



ARTICLE IN THE SPECIAL SECTION

Social Profile of Mothers Raising Children With Disabilities: A Survey in Rural and Small-Town Russia

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ABSTRACT

Like any other family, families with disabled children have their share of joys and sorrows. However, social attitudes and prejudices towards disabilities often pose more significant challenges than the child's condition itself. Discrimination against mothers raising disabled children comes to the fore in social interactions, where the child's disability can unfairly define the mother, subjecting her to stigmatization. The ability of parents, particularly mothers, to mobilize resources is crucial for the family's well-being, as they often bear the primary responsibility for child care. In Russia, one in three disabled children is raised by only one parent. Social services for families with disabled children are evolving in response to families' needs, but there is currently no unified system to verify their effectiveness. Our study was conducted in 2024 in Vladimir and Nizhny Novgorod Oblasts and explored socio-psychological distress in families with disabled children. Through semi-

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structured interviews with 98 women whose children attend social rehabilitation institutions, we gained insights into mothers' experiences, including their life satisfaction, access to state and social support, as well as daily stigmatization. These findings provide a comprehensive understanding of the challenges faced by women raising disabled children, highlighting areas of social disadvantage and stigma in provincial contexts.

KEYWORDS

disability, family with a disabled child, motherhood, parenting a child with a disability, stigmatization, social support

Introduction

Analysis of the social status of mothers with disabled children at a microlevel offers valuable insights into the daily challenges they face. It also helps identify mechanisms in social welfare and support systems that either exacerbate or alleviate inequality and social distress. Many everyday practices and interactions are underpinned by the assumption that a child's disability is a consequence of the mother's marginalization, such as her unhealthy lifestyle, antisocial behavior, or failure to follow medical advice.

The life stories of the women in our study shed light on the survival strategies employed by families raising atypically developing children within the evolving landscape of social policy and society. Ironically, despite advancements in social protection, women raising children with disabilities often find their needs overlooked. These women face a myriad of challenges, including difficulties in socializing their children, household chaos, career obstacles, single parenthood, emotional exhaustion, and physical fatigue. Their personal struggles exacerbate the stigma surrounding disability and contribute to negative societal attitudes towards inclusion.

Moreover, women living in provincial areas face even greater challenges compared to residents of regional centers and large cities. The limited resources and support available in provincial settings exacerbate the difficulties faced by these families.

Our research aims to uncover the most pressing socio-psychological issues in families with disabled children, create a social profile of mothers in these families, and propose strategies to address these challenges at the community level.

Theoretical Framework

Since the latter half of the 20th century, *disability studies* have emerged as a distinct field of inquiry, challenging the traditional medical perspective on disability. There is growing recognition of the need to integrate socio-cultural, socio-anthropological, legal, and gender perspectives to gain a comprehensive understanding of disability as a social issue.

This work explores the themes of atypicality and otherness by drawing on various sources, the most important of which are (a) the insights of M. Foucault regarding medicine, prisons, madness, and sexuality; (b) contemporary perspectives on stigma and stereotyping; and (c) theory of social exclusion and poverty (Abrahamson, 2001).

The development of disability sociology in Russia owes much to the conceptualization of themes related to atypical development in the works by Chernyaeva (2005), Iarskaia-Smirnova (1997), Maleva et al. (1999), Romanov & Iarskaia-Smirnova (2010), and Yarskaya (2008). More recent contributions to this research area were made by Detochenko (2020), Fomina (2021), Fomina & Gulyaev (2024), Naberushkina & Besschetnova (2023), Rostovskaya et al. (2021), Voevodina (2021), and some others.

A recent study highlights the discriminatory experiences of people with disabilities in various aspects of public life (Breffka et al., 2023). Discriminatory attitudes are rooted in stereotypical beliefs held by non-disabled individuals about the causes of disability and the cognitive and physical abilities of disabled individuals.

As international norms for inclusive social development are adopted by more and more countries, the situation gradually changes. However, disabled individuals continue to face limited agency, as emphasized in both Russian and international academic literature. To enhance the participation of people with disabilities and promote their full citizenship, it is crucial to involve them in community activities such as self-help groups, volunteering, and civic organizations, as advocated by J. M. Levitt (2017).

Contemporary disability studies emphasize the agency of individuals with disabilities (McCrary, 2016). This concept is viewed by Russian scholars as the capacity for significant social and political engagement (Iarskaia-Smirnova & Yarskaya, 2020). The education system in modern Russia is a notable sphere where this agency is evident (Iarskaia-Smirnova et al., 2024).

