responsibility for and participating in care for their child:

> He left . . . that is. I . . . well, I came to the conclusion myself, that it would be better for us to live alone, because such a life did not suit me. He just did not need that kind of family. Do you understand? . . . I understood it all and simply said: "Why should we suffer, better to get a divorce." Well, at first he did not want to. He said, "Let's think, how will you survive?" and so on. . . . But, that's all over.

Women's accounts show that they often broke relationships in the family network, trying to escape both from dependency and from crisis. When asked whether her relationship changed after her husband learned their child was sick, one woman replied:

> Our relationship . . . or rather, I should say, my relationship with him . . . my relationship has changed. I somehow feel all this more sharply. . . . I always accuse him of indifference—I initiate everything. He will say, "Well, of course you do all the looking after, I never forbid, I never stop you." There are of course difficult moments. . . . Nerves are strained of course. In everything you feel yourself to be deficient somehow.

This woman deprived others, in this case, her husband, of his right to be included, to participate, to share the responsibility, making him silent in decision making. There are historical factors that contribute to men's exclusion. As Larissa Lissyutkina writes, men in Russia today need renewed purpose as never before, for their traditional identity has been destroyed, and they often cannot adjust to life, freedom, or their relationships with women: "Instead of equality between men and women, there has been a lowering of both sexes to poverty and to deprivation of political rights. There are men, but they are as a rule not real comrades in misfortune, capable of sharing with women the burdens of everyday life, poverty, and endless uncertainty."[22] A woman may choose as a scapegoat not only her husband, but his kin. As one woman put it, "Recently I realized that the grandparents [husband's parents] do not let him grow, well, he plays a game, and they do too, but they do not suggest anything new to him."

Generally, mothers choose themselves to blame, rejecting their roles as wives, professionals, or members of an organization, keeping and sometimes exaggerating caregiving identities. The last phenomenon results in less self-confidence for the child, who is overprotected by the mother. For example, one woman said, "Our boarding school is just wonderful, but to tell the truth, it is the fourth year now since I gave up the job, just because he went to school. And only because of that. Because I am not only helping him to learn, but I also go to the school and sit in the classroom."

Since the breakup of the Soviet Union in 1991, Russia has passed a significant amount of legislation intended to protect children's rights to education, health, and special protection against hardship consequent to reform. In particular, the laws call for increased efficiency of state programs and for helping poorer families provide a stable home environment in which to grow. However, in practice, the new policies instituted in 1991 have not changed the old stereotype, and because the woman is most likely to be responsible for the day-to-day care giving, it is also her pattern of employment, her job and career opportunities, that are directly affected by the presence of a child with a disability in the family. As the period of transition from communism was followed by reduced social support and welfare programs, requirements to join the work force increased. According to Russian feminist writer Zoja Khodkina, under such conditions women who traditionally care for the family will be much more vulnerable and harmed both within the family and at work. Russian ideology views women as being both proud parents and proud professionals, yet, even in the best of conditions, the family living conditions, salaries, and career opportunities for women in Russia are more likely to exploit them than to give them opportunities for self-fulfillment. Mothers of children with disabilities face particularly harsh alternatives—or no alternatives. Even if they want to be proud parents and proud professionals, it is impossible because of the lack of suitable jobs and social support programs. Thus, women of children with disabilities face a double bind and are often blamed for their intention to be more then just caregivers while forced to be both breadwinner and caregiver. The following excerpt shows how these factors can result in overdependence between the mother and the child. It also represents the difficulties in overcoming the limits that this interdependency places on the future opportunities for both the mother and child:

> I have not been able to keep a job. And he is afraid to let go of me. I tried to get him into a kindergarten when he was three, but it was not a success. I arranged to work as a laundress there so as to be near, so I thought, but he absolutely resisted going to class. Every time he began, "Mum, mum," so we gave up work and the kindergarten.

