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ИНСТИТУТ РЕПОРТАЖЕЙ ВОЙНЫ И МИРА

CARING FOR THOSE WHO CARE:

PSYCHOLOGICAL SUPPORT
FOR PARENTS AND GUARDIANS
RAISING CHILDREN WITH
DISABILITIES IN KAZAKHSTAN

POLICY BRIEF

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ABOUT «MAMA PRO»

The «Mama Pro» Foundation for the Support and Development of Socially Vulnerable Women was founded in 2018 by parents of children with special needs. The foundation helps women acquire relevant knowledge in entrepreneurship, receive psychological counseling, and gain skills in starting and running a business without being separated from their children. **The foundation's mission:** to improve the quality of life for families raising children with special needs.

ABOUT IWPR



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ABSTRACT

THE PURPOSE OF THIS DOCUMENT IS

to propose specific measures for integrating psychological support for parents and guardians raising children with disabilities into the system of public services in Kazakhstan. The document is based on data from research conducted by the «Mama Pro» Public Foundation and international best practices.

Parents and guardians, predominantly women, raising children with disabilities, special needs, or those at risk, are in a state of chronic stress and emotional burnout. Psychological assistance for parents and guardians is not prioritized and is not included in the individual rehabilitation program (IRP), the psychological and pedagogical correction center, the healthy child clinic service at the psychological, medical, and pedagogical service (PMPS), and other government services. There is a lack of systemic support for parents as partners in the rehabilitation and care process.

MAMA PRO'S MAIN RECOMMENDATIONS:

- 1 Include psychological support for parents and guardians in the individual rehabilitation program (IRP).
- 2 Establish the function of psychological support for families within the activities of psychological and pedagogical correction centers.
- 3 Introduce mandatory psychological assistance for parents of children with disabilities into the standards of primary health care.
- 4 Support the development of parent communities and NGO initiatives through state funding and compulsory health insurance mechanisms.



PROBLEM AND CONTEXT

The main problem at the moment is that the state **does not consider the psychological well-being of parents as part of the overall support for families with children with disabilities.**

In Kazakhstan, there are 103,000 families raising children with disabilities, and this does not include families with children with special needs. According to research by international organizations, families with children with special needs are living in conditions of so-called «disability poverty» (OECD, WHO).

High costs of care and adaptation for the child have to be combined with low incomes, part-time employment, or lack of employment due to the need for constant care of the child. **Along with economic vulnerability, parents and guardians face a disproportionately high level of parental stress.** The reasons for this include both medical or behavioral characteristics of the child, as well as social isolation, lack of understanding, and the absence of systemic emotional support.

ACCORDING TO A NATIONAL STUDY CONDUCTED BY THE «MAMA PRO» FOUNDATION (2025):

- 1 **40%** of parents and guardians report constant physical and emotional overload;
- 2 **73%** experience constant worry and anxiety about their child's future;
- 3 **another 40%** face social isolation regularly, and almost 20% feel lonely on a constant basis.

Most parents and guardians have to cope with this experience on their own. Less than half of the respondents receive constant help from their partners. **State assistance, firstly, remains inaccessible** (only 15% of those surveyed are aware of all sources of support), **and secondly, lacks a comprehensive approach.** International studies show that the higher the degree of unpaid and unshared caregiving, the higher the risk of poverty, depression, and social isolation in families with children with disabilities.¹

Thus, parents and guardians are left without psychological support, which negatively affects the stability of families, the implementation of inclusive education, and the integration of children into society.

International practices demonstrate a wide range of tools to support parents of children with disabilities. However, directly adopting these solutions is impossible without considering the specifics of the Kazakhstani social and institutional environment.

EXISTING OPPORTUNITIES:

» **Extensive infrastructure:** a developed system of public service centers, psychological-medical-pedagogical commissions, schools, and polyclinics already exists and can be used to implement psychological support for parents.

Regulatory framework and programs: Individual Development Plans (IDPs), compulsory social health insurance (OSMS), and the Social Code of 2023 provide a formal basis for integrating psychological assistance into existing mechanisms. Making minor amendments to existing programs could be the first step towards institutionalizing this service.

Active NGO sector and parent communities: organizations such as «Mama Pro», «Erekche Bakyt», or the «Union of Parents of Special Children» already conduct peer-to-peer groups and psychological training. These initiatives can be scaled up and supported with government funding, transforming them into a full-fledged element of the national system.