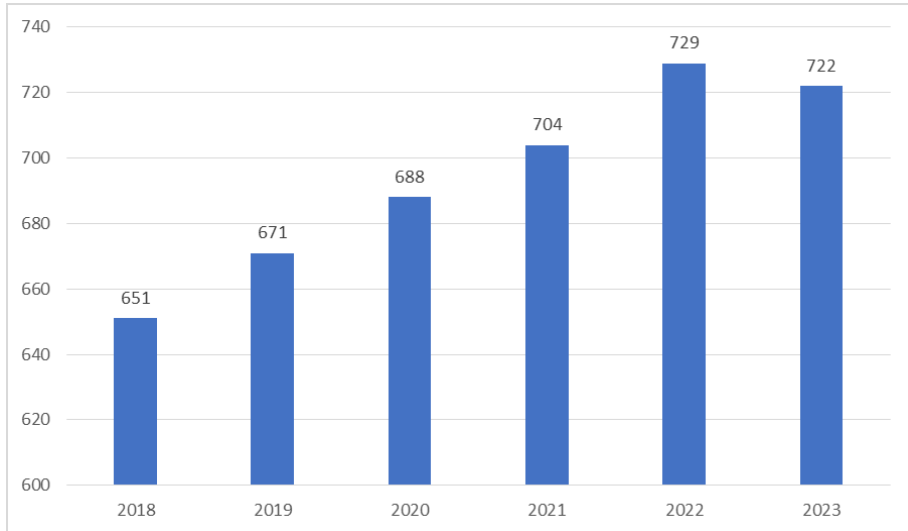
In their study of the characteristics of British students with chronic illnesses, Hamilton et al. (2023) have shown that individuals with non-visible disabilities may go unrecognized as having disabilities by university staff and peers, who perceive them as “less ill” than those with visible impairments.

Internationally, a diverse range of studies addresses stigma and socio-psychological challenges encountered by people with disabilities. Research on family stress and life satisfaction among mothers raising children with disabilities explores the effectiveness of educational and training programs in reducing stress levels (Çalışkan et al., 2024).

Another interesting aspect is the examination of the experiences of individuals with disabilities in relation to socio-spatial-political phenomena such as disability policies and laws, economic conditions, disability movements, and social welfare systems in Asian countries (Chou et al., 2024). The works of these authors underscore disability as a basis for discrimination and oppression.

According to Rosstat [Federal State Statistics Service], the number of disabled children increased between 2018 and 2023, reaching 722 thousand individuals by 2023, including 197 thousand children under the age of seven (Figure 1).

Figure 1
Number of Children With Disabilities in Russia



Note. Based on data from Rosstat [Federal State Statistics Service].

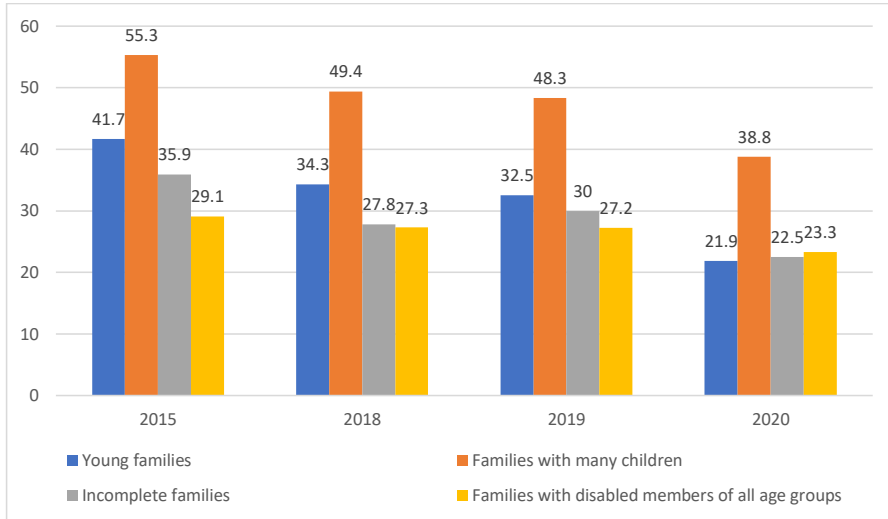
Among children under 18 with primary disabilities, the distribution by illness/condition is as follows: mental and behavioral disorders account for the largest share (24,506 people), followed by diseases of the nervous system (8919), and congenital anomalies, deformities, and chromosomal disorders (10,378).

In the structure of low-income population, families with disabled children accounted for 9.3% in 2020 according to data from a sample survey of households. Among these households, 1.9% are families with disabled children under 18. It should be noted that although disabled children are considered to be in a risk group, they still find themselves in a more favorable socio-economic position compared to children from large families and young families (Figure 2).

Children under 18 with disabilities receive social pensions, with an average payment of 14,998.4 rubles in 2022. Families with disabled children also receive monthly cash payments, averaging 2,272 rubles in 2022. However, researchers note challenges in analyzing the socio-economic status of these families due to insufficient statistical data. Discrepancies exist between the data provided by the Pension Fund and the Ministry of Health and Social Development.

Safiullina and Morozova (2020) argue that families with disabled children typically experience lower material well-being compared to those without such children, primarily because one parent, typically the mother, dedicates herself entirely to caregiving. This often leads to reduced employment or career opportunities as mothers may transition to low-paying, unskilled jobs, often home-based, affecting the family's overall quality of life. Consequently, the father often becomes the primary breadwinner, seeking additional income sources and having limited time for childcare. As a result, caregiving responsibilities predominantly fall on the mother.

Figure 2
The Level and Profile of Poverty Among Children Under 18 in Household Categories



Note. Source: Rosstat & Civic Chamber of Russian Federation (2022, p. 100).

Karpunina (2022) analyzes data from families with disabled children to identify common features among disadvantaged families and the experiences of the disabled child within them. She emphasizes the closed nature of these families, their isolation, and the barriers hindering interventions from social protection institutions as significant factors contributing to social exclusion.