Sources of help for families raising children with disabilities that are well established in the West—such as books and other reading materials about raising a child with a disability, parent support groups, and education for parents—are absent in Russian women's narratives. The problem is, perhaps, that parents of children with disabilities in Russia simply have never had access to books, articles, or other informative sources on families with children with disabilities. Lacking supportive social policy and access to education, a family rearing a child with special needs in a cultural environment that traditionally institutionalizes people with disabilities faces innumerable obstacles. Compounding the lack of information about raising a child with disabilities is the inadequecy of the existing network of special education provisions that do exist for children and adults with disabilities, which together make it almost a foregone conclusion that such individuals will live their lives separated from the rest of the world.[23]

While the circumstances of child rearing and attitudes toward children with disabilities are gradually changing, support essential to families of children with disabilities lags far behind needs. Meanwhile, the number of children identified with disabilities in the Saratov region by 1993 was almost double that in 1990, a trend evident in all Russian regions that is largely due to a change in the definition of disabilities.[24] The Health Care Ministry Act of 1991 revised the 1979 Act by broadening the definition of eligibility for social pensions and other services provided by the state. Examples of diagnoses recently accepted by law as "handicap" (or "invalid" in Russian) are hearing impairments of different levels, "inherent and genetic illnesses leading to a partial disturbance of life activity and social disadaptation," visual impairments or loss of one eye, and HIV infections. The registration of children whose impairments and illnesses are now recognized as disabilities is a responsibility of local social security departments. Social workers from the rehabilitation centers are a great help in this identifying process because families, particularly those living in rural areas, sometimes do not register their children and are unaware of the services that are offered by the state. Early registration can help facilitate early assessment and intervention to prevent further developmental delay and social exclusion of the child.

The concept of discriminatory language is very new in Russia, and people may not always recognize discrimination as attached to the words they use. For example, the term "invalid" is used very widely to define the status of a person in the welfare system. The World Health Organization's language is new to scholars and people in Russian government and, except for a few professionals who use the term "limited abilities of a child," little has changed in the language of professions or Russian welfare legislation. Furthermore, the medicalized model for dealing with all types of problems is still employed all over Russia: In 1993, the Ministry for Health Care and Medical Industry of Russian Federation distributed through health care centers, schools, and child care centers a manual titled "An Arrangement for Medical Supervision of the Development and Health of Pre-school and School Aged Children, and their Sanitation at Kindergarten, School." This comprehensive manual of preventive, diagnostic, and correctional methods to be used by doctors and nurses recommends that the medication glycine, an amino acid with a calming effect, "be prescribed when the child experiences deprivation from the parents. . . . One should remember that the patient's micro environment (especially family) is the main provoking and the main therapeutic factor. Therefore, Glizin may be considered as a typical 'family' medicine, and it should be recommended as a medicine for mother, child, grandmother; alcoholic patient, his wife, etc."[25] The wide-scale prescription of glycine by the Russian population is thus being suggested by the Health Care Ministry as an easy way for dealing with child abuse, family violence, alcoholism, and other severe social problems.

In 1994 a rehabilitation center for children with disabilities was established in Saratov. Its programs consist of family support networks, coordinated services for children, and assessment of family needs. One of the effective partners in this network is a new sports club with instructors for disabled children. However, a serious obstacle in the process of rehabilitation is that the social security system in Russia has traditionally tended to define social work as a profession not requiring education. Many public officials still lack conviction about the role of social work, and they also underestimate the necessity of university training for social workers. Consequently, the majority of social workers in the Saratov region do not have adequate training to understand and solve many problems experienced by the children and their families. Those who are responsible for working with the children today are gradually acquiring the necessary skills and knowledge of the vast multidisciplinary work that has been done in the area of education and treatment of those with disabilities. They try to help the parents who desperately need information and services to supplement their exhausted personal and financial resources. Meanwhile, family support networks are still very weak, state facilities are only in the early stages of development, and the community is still undervalued as a potential source of help.[26]

When women do take part in an association of parents of children with disabilities, they report that they have acquired new resources, minimized their level of stress, and improved their social lives. Women, such as the respondents quoted below, say that they make new friendships among people who deal with similar problems and achieve recognition of their rights in society. A mother was asked how she located a special school for her disabled child:

> Hmm. . . . Just, well, by being pushy. We were told that there was a special kindergarten. Well, I went to the administration. . . . I also took part in the Parents' Association. After two years work, we achieved something, we got to know what was going on, started to fight for this kindergarten, so that two or three children got in.