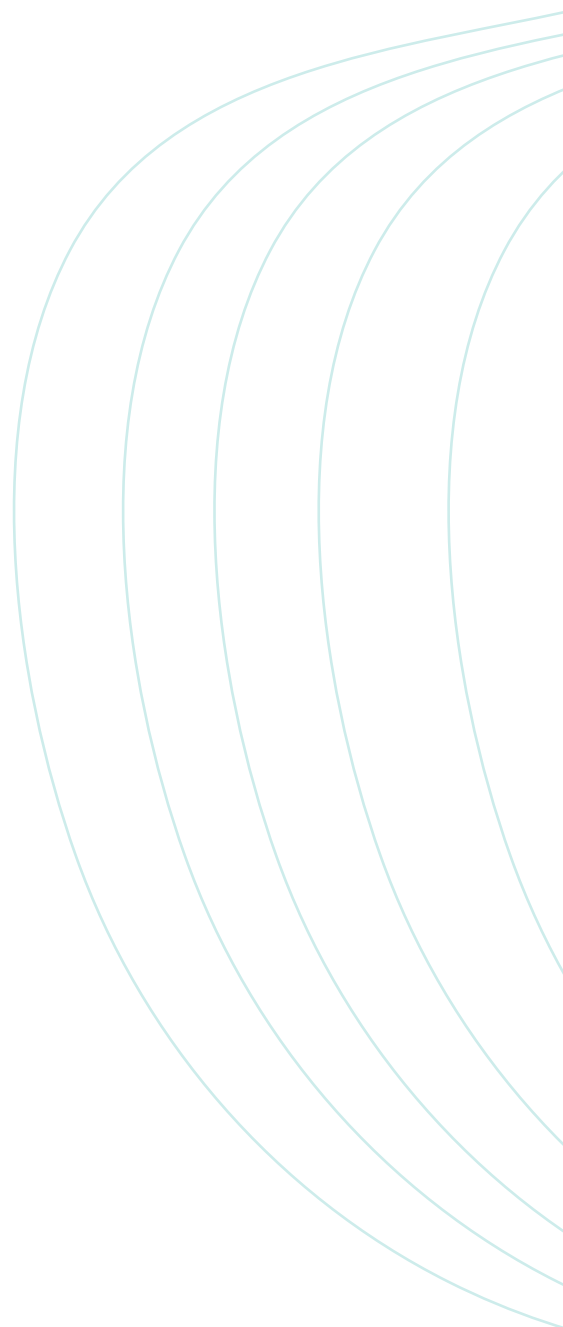
¹ Brehaut, J., Garner, R., Miller, A., Lach, L., Klassen, A., Rosenbaum, P., Kohen D. (2011). Changes Over Time in the Health of Caregivers of Children With Health Problems: Growth-Curve Findings From a 10-Year Canadian Population-Based Study. *American Journal of Public Health* 101, 2308-2316; Gallagher, S. and Whiteley J. (2013). The association between stress and physical health in parents caring for children with intellectual disabilities is moderated by children's challenging behaviours. *Health Psychology* 18(9), 1220-31: [doi: 10.1177/1359105312464672](https://doi.org/10.1177/1359105312464672). Epub 2012 Nov 5. PMID: 23129834.

LIMITING FACTORS:

Staff shortage: the number of specialists with specific expertise in working with parents of children with special needs is limited, especially in the regions.

Regional inequality: private services and NGO initiatives are available in large cities, while in rural areas parents have virtually no access to assistance.

Social barriers and stigma: the culture of seeking psychological help in Kazakhstan is still underdeveloped, and seeking help from a psychologist is often perceived as a sign of «weakness».



RECOMMENDATIONS

To create a sustainable, equitable, and scientifically sound system of support for parents and guardians raising children with disabilities, it is necessary to implement a number of interconnected measures and foster interaction between the healthcare, education, and social protection systems.

In this regard, Mama Pro makes the following recommendations for improving the regulatory framework in the short term:

1. SUBMIT THE RESEARCH FINDINGS FOR DISCUSSION TO THE PUBLIC COUNCIL AND THE COORDINATION COUNCIL OF THE MINISTRY OF LABOR AND SOCIAL PROTECTION OF THE REPUBLIC OF KAZAKHSTAN

Present the results of the «Caring for those who care» study and the developed recommendations to the Public Council and the Coordination Council of the Ministry of Labor and Social Protection of the Republic of Kazakhstan, with the aim of integrating the proposed measures into existing and planned state programs to support families raising children with disabilities and special needs.

2. ENSHRINE THE RIGHTS OF PARENTS, GUARDIANS, AND LEGAL REPRESENTATIVES OF CHILDREN WITH DISABILITIES TO RECEIVE FREE PSYCHOLOGICAL SUPPORT IN THE SOCIAL CODE OF THE REPUBLIC OF KAZAKHSTAN

It is recommended that «Clause 1. Article 157. Individual Program, Paragraph 1. General Provisions, Chapter 13. State Support for Persons with Disabilities, Section 3. Areas of Social Protection of the Population and the Procedure for Their Implementation, Special Part of the Social Code of the Republic of Kazakhstan dated April 20, 2023 No. 224-VII LRK» be amended to read as follows:

«The individual program also includes the names of technical assistive (compensatory) devices, special means of transportation and services that a person with a disability needs, in accordance with the classifier of technical assistive (compensatory) devices, special means of transportation and services provided to persons with disabilities, measures to provide psychological support to parents, legal representatives and guardians of persons with disabilities, in the manner determined by the authorized state body».