One effective means of aiding parents with disabled children is through offering them professional retraining opportunities, potentially incorporating flexible work arrangements. The task of caring for a child with disabilities requires specialized skills, knowledge, and a level of psychological preparedness akin to that of a full-time job. Acknowledging this reality, the Russian government endeavors supports such parents by offering avenues for early retirement. As per pension regulations, to qualify for this provision, parents must be actively caring for disabled children up to the age of eight. Mothers become eligible for early retirement at 50, while fathers are eligible at 55 (Koshkin, 2021).

Home visiting services, where families receive regular visits from a team of specialists to enhance the child’s social and psycho-pedagogical adaptation, are gaining popularity. During such visits, social and pedagogical services are provided, including corrective sessions and developmental games in a home setting involving other family members.

The research evidence shows that families with disabled children face specific issues such as social withdrawal and isolation, parental guilt, feelings of inadequacy among siblings, parents’ misconceptions about the child’s abilities, as well as limitations and barriers to accessing leisure and recreational opportunities. Additionally, family breakdown may also occur (Andriushchenko & Brusneva, 2021).

Psychological support for families with disabled children is primarily aimed at overcoming the significant stress experienced by parents. According to Dautova and Dikhanbaeva (2018), the birth of a child with disabilities disrupts the normative expectations in families, triggering changes across three key levels: psychological, social, and somatic.

At the *psychological* level, shifts occur in intra-familial dynamics. The arrival of a child inevitably alters the established relationship between spouses, irrespective of the child's health status. Mothers, in particular, are vulnerable to emotional exhaustion and depressive episodes due to hormonal fluctuations and the constant care demands of the infant. Some may grapple with unfounded guilt, further compounded by societal prejudices. It becomes crucial for parents to extend mutual emotional support and redistribute responsibilities amidst these new circumstances.

Socially, families tend to withdraw and become more selective in their interactions, potentially stemming from experiences of stigma, even from within their own extended family networks. There are also changes in the labor sphere as parents are adapting to their new socio-economic circumstances.

The *somatic* level encompasses the physical toll of stress on parental health. Specialists note heightened risks of hypertension, insomnia, migraines, and neurotic disorders among parents. Furthermore, as the child ages, accumulated stress may exacerbate health issues, particularly affecting maternal well-being over time.

Hence, psychological support for families with disabled children should target three primary aspects:

- creating a supportive microsocial environment within the family conducive to the child's development;
- addressing and enhancing the socio-psychological well-being and self-awareness of parents;
- cultivating constructive relationships with extended family members and close associates, fostering a positive outlook towards the child with a disability.

Various strategies for supporting families of disabled children aim to prevent and address social orphanhood. In 2021, Russia had 390,949 orphaned or parentless children (Podderzhka detei-sirot i detei, n.d.). While accurate statistical data on the proportion of disabled children among them is scarce, most analytical studies suggest that children with severe health impairments are adopted less frequently than their typically healthy counterparts.

As of June 2022, the federal database on children left without parental care revealed that over half (60%) had health statuses classified as groups 3, 4, and 5, indicating various degrees of severity of chronic illnesses (Rossiiskoe sirotstvo v tsifrah issledovaniia, 2022). Nearly half of the families unable to find a child to adopt in 2021 restricted their consideration to children with mild health conditions.

Methodology

This study draws from the results of the survey conducted by a research team from the Murom Institute (Branch) of the Vladimir State University. The study took place

in early 2024 at the Murom Rehabilitation Center for Children and Adolescents with Disabilities (Murom, Vladimir Oblast) and the Children's Support Center *Sozvezdie* (Vyksa, Nizhny Novgorod Oblast)¹. The aim of the survey was to identify the spectrum of socio-psychological issues and create a social profile of women raising children with disabilities in the Russian province. The survey involved 98 mothers of children attending these institutions.

The semi-structured questionnaire we used served several key objectives. Firstly, it helped us identify the most challenging aspects of life for families with atypical children. These included dimensions such as life satisfaction, assessment of government and societal support, factors contributing to mother stigmatization while raising disabled children, financial status, housing conditions, education, employment, and specific interests that mothers have regarding their disabled children.

Moreover, the questionnaire enabled us to explore a broad spectrum of problems associated with child upbringing and education. It shed light on issues related to medical and social support, as well as psychological and pedagogical assistance in the rehabilitation and socialization of children with disabilities.

For our study, the following key areas were selected:

Socio-psychological and socio-cultural factors:

- access to social support networks and the need for certain types of family assistance;
- subjective evaluation of well-being and the influence of attitudes and stigmatizing beliefs of people around them.

The resources and agency of a family with a disabled child:

- readiness for childbirth and child-rearing (barriers to childbirth, personal fears, goals, and moral attitudes);
- agency (engagement in active actions to improve one's own and others' well-being).

Social factors:

- barriers and opportunities for accessing education, conditions and opportunities for employment;
- the level of satisfaction or dissatisfaction with state support, types of necessary support.

Medical factors:

- access to and satisfaction with medical technologies and services for children with disabilities;
- availability and accessibility of rehabilitation programs.

Economic factors:

- the family's income level, access to social benefits;
- housing conditions;
- working conditions and opportunities for balancing family and professional roles.