Another woman responded:

> I am in this society for the handicapped. I did not even know that we had such a thing. Now it is already four years since we actively got involved together, festivals, New Year, and so on. Then we started organizing a sport-school. At first we had only five kids in there, now there are one hundred. . . . They are equal there, you see. They don't even think that this one is sick, that one is worse, another is better in terms of their condition. They just catch him up and run.

When a child is succeeding in some sort of activity, for example in a sport school, the child is changing his or her self-image and getting respect among peers, even among those who have no disabilities. A woman explained:

> Her [the child's] ability to communicate, especially, progressed when she started going to the sport-school. I noticed that the children in the yard began to gather around her. . . . She won respect, somehow she picked up self-confidence, she felt no worse than the others, that she was capable of achieving.

However, women experience difficulties when they try to cope with the feelings of guilt even if they are actively involved in their child's treatment and education. Below we see that institutional and personal practices of exclusion are very powerful in the experience of mothers:

> I see positive changes from the treatment. I can see it helps him. That's why I do hope for treatment. But if I do not get him treatment for a year, it terrifies me. I blame myself for not taking him for treatment. We lost a year, which means so much for us. Because the illness develops at an early age, it becomes worse and more difficult the older you are.
>
> I do not need anything, I wish only that the child would get treatment.

The last sentence represents a central need of these women—to confront the insult of disability in a child. The use of the subjunctive indicates the uncertainty of the speaker about the future of her child. But quite confidently, she ignores her own many needs.

Conclusion

As social, cultural, and educational change in Russian gets underway, it is important to examine the implications of these changes for children with disabilities and their families. The legal and civil rights of persons with disabilities are now implemented on a broader scale than before; however, discriminatory stereotypes are not easy to change. The practice of exclusion and its critique must be central in the analysis of mothering children with disabilities in Russia as a socially constructed phenomenon. A child's diagnosis as disabled works to create a world of outcasts, where children are defined as social, biological, and psychological exceptions to the rules.[27] The socially constructed label as "defective" spreads to his or her family like a racial stigma,[28] excluding the child and family from the world through lack of tolerance, casting them out of the web of reciprocal relationships.

The analysis of Russian motherhood as an institution and as experience shows that the exceptional identity is built upon entrenched cultural meanings prescribed to women as mothers and caregivers. Among those meanings are the bonds of the mother to her child, and the implication that she is responsible for the "results" of reproduction. The exceptional identity of the mother can result in her hostility to others (breakdown in the relationships with husband and his family), feelings of guilt (resulting in projection and scapegoating), overprotection (repression of a child's self), and autonomisation (escaping social contacts through self-isolation). If this is to be avoided, it is necessary to establish an ethics of individual responsibility for others in contexts where only stereotypes now reign.

Although it is impossible in one article to bring into focus the reality of all the current changes in the life of Russian people, it might be proposed that two processes are required now in the course of social development in Russia: 1) humanizing existing social institutions and establishing new institutions that respond more effectively to social needs, and 2) community-building.[29] Both processes involve the "reconstruction of common sense" by dismantling old stereotypes that lead to rigid social systems. In harmony with these recommendations are several offered by international relief and human rights organizations, which have called for medical personnel to stop pressuring parents to institutionalize newborns with disabilities. They have also called for Russia to develop a plan to deinstitutionalize children with disabilities, to provide assistance to families in caring for children with disabilities, and to ensure that such children receive full respect for their human rights, including protection of their civil rights and right to be educated. In addition, the organizations have called on Russia to develop an educational plan for addressing the cultural prejudices against people with disabilities.[30] Social work programs in many Russian universities are making efforts to prepare practitioners for helping children with disabilities and their families, and such programs will develop over time.[31] Sociocultural reframing in Russia will require a contextual shift within society, a shift to redefine civil and civic rights based on concepts of human dignity rather than on diagnosis. For this to happen, Russia will have to make a considerable effort to build a form of development that embraces everyone and to develop an approach to citizenship in which each individual accepts his or her obligations to others. Then positive changes, both in societal organization and in living conditions, will open the door for the kingdom of the outcasts where inexpressible pain now reigns alone.

