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STATE POLICY OF THE RUSSIAN FEDERATION FOR
PROTECTION OF DISABLED CHILDREN'S RIGHTS

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Abstract

The research subject is the main directions, approaches, and priorities of state policy in the Russian Federation in health protection and protection of the rights of disabled children over the past twenty years. Particular attention is paid to the problems and results of its reform. It is emphasized that public policy remains the primary public mechanism in defining, categorizing, and legalizing disability. State policy allows preserving the possibility of dialogue between generations, ensuring a balanced combination of traditions and innovations in understanding modern social relations concerning children with disabilities. The research methodology is based on the principles of historicism, scientific objectivity, consistency, and complexity. These methodological principles make it possible to study the experience and modern problems of the formation and implementation of the Russian Federation's state policy in the field of health protection and protection of the rights of disabled children as a complex problem. The study's main conclusions are the peculiarities of the implementation of the state policy of the Russian Federation in the field of health protection and protection of the rights of disabled children in the framework of two stages: 1991 – 2001 and 2001 – 2020. An exceptional contribution of the authors to the study of the topic is a comprehensive analysis of the evolution of approaches, priorities, and directions of the Russian Federation's state policy in health protection and protection of the rights of disabled children over the past twenty years.

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1. Introduction

In recent decades, the world has developed stable trends and mechanisms for shaping policy in health protection and protection of the rights of children with disabilities. Governments of various countries provide support in developing approaches to solving this social group's problems and assisting state and public institutions in defining and implementing policies for people with disabilities. At the same time, there remains a multi-vector approach and a wide range of models for implementing state policy concerning children with disabilities, determined by historical, social, and economic conditions.

2. Problem Statement

We consider it important to identify the dynamics of the Russian Federation's state policy's main directions and priorities in protecting the rights of children with disabilities over the past twenty years.

3. Research Questions

The solution to the problem requires the designation of the following research questions:

- 3.1. What were the rights of children with disabilities guaranteed by Russian legislation?
- 3.2. How did the changes in the Russian regulatory framework affect the situation of children with disabilities?
- 3.3. What is the essence of the main approaches to organizing the process of rehabilitation and habilitation of disabled people in Russia?
- 3.4. How are international standards for protecting the economic, social, legal, and other rights of children with disabilities applied in Russia?

4. Purpose of the Study

The study aimed to identify the stages, primary directions, and priorities of the Russian Federation's state policy in health protection and protection of the rights of disabled children in the 1990 – 2000s.

5. Research Methods

For the study's goal, a content analysis of regulatory legal documents developed and effective in 1990 – 2020 was carried out. Content analysis of the documents was aimed to identify and summarize the fundamental directions and priorities of the Russian Federation's state policy in health protection and protection of the rights of disabled children. The work is also based on historiographic and comparative-historical methods.

6. Findings

In Russia, the state policy concerning children with disabilities has a long history, the study of which is necessary in order to objectively assess its current state and identify the factors and conditions that determine the strategies and development prospects.

Following the Decree of the President of the Russian Federation, the problem of the survival, protection, and development of children was recognized as a priority for the Russian state policy (RF President, 1992). This period is also characterized by a change in conceptual approaches to solving problems associated with all categories of disabled people, bringing the Russian legal system in line with ratified international acts. The basis of state measures to support the disabled was based on their comprehensive rehabilitation principle in an accessible environment.

When developing the legal framework for state policy concerning children with disabilities, special attention was paid to the norms enshrined in international documents (UN OHCHR, 1969; UN OHCHR, 1971; UN OHCHR, 1975; UN, 1982; UN OHCHR, 1989).

The adoption of federal laws "On veterans," "Social services for elderly citizens and disabled people," "On state social assistance," as well as "On social protection of disabled people in the Russian Federation," which were the right of disabled children to social protection, a system of "state-guaranteed economic, legal and social support measures that provide disabled people with conditions for overcoming, replacing (compensating) the limitations of life activity" (RF Government, 1995) is enshrined.

Russian legislation guarantees that children with disabilities have both general rights for children and special rights. The rights common to all children are the right to life, to be raised in a family environment, to receive free medical care, and the right not to be subjected to cruel or degrading treatment. The specific rights of children with disabilities are the rights to rehabilitation, education, spa treatment, the provision of special means of transportation, barrier-free access to residential buildings, educational and health care institutions, sports facilities, recreation, and cultural institutions. The Russian legislation of that time reflected the principle of respect for the developing abilities and the right of disabled children to preserve their individuality. The goal of state policy in children's interests was to promote children's physical, intellectual, mental, spiritual, and moral development (RF Government, 1998).

In order to create equal opportunities for all citizens to participate in the life of society, the development and implementation of both promising and short-term targeted measures to assist children with disabilities, children with disabilities, and families raising such children began. Against the background of a gradual increase in the number of disabled children in Russia, it became necessary to adopt the Federal Comprehensive Target Program "Children of Russia," a part of which was the Federal Target Program "Children with Disabilities" (RF Government, 1993). Later, this program received the status of a presidential program. Since the 1990s, Russia has adopted several hundred normative legal acts to protect the rights and interests of disabled children. However, the adopted laws' implementation required the adoption of many bylaws since specific provisions of the laws could not be implemented due to the established practice's peculiarities, lack of experience, or the budget deficit.

In 1990, the Federal Law "On the Education of Persons with Disabilities" was never adopted. Also, no normative legal acts have been developed to regulate rehabilitation centers' activities for

disabled children. Given that, at the same time, there was no legal framework governing creating a system for registering children with disabilities in the country. This circumstance made it difficult to form and implement state policy concerning this category of the population.

The situation began to change only at the next stage, namely in 2001. In 2001, the 54th World Health Assembly adopted the International Classification of Functioning, Disability, and Health (ICF). This standard, developed by the World Health Organization, addresses the measurement of the health status and disability of both an individual and the general population. This standard indicated the multidirectional approaches to organizing the rehabilitation process for disabled people, implemented in Russian and international practice. So, the World Health Organization standard designated as the most effective, consolidated, interdepartmental, systematic approach to organizing rehabilitation and habilitation of people with disabilities focused on eliminating the complete compensation for the limitations of their life in all spheres.

At the same time, the legislation of the Russian Federation lacked a clear definition of the medical and social examination of children with disabilities and people with disabilities from childhood, as well as the norms defining the essential characteristics of complex rehabilitation and the process of organizing the life of disabled people from childhood