¹ These centers provide rehabilitation services for children aged one month to eighteen years with various diagnoses, including cerebral palsy, Down syndrome, autism spectrum disorders, mild to moderate intellectual disabilities, hydrocephalus, and residual hearing and vision impairments.

Results

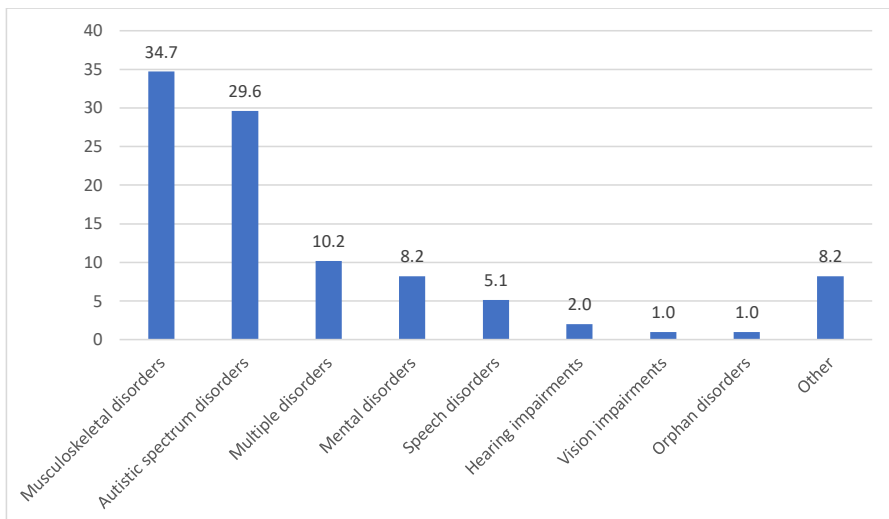
The study covered 98 mothers of children with disabilities. Respondents were aged 26–60, most of them (60%) were married and 10.2% were living in a cohabiting union, while the remainder were divorced or single-handedly raising children due to various circumstances (4.1% widows and 4.1% single mothers). Nearly half of the women have two children; 24.5% have one child, and 24.5% have three children. Only 2% of respondents have four or more children. On average, the surveyed families have one child with a disability, with only 2% of respondents raising two disabled children.

In our survey, we found that for most mothers, their child with health issues was their firstborn. Mothers who did not fall into this category often attributed the birth of a disabled child in their third or fourth pregnancies to factors such as “advanced maternal age” or “medical error.” Another significant aspect we explored was the question of whether women chose to have another child after giving birth to a disabled child. Our findings revealed that 32.7% of women opted to have another child, while 66.3% did not.

The age ranges of our informants’ children with disabilities varied: 13.3% were between 1 to 5 years old, 50% were between 6 to 10 years old, and 23.5% were between 11 to 15 years old. The remaining respondents cared for children aged 16 and older, as well as those deemed incapacitated due to the nature of their illness. Our informants’ children with disabilities span the following age ranges: from 1 to 5 years old (13.3%), from 6 to 10 years old (50%), and from 11 to 15 years old for 23.5% of respondents. The remaining respondents care for children aged 16 and older, as well as those deemed incapacitated due to the nature of their illness.

The nosological picture of childhood disability in the studied families is mainly represented by musculoskeletal disorders and autism spectrum disorders (Figure 3).

Figure 3
The Type of Illness or Condition of Children



Most commonly, the child's condition was diagnosed from birth (65.3%); in nearly a quarter of cases it was identified in early childhood; in preschool age, in 7.1% of cases; and in the youngest school age, in 2% of children.

Speaking of the child's status, 38.8% of mothers noted that the child had the status of "disabled child," which was assigned based on the conclusion of the Pediatric Medical-Psychological-Pedagogical Commission (PMPC) and the Medical-Social Expert Commission (MSEC). Additionally, 48% of respondents mentioned that their child had the "disabled child" status determined solely by MSEC. The remaining respondents are raising children with developmental differences but without an officially confirmed medical disability status.

The most important issues and relevant demands in medical and social assistance mentioned by our respondents are as follows:

- the child requires constant support, 55.1%;
- the child requires constant monitoring, 48%;
- the child cannot take care of themselves due to illness, 39.8%;
- the child constantly requires medication, 29.6%;
- expensive medication is constantly required, 19.4%;
- the child requires additional support equipment (such as a wheelchair or a lung ventilation device), 11.2%.

Of all the respondents, 10.2% reported that their children cannot move independently, and 5.1% of women emotionally expressed their concerns about "hopelessness of treatment," "understanding that neither I nor my child are needed by anyone," "poverty," and the "lack of any prospects for the child in life" (Trans. by Ekaterina Purgina—E. P.)

The set of questions concerning the accessibility of education and services provided by supplementary education institutions, as well as visits to cultural and leisure facilities helped us identify a serious problem inherent in the implementation of inclusive policies. Inclusion in education is crucial for successful integration of people with disabilities into social life. Nowadays, ensuring access to inclusive education for people with disabilities is a fundamental aspect of social policy. However, certain challenges still persist in the practice of educational inclusion.