Notes

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1. Ludmilla V. Popova, "Otnoshenijek Sociokulturnym Roljam Zhenshin: Krosskulturnoje Issledovanije" ["Attitude Toward Sociocultural Women's Roles: Crosscultural Research"], in *Gendernye Aspekty Socialnoy Transformazii* [*Gender Aspects of Social Transformation*], ed. Marina M. Malysheva (Moscow: Russian Academy of Sciences, Institute of Transformation, 1996), 161–74.
2. See Bernice W. Madison, "Programs for the Disabled in the USSR," in *The Disabled in the Soviet Union: Past and Present, Theory and Practice*, ed. William O. McCagg and Lewis Siegelbaum (Pittsburgh, Penn.: University of Pittsburgh Press, 1989), 167–98.
3. See Human Rights Watch, "Summary and Recommendations," in *Abandoned to the State: Cruelty and Neglect in Russian Orphanages* (New York: Human Rights Watch, 1998), 1–11. Human Rights Watch has concluded that strong biases exist in Russia against adopting any relinquished child because of a fear that "the child will in some way be 'damaged goods' [stemming] from the knowledge that mothers of mentally and physically handicapped children are routinely advised by doctors to put their baby in an orphanage and 'try again.' Consequently, healthy babies who are given up for financial or domestic reasons are unfairly branded 'defective'" ("Summary and Recommendations," 2).
4. All demographic information about Saratov cited here was obtained from the Saratov Social Security Department, Saratov, between 1994 and 1996.
5. One example of the decline in public spending is provided by examining the number of preschools available to children between 1980 and 1993. During 1993, the number of preschools of different kinds (crèches, kindergartens, preschools, children homes, child care centers) in Saratov diminished by 105 and in 1994 by 80. Correspondingly, the number of children attending those preschools decreased by 20,000.

Number of preschools divided by the number of children preschool age, as percentage

	1980	1985	1989	1990	1991	1992	1993
Russian Fed.	64.9	68.3	69.3	66.4	63.9	56.8	56.6
Astrakhan	60.5	66.5	68.9	65.7	63.2	54.1	54.1
Volgograd	66.1	67.3	65.4	60.3	57.2	50.2	50.6
Penza	53.7	62.6	67.7	64.5	61.1	55.0	58.3
Samara	68.5	72.4	70.1	66.7	64.8	58.1	58.3
Saratov	67.1	70.9	70.6	67.7	63.2	52.7	51.3
Ulianovsk	57.0	63.9	67.1	63.7	66.0	59.0	57.7

6. See, for instance, Ludmilla F. Bezlepkina, ed., *Gosudarstvennyi Doklad o Polozhenii Detei v Rossijskoy Federazii* [*State Report About the Situation of Children in the Russian Federation*] (Moscow: Sinergia, 1995).
7. For an example of this methology, see Catherine K. Riessman, *Divorce Talk: Women and Men Make Sense of Personal Relationships* (New Brunswick, N. J.: Rutgers University Press, 1990), 17.
8. Catherine K. Riessman, *Narrative Analysis* (Thousand Oaks, Calif.: Sage Publications, 1993), 64.
9. Anthony P. Kerby, *Narrative and the Self* (Bloomington: Indiana University Press, 1991), 84.
10. Kerby, *Narrative and the Self*, 84, 3–4; and Tim Booth, "Sounds of Still Voices: Issues in the Use of Narrative Methods with People Who Have Learning Difficulties," in *Disability and Society: Emerging Issues and Insights*, ed. Len Barton (New York: Longman, 1996), 253.
11. Emmanuel Levinas, *Emmanuel Levinas: Basic Philosophical Writings*, ed. Adriaan T. Peperzak, Simon Critchley, and Robert Bernasconi (Bloomington: Indiana University Press, 1996).
12. Janet Read, "There Was Never Really Any Choice: The Experience of Mothers of Disabled Children in the United Kingdom," *Women's Studies International Forum* 14:6 (1991): 568–69.
13. Elena Iarskaia-Smirnova, "Comparison of Russian Family Life Then and Now," *Social Development Issues* 18:1 (1996): 53–65.
14. See Tatiana A. Dobrovolskaja, Natalya B. Shabalina, "Sozialno-psihologitcheskie Osobennosti Vzaimootnoshenii Invalidov i Zdorovyh" ["Socio-psychological Pecularities of Relationships Between the Handicapped and the Healthy"], *Sociologitcheskije Issledovanija*, no. 1 (1993): 62–66; and Sergei A. Zavrazhin, "Podrostkovaja Delinkventnost: Transkulturalnaja Perspectiva" ["Adolescence Delinquency: Transcultural Perspective"], *Sociologitcheskie Issledovanija*, no. 2 (1995): 125–31. Dobrovolskaja and Shabalina describe a 1991 survey of 1,320 adults of different levels of handicap and socioeconomic status who lived in Moscow, Tsheljabinsk, Vologda, and Ufa, in both urban and rural areas. In addition, 120 people were interviewed who were representatives of the "intelligencia," high school graduates, orthodox charity