3. ADDITION OF THE BLOCK «DEVELOPMENT OF THE FAMILY SUPPORT INSTITUTE» TO THE CONCEPT OF INCLUSIVE POLICY OF THE REPUBLIC OF KAZAKHSTAN

It is proposed to supplement the section «Development of the Family Support Institute» with an indication of the need to develop a system of psychological support for parents and guardians caring for children with disabilities. To provide accessible counseling services, support, prevention of emotional burnout, and programs to improve parental competence, as a key factor in sustainable inclusion and prevention of institutionalization.

4. INCLUSION OF THE SERVICE «PSYCHOLOGICAL SUPPORT FOR LEGAL REPRESENTATIVES» IN THE SOCIAL PART OF THE INDIVIDUAL REHABILITATION PROGRAM (BASED ON PROPOSALS TO ORDER NO. 260 OF THE MINISTRY OF LABOR AND SOCIAL PROTECTION OF THE POPULATION)

It is recommended to supplement the list of social rehabilitation measures with an item on psychological support for legal representatives, including:

- individual counseling;
- participation in self-help groups;
- preventive psychotherapy.

5. STRENGTHENING PSYCHOLOGICAL SUPPORT FOR PARENTS IN THE ACTIVITIES OF PSYCHOLOGICAL AND PEDAGOGICAL CORRECTION CENTERS (BASED ON PROPOSALS TO THE MINISTRY OF EDUCATION AND SCIENCE ORDER NO. 385)

It is proposed to clarify the functions of psychological and pedagogical correction centers by adding a provision to subparagraph 6 of Article 149 stating that the center provides not only family counseling, but also full-fledged psychological support to legal representatives, including participation in self-help groups and preventive psychotherapy.

6. EXPANDING THE COMPETENCIES OF PRIMARY HEALTHCARE PSYCHOLOGISTS IN SUPPORTING PARENTS OF CHILDREN WITH DISABILITIES (BASED ON PROPOSALS TO THE MINISTRY OF HEALTH OF THE REPUBLIC OF KAZAKHSTAN ORDER NO. 49)

It is recommended to supplement the standard for providing primary healthcare with an indication of the mandatory provision of psychological assistance to legal representatives of children with disabilities and limited abilities, who apply through referral or independently.

7.7. LAUNCHING PILOT PROJECTS IN ALMATY AND ASTANA WITH THE SUPPORT OF PUBLIC ORGANIZATIONS

Implement pilot projects to introduce systemic psychological and methodological support for parents and guardians in the cities of Almaty and Astana. The pilot projects should include: free psychological support services, including counseling, support, and programs for preventing emotional burnout for parents, legal representatives, and guardians of children/persons with disabilities and limited abilities.

8. ALL PROPOSALS FOR AMENDING LEGISLATION SHOULD BE SUBMITTED WITHIN THE FRAMEWORK OF THE DISCUSSION OF THE DRAFT LAW «ON COMPREHENSIVE SUPPORT FOR CHILDREN (PERSONS) WITH DISABILITIES».

All proposals for improving legal regulation, including securing the right of parents to psychological support, developing community-based services, and strengthening mechanisms for support and prevention of institutionalization, should be submitted for consideration within the framework of the draft law «On Comprehensive Support for Children (Persons) with Disabilities».

The draft law is a key platform for integrating modern international standards of family-oriented support.

These recommendations are balanced in terms of regulatory feasibility, economic efficiency, and social significance. They do not require the creation of new institutions, but utilize sustainable and familiar mechanisms for regulating and financing medical services, which allows for the integration of new services without creating a separate budget. At the same time, these proposals create a systemic approach and a single standard of support for parents through three key points – rehabilitation, education, and healthcare.

THIS APPROACH ENSURES:

- 1** interdepartmental coordination and continuity of services;
- 2** equal access for families in all regions of the country;
- 3** strengthening the institution of the family as a partner of the state in the process of child rehabilitation.

LONG-TERM MEASURES

While regulatory changes are a priority in the proposed Mama Pro approach, there are other measures needed to form a holistic approach, the implementation of which is possible in the longer term.

SPECIFICALLY, THE FOUNDATION RECOMMENDS THE FOLLOWING STEPS:

- 1 Creation of a single **national information platform** on support measures, services and opportunities for parents.
- 2 Launching **online consultations and hotlines for parents**, especially in the regions;
- 3 Institutionalization of **peer-to-peer communities** and parent support groups with the participation of NGOs and local administrations;
- 4 Piloting **respite care** services based on social centers;
- 5 Development of **comprehensive family support centers** (similar to Family Hubs in the UK), combining services «under one roof»;
- 6 Promoting a culture of psychological well-being and mutual support through **government campaigns** to reduce stigma and support civil initiatives.

CONCLUSION

The measures proposed in this [policy brief](#) are aimed at creating a comprehensive, sustainable system of support for families raising children with disabilities. Their implementation will allow the state to move from a «care» model to a partnership model with families, ensuring that Kazakhstan fulfills its international obligations under the UN Convention on the Rights of Persons with Disabilities.