The concept of inclusive education was initially introduced by the Federal Law No. 273-FZ *Ob obrazovanii v Rossiiskoi Federatsii* [On the Education in the Russian Federation], ratified on December 29, 2012. Article 2, Paragraph 27 of this law defines inclusive education as "ensuring equal access to education for all students, giving due regard to the diversity of special educational needs and individual capabilities" (Ob obrazovanii, 2012; Trans. by E. P.).

The law was further clarified when the status of "students with disabilities" (SWD) was established. It is important to distinguish this status from another one, that of "disabled," which is assigned by the MSEC. The status of a student with disabilities is determined by the PMPC, and thus it is not directly linked to the presence of disability. According to the law, a student with disabilities is "an individual who has deficiencies in physical and/or psychological development, confirmed by a psychological-medical-pedagogical commission and hindering the acquisition of education without special conditions being provided" (Ob obrazovanii, 2012; Trans. by E. P.).

Furthermore, the law mandates the provision of special conditions for both students with disabilities and those with special educational needs (SEN). These conditions include the development of specialized education programs, the utilization of technical aids, access to special literature, and the implementation of pedagogical support technologies, among others (for a detailed description, see Article 79).

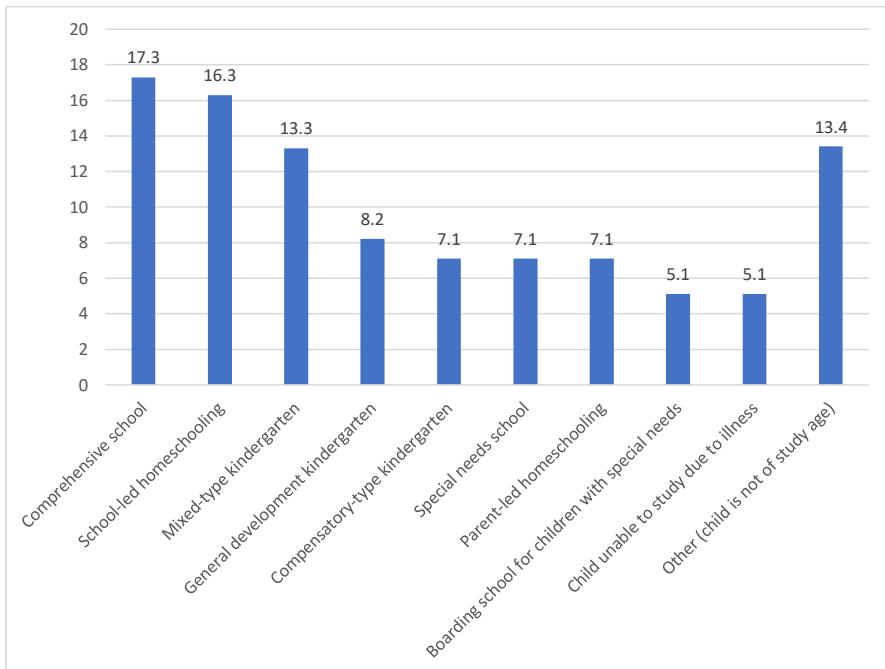
Educational conditions, including program content and pedagogical aspects, are determined, according to the law, by two documents: the Individual Rehabilitation Program (IRP) for students with disabilities, and the adapted educational program for students with special educational needs (Article 79). *The Adapted Educational Program (AEP)* is a program tailored for the education of individuals with disabilities, considering the nuances of their psychophysical development and individual capabilities. It may include interventions to address developmental challenges and promote social adaptation as needed.

The Federal Law No. 273-FZ *Ob obrazovanii v Rossiiskoi Federatsii* [On the Education in the Russian Federation] of 2012 abolished the concept of correctional (special) educational institution.

The majority of our respondents reported that children with disabilities do not have the opportunity for full inclusion in educational, leisure, and cultural activities due to various reasons, and this is by no means solely related to the child's health condition (Figure 4).

Figure 4

Involvement of Children With Disabilities in Inclusive Educational, Cultural, and Leisure Activities



Almost all children from the surveyed families attend clubs and extracurricular institutions, with sports sections and drawing clubs being the most common. For family leisure activities, parks (45.9%), shopping and entertainment centers (30.6%), cinemas (26.5%), and swimming pools (24.5%) are the preferred accessible options for visiting with a disabled child.

If we look at earlier public opinion surveys, dating back to 1991, we can see that they indicated a lower level of public awareness regarding the issues of education and socialization of disabled children. According to VCIOM² (Russian Public Opinion Research Center), 84.6% of respondents noted instances of injustice towards people with disabilities, but only 37.2% believed that inequality also extends to the sphere of education. Since problems faced by people with disabilities were rarely discussed in public discourse, the general public lacked an understanding of their educational needs and overall life experiences.

In surveys conducted in 2001–2002, respondents were already aware of these peculiarities. The studies revealed varying attitudes towards individuals with disabilities of different types. Children with musculoskeletal disorders were viewed most positively, while those with hearing and vision impairments received less favorable perceptions. Individuals with intellectual disabilities faced low loyalty and high detachment, as many respondents suggested they should only be educated in special (corrective) schools.

While the majority of surveyed parents (70%) supported the educational integration of children with musculoskeletal disorders, fewer than 40% of teachers shared this sentiment. For children with speech, hearing, and vision impairments, parental support for educational integration stood at 36%, compared to only 20% among teachers. Parents demonstrated greater acceptance of inclusive education compared to teachers: only 16% of educators expressed their readiness to teach in an inclusive classroom that includes children with musculoskeletal disorders, whereas 80% of parents were not opposed to such innovation (Iarskaia-Smirnova & Loshakova, 2003).