school students ("sisters"), and professionals from the field of social protection (scientists and administrators). The distribution of the opinions about the disabled among the "healthy" people in that survey breaks down as follows:

Negative evaluation average of a situation when a disabled person is a . . .	Social protection professional	Youth	Charity orthodox sister	Intellectual	Average
Neighbor in your house	—	28.8	3.1	9.4	10.0
Neighbor in your flat	20.0	62.2	12.1	50.0	7.3
Your relative	33.3	64.0	27.4	40.6	39.1
Your employee	26.7	48.0	9.2	18.8	22.7
Colleague	6.7	44.0	3.1	6.3	13.6
Boss	33.3	52.0	14.9	28.1	29.1
Person from the government	46.7	48.0	21.3	12.5	27.3
Classmate of your child	—	28.0	3.1	6.3	9.1
Teacher of your child	20.0	44.0	9.2	15.6	20.0

Zavrazhin's 1994 report of 135 Russian and 98 U.S., Canadian, Austrian, and German respondents comprised of university students, teachers, and administrators about the differences in attitudes between the groups of the respondents.

Attitude toward adolescent deviants and delinquents (%)

What should be done with...	Liquidate	Isolate	Assist	Ignore	Other measures
Russian respondents					
Bikers ("rokery")	14	20	8	30	28
Homosexuals	8	22	14	42	14
Drug users	28	20	44	2	6
Antisocial groups	66	14	6	6	14
AIDS infected	2	20	80	2	4
Vagabounds	18	6	62	8	6
Prostitutes	26	10	12	30	34
Physically disabled	4	10	84	—	2
Mentally disabled	2	44	50	2	4
Foreign respondents					
Bikers ("rokery")—	10	19	35	36	
Homosexuals	—	—	33	12	55
Drug users	—	—	79	11	10
Antisocial groups	—	8	80	—	12
AIDS infected	—	—	100	—	—
Vagabounds	—	9	72	—	19
Prostitutes	—	—	82	8	10
Physically disabled	—	—	96	—	4
Mentally disabled	—	—	98	—	2

15. Read, "There Was Never Really Any Choice," 563.
16. For example, the social pension for children with handicaps is as large as the minimum pension at retirement, supplemented with another two-thirds of the minimum pension and some other additional benefits. However, pensions do not offset the financial burden. Children with handicaps are allowed free public transportation, but the adults who accompany them must pay for their own tickets. Children with handicaps are provided with places in kindergarten at no charge but have to wait for years to get a place. This is partly because the general economic decline influences not only the family budget but also forces decreases in public expenditure on child care, health care, education, and the family support social network.
17.

Income rates, average wages, December 1994

	Per capita real income (1000 rubles)	Minimum income (1000 rubles)	Subsist. minimum ratio	By income/ subst. min. ratio	Wages (1000 rubles)
Russia	378.6	145.4	260.4		354.2
Astrakhan	195.5	119.7	163.3	47	260.9
Volgograd	212.7	129.1	164.8	45	304.6
Penza	175.8	101.2	173.7	39	212.2
Samara	292.3	119.1	245.4	8	390.5
Saratov	205.4	146.3	140.4	58	235.0
Ulianovsk	187.8	75.8	247.8	6	265.3

18. Michel Foucault, *The History of Sexuality* (London: Penquin Books, 1976), 84.
19. Read, "There Was Never Really Any Choice," 568–69.
20. Larissa Lissyutkina, "Soviet Women at the Crosroads of Perestoroika," in Nanette Funk and Magda Mueller, eds., *Gender Politics and Post-Communism: Reflections from Eastern Europe and the Former Soviet Union* (New York: Routledge, 1993), 277.
21. Jessica Benjamin, *Bonds of Love: Psychoanalysis, Feminism, and the Problem of Domination* (London: Virago Press, 1988), 221.
22. Lissyutkina, "Soviet Women at the Crossroads," 283–84.
23. For the theoretical background, achievements, and pecularities of these educational programs, see Andrew Sutton, "Backward Chidren in the USSR: An Unfamiliar Approach to a Familiar Problem," in Jenny Brine, Maureen Perrie, and Andrew Sutton, eds., *Home, School, and Leisure in the Soviet Union* (Boston: Allen and Unwin, 1980), 160–91. For background on work and everyday problems, see Stephen P. Dunn and Ethel Dunn, "Everyday Life of the Disabled in the USSR," in McCagg and Siegelbaum, *The Disabled in the Soviet Union*, 199–234; and Bernice W. Madison, "Programs for the Disabled in the USSR," in McCagg and Siegelbaum, *The Disabled in the Soviet Union*, 167–98.

24.

Number of children with disabilities in Volga cities and total in Russian Federation

	1981	1986	1990	1991	1992	1993	1994
Samara	1,231	2,457	3,626	4,267	5,476	6,737	7,707
Saratov	1,095	1,671	2,748	3,224	3,667	4,951	5,987
Ulianovsk	686	925	1,418	1,734	2,139	2,858	3,465
RF	52,881	90,617	138,065	155,151	212,004	284,717	344,870

25. Galina N. Serdjukovskaja, ed., Organizatsiia Meditsinskogo Kontrolia za Razvitiem I Zdoroviem Doshkol'ikov b Shkol'nikov na Osnove Massovyh Skriningtestove I ih Ozdorovlenie v Usloviiah Detskogo Sada, Shkoly (*An Arrangement for Medical Supervision of the Development and Health of Pre-school and School Aged Children, and Their Sanitation at Kindergarten, School* (Moscow: Association of Preventive Medicine and Ecology ["Promedok"], Ministry of Health Care and Medical Industry of Russian Federation, 1993).

26. For a discussion on the professionalization of social work in Russia in the 1990s, see Elena Iarskaia-Smirnova, "Social Work in Russia: Professional Identity, Culture, and the State," in *International Perspectives of Social Work: Social Work and the State*, ed. Bogdan Lesnik (Brighton, England: Pavilion Publishing, 1999), 331–44. See also Mary A. Burke, *Child Institutionalization and Child Protection in Central and Eastern Europe*, Innocenti Occasional Papers, Economic Policy Series, No.52 (Florence, Italy: UNICEF International Child Development Centre, 1993).

27. Emmanuel Levinas, "Philosophy and the Idea of Infinite," in Adriaan Peperzak, *To the Other: An Introduction to the Philosophy of Emmanuel Levinas* (West Lafayette, Indiana.: Purdue University Press, 1993), 39–72.

28. Erving Goffman, *Stigma: Notes on the Management of Spoiled Identity* (New York: Touchstone, 1986), 4.

29. R. J. Estes, "Education for Social Development: Curricular Issues and Models," *Social Development Issues* 16:3 (1994): 68–90.

30. Human Rights Watch, "Summary and Recommendations," 7–8.

31. For instance, social work education in Saratov has existed since 1991 at the Department of Social Work at Saratov State Technic University (SSTU). The following programs are offered in the department: Bachelors of Social Work, Masters of Social Work, Graduate Diploma in Social Work (a five-year program), Candidate of Sociology, Doctor of Sociology, and Graduate Diploma in Social Anthropology (a five-year program). The research interests of the faculty are focused on social inequality and social policy, in particular on gender and disability issues. The Department of Social Work collaborates with Saratov social services, rehabilitation centers for children with disabilities, and NGOs, including women's organizations and associations of people with disabilities.