The study examining the subjective attitudes of parents with typically developing children towards children with disabilities and SEN in educational settings revealed the following: 30% of respondents expressed “pity and sympathy” towards children with disabilities, 20% indicated “dislike and repulsion,” another 20% reported “indifference,” while “kindness and friendliness” were felt by 20% of respondents. Additionally, 10% of respondents offered their own variations of responses (Fomina, 2021).

The resilience and agency of a family with a disabled child depend significantly on the availability of support channels and the family’s social capital such as extended family networks, community assistance, and involvement in social networks provided by parental non-profit organizations. Parents who actively seek social changes and are highly involved in their child’s socialization are typically those with a positive outlook on life and support from family and close relatives. However, traditionally, the full responsibility for care falls entirely on the parents of the disabled child.

² <http://sophist.hse.ru/db/oprview.shtml?T=S&S=974> (currently unavailable).

Approximately 27.6% of women stated they receive assistance from relatives living separately, while 22.4% receive help from family members. Additionally, 4.1% of respondents turn to the services of social workers, and 2% are compelled to hire caregivers, either nannies or attendants. Meanwhile, 41.8% of mothers strive to manage independently, primarily relying on their own efforts.

To gain a better understanding of the women's social background, we need to look at their level of education and professional experience. Women with disabled children often confront double discrimination in both employment and admission to educational institutions, stemming from their gender and family status. Consequently, mothers of disabled children constitute a unique demographic group, grappling with the repercussions of regional and gender disparities, alongside additional structural inequalities exacerbated by the constraints they encounter amidst ongoing social policy reforms.

A significant portion of women in our study, that is 27.6%, have completed secondary vocational education, 4.1% have completed primary general education, 5.1% secondary general education, and 8.2% primary vocational education (vocational school or lyceum). Fifty percent of women have completed higher education (Bachelor's, Specialist, or Master's degrees), while 5.1% have some college education but have not completed their degree. As many as 32.7% of women are officially employed full-time, 2% are informally employed, and 4.1% are self-employed.

An estimated 42.9% of mothers are not employed due to their caregiving responsibilities, while 12.2% work part-time. Additionally, 3.1% of respondents would like to have full-time employment but are currently unemployed. The remaining respondents are either retired or unable to work due to their own health conditions.

Employed respondents mostly work in the spheres of industry and manufacturing, healthcare, education, trade, and the service sector. Some women also mentioned engaging in activities such as "sewing children's clothing," "dressmaking," "raising goats and rabbits," "maintaining a garden to sustain our household," and "earning money by babysitting neighbors' children as I am at home anyway."

Economically, these families rely primarily on their spouse's (father's) salary, which serves as the main source of income for 68.4% of them. Additionally, for 64.3% of families, income comes from a monthly monetary allowance for the disabled child (or children). Of surveyed mothers, 44.9% indicated their own salary as a source of income, while 3.1% mentioned assistance from another family member residing with them, such as the disabled child's grandparents. As many as 11.2% of the respondents have side jobs.

Social benefits, payments, and subsidies also contribute to family income: 8.2% receive child support, 3.1% receive pensions, and 12.2% mentioned disability pensions for another family member. Additionally, 16.3% receive monthly child benefits when the per capita income is below the minimum living wage set in the region, and 3.1% receive other social payments. Only 1% of mothers receive financial assistance from relatives, acquaintances, or neighbors.

Only a small percentage of women consider themselves financially secure, indicating that they "have sufficient funds for comfortable living, major purchases

(such as a car or housing), and leisure” (3.1%). For 34.7% of mothers, they mentioned having enough money for essential expenses but need to save or take out a loan for major purchases and leisure activities. Similarly, another 34.7% stated that they have enough money only for basic necessities like food, clothing, utility bills, and medicine. More than a quarter of all respondents either “struggle to afford essential expenses related to food, clothing, bills, and medical treatment” (19.4%) or are forced to borrow money because they lack funds for these necessities.

Satisfaction with housing conditions varies depending on the place of residence. The majority of surveyed women live in administrative towns, with 9.2% residing in urban-type settlements, 9.2% in villages, and 6.1% in rural areas. Additionally, 7.1% of respondents live in larger cities with the status of a regional center. Nearly everyone has their own housing: 24.5% of women live in housing acquired by their family’s own means, 22.4% inherited housing, and 26.5% bought property through a mortgage. Of respondents, 21.4% live in houses or apartments owned by other relatives, while 4.1% rent or have social (municipal) housing. Regarding housing conditions, 30.6% reside in privately built houses with indoor sanitation facilities, while 2% live in private houses with outdoor amenities. While 13.3% of families live in a multi-story building with an elevator, 31.6% of respondents reported living in multi-story buildings without an elevator. Additionally, 7.1% of families live on the ground floor, 2% of families live in a one-room apartment in a private house, 8.2% reside in a two-room apartment, and 10.2% of families have three or more rooms in a private house.

Only 37.8% of mothers consider their housing fully suitable and comfortable for living with a disabled child. Whereas 31.6% consider their housing sufficiently comfortable for living with the disabled child, 9.2% of respondents reported their conditions being inadequately suited (arranged) for living with a disabled child. Notably, 18.4% of families independently adapted their housing to meet the needs of their disabled child.

To gauge the well-being of families with atypically developing children, we need to delve into concepts like discrimination, stigmatization, social exclusion, and community dynamics. These challenges are not only confined to cities but also affect small towns and rural areas. Of special interest in this respect are the studies that examine the factors influencing the formation of these phenomena. The theory of Erving Goffman (1963), who is one of the leading proponents of symbolic interactionism, helps us understand the mechanisms of impression management and the dramaturgy of life in families with disabled children. Additionally, his theory of stigmatization provides us with some insights into how individuals perceive each other. Michel Foucault’s (1975/1999) theory helps to look at social space from the perspective of disciplinary order and decipher the rules of social differentiation.

Our survey revealed high emotional fatigue among mothers raising disabled children. Of all the respondents, 86% experienced stigmatization, with 53.1% facing disapproval after their child’s birth. A total of 54% reported discrimination toward their child, and 37.8% had to face personal neglect and offensive behavior. Many reported being told that mothers who give birth to a disabled child should not have any more

children. Many mothers (58.2%) indicated that there were instances when those around them expressed the opinion that disabled children are a “burden on the family” and that they “do not contribute anything useful to society” (55.1%).

Almost half of the women in the study have heard at least once the opinion that disabled children should live and be raised separately from other (typically developing) children.

The situation becomes even worse when it comes to the reproductive rights of disabled children and the mothers of such children. 39.8% of women have encountered quite aggressively and emotionally charged opinions from those around them that disabled individuals should not have offspring, while 25.5% of mothers have faced similar remarks directed towards themselves.

In respondents' own words, these opinions are often articulated the following way:

“Freaks of nature should be banned from reproducing,” “invalids are burdens on the state's neck,” “they give birth to invalids on purpose, to receive benefits” (Trans. by E. P.).

Women experience discrimination in almost every sphere of life: in healthcare and social protection systems, when they are forced to defend their own rights and the rights of their children to access necessary information, treatment, services of specialists, material assistance as provided by law; in education and employment, being compelled to forgo education and professional development, lowering wage and job requirements to raise their children; in social relations and from the government, imposing on them a sense of guilt for giving birth to disabled children, fostering a sense of powerlessness in society and the state.

In every aspect of public life, women with disabled children face the burden of dual inadequacy, as their reproductive and economic roles come under scrutiny. The stigma surrounding these women contributes to feelings of guilt in half of them for giving birth to a disabled child, with 7.1% even admit considering abandoning their child. These thoughts and emotions arise amidst profound emotional fatigue and depression, leading to 33.7% of mothers feeling guilt and shame for having such thoughts:

I feel exhausted and drained ... sometimes I just want to cry, I'm so tired ... there's no light at the end of the tunnel, it's the same thing every day, day in and day out ... I'm so tired that sometimes I fall asleep without even taking off my robe ... I don't see any joy in life when I'm tired, I dream of spending at least one day without laundry, cooking, or massages for my son ... sometimes I feel like I'm slowly losing my mind, my day is like Groundhog Day ... I ask myself, what have I done to deserve this? Why did he [God] punish me? (Trans. by E. P.)

A total of 48% of mothers report experiencing physical fatigue daily, and the same percentage (48%) stated that they experience psychological fatigue daily as well. At the end of the week, 34.7% of women feel physical fatigue, and 19.4%, psychological fatigue (Table 1).

Table 1
Stress and Feelings of Distress

Responses to the question: “What symptoms of stress do you experience?”	Responses	%
Irritability	62	63.3
Fatigue	61	62.2
Mood swings	48	49.0
Sleep disorders	47	48.0
Headaches	46	46.9
Anxiety	41	41.8
Forgetfulness (memory problems)	38	38.8
Increased irritability, feeling of anger	29	29.6
Hair loss, dry skin	16	16.3
Lack of joy and hope	15	15.3
Feeling tearful and moody	14	14.3
Eating disorders	14	14.3
Depression	12	12.2
Loss of will to live	5	5.1

At the same time, 35.7% of respondents benefit from specialist psychological assistance, 50% receive support from family and relatives, 57.1% find understanding from friends and acquaintances, 17.3%, from work colleagues, while 6.1% reported having no support.

It should be noted, however, that despite the difficulties, complexities, and problems, the majority of survey participants responded that they are “happy to be mothers”: “When you see your child smile, you understand that it’s worth living for” (Trans. by E. P.).

As many as 36.6% of mothers want more children if they receive sufficient financial support from the state (11.2% of respondents). The reasons why mothers do not plan to have any more children are listed in Table 2.

Table 2
Factors Affecting Respondents’ Decisions to Have More Children
(Gathered From Research Findings)

Responses to the question: “Would you like to have one more child?”	Responses	%
No, because of psychological fatigue and emotional burnout	28	28.6
No, because of financial constraints	17	17.3
No, because I’m afraid of having another child with a disability	16	16.3
No, because I’m a single mother	14	14.3
No, because I am struggling to raise a disabled child.	9	9.2

Table 2 Continued

Responses to the question: “Would you like to have one more child?”	Responses	%
No, because I don't have enough support from my relatives and friends	9	9.2
No, because of the lack of proper medical care	6	6.1
Yes, I'm planning to have another baby	11	11.2
Yes, I plan to have two more children	1	1.0
I would like to have more children provided I get state financial assistance	11	11.2
I would like to have more children if I had help from my family and friends	7	7.1
I'd consider having more kids if I had professional help	5	5.1

However, around 12% of women plan to give birth to another child or several more, and about 20% would have wanted this if they had financial assistance from the state, as well as support from relatives.

Conclusions

The well-being of families with disabled children hinges, firstly, on their internal resources, such as human and social capital, and support from extended family networks. Their ability to advocate for rights, join parent groups, and receive support from religious communities also impacts their well-being.

Secondly, an important role is played by external resources, including those provided by social protection institutions and other organizations equipped to aid families with atypically developing children. Their function is to determine whether the requests align with regulatory requirements and facilitate the provision of assistance to the family.

Thirdly, the living conditions of families are influenced by socio-cultural factors, such as the level of acceptance or stigmatization from their community, as well as the prevalence of discriminatory stereotypes regarding disability and mothers of disabled children.

Attitudes toward disability are evolving towards inclusion and inclusive development. However, there is still much social resistance, especially within social institutions. This resistance is apparent in the gap between legislation supporting inclusive education and the actual implementation of educational and nurturing services for disabled children. Families with children who have mental differences, like autism spectrum disorders, encounter these obstacles more frequently than those with physical differences.

Our analysis of the social status of mothers of disabled children on a microlevel enables a deeper understanding of the daily challenges these women face. It also helps us identify mechanisms in social welfare and support systems that contribute to or perpetuate inequality and social distress. In everyday practices and communications,

the assumption that the birth of a disabled child is a consequence of the mother's own marginalization is often revealed.

The problems of socialization of disabled children, household disarray, difficulties in the professional realization of women with disabled children, single-parenthood, psychological and emotional burnout, and physical fatigue generate serious personal issues for women. These issues exacerbate the stigma of disability and provoke negative social attitudes towards inclusion as a whole.

Meanwhile, the situation of women residing in provincial cities is even worse compared to that of residents of regional centers and megacities, where there are more opportunities to gain resources and receive social, psychological, and material assistance.

The arrival of a child invariably alters the established dynamic between spouses, regardless of the child's health. Additionally, mothers often face heightened emotional strain and may experience depressive symptoms due to hormonal changes and the continuous care required for the infant. Some mothers may also grapple with unwarranted feelings of guilt associated with having a child with special needs, often exacerbated by social prejudices.

Our study confirms that mothers of children with disabilities are more prone to stress-related physical ailments such as hypertension, insomnia, migraines, and neurotic disorders. Furthermore, as the child grows older, accumulated stress may lead to the emergence of severe health issues in some mothers as they age.

As far as social and medical assistance is concerned, families with a disabled child face several significant challenges and demands, including the constant need for support and monitoring for the child due to their condition. Another significant obstacle arises from the child's inability to independently care for themselves, along with the need for costly medications. Additionally, families often require additional support, including specialized equipment such as wheelchairs or artificial lung ventilation apparatus.

The resilience and agency of a family with a disabled child depend significantly on the availability of support channels and the family's social capital, e.g., extended family networks, community assistance, and involvement in social networks provided by parental NGOs. Parents who actively seek social changes and are highly involved in their child's socialization typically have a more positive outlook on life and enjoy support from family and close relatives.

The socio-economic profile of women with disabled children indicates that for most families raising such children, the primary income source is the spouse's (father's) salary or a monthly allowance for the disabled child (or children). A quarter of those surveyed either find it difficult to afford essential expenses like food, clothing, bills, and medical treatment, or they are compelled to borrow money due to insufficient funds for these necessities.

To grasp the discomfort and psychological strain experienced by families with atypical children, we need to delve into concepts like discrimination, stigmatization, social exclusion, and community attitudes. Our survey detected a high level of emotional fatigue among mothers of disabled children, as can be seen from their

responses to questions about emotional burnout, fatigue, guilt, and social issues. Nearly all participants encountered instances of stigmatization, with the majority facing judgmental reactions and experiencing discrimination and offensive attitudes towards their child from others.

Caring for a child with a disability requires specific skills and knowledge, as well as psychological readiness, akin to full-time employment. Recognizing this situation, the Russian government offers support to such parents by providing early retirement options. Social-psychological support for families with disabled children should primarily focus on helping parents overcome the stress they experience. The birth of a disabled child often disrupts the family members' normative expectations, causing changes in the family on psychological, social, and somatic levels.

Families with disabled children often face a shortage of resources, but this can be compensated by state and non-state institutions. State support, including subsidies and preferential lending, is provided through federal and regional programs. As for NGOs, our research indicates that families do not always seek assistance from such specialized organizations and funds, which happens for two main reasons: firstly, the scarcity of NGOs, especially in peripheral parts of the country; and secondly, families' limited awareness of or trust in these institutions.

To improve the socio-psychological well-being of families with disabled children, it is important for family members to be able to access and use available resources effectively. Overcoming stigmatizing socio-cultural attitudes requires fostering supportive institutional conditions and highlighting successful examples of families raising disabled children through relevant channels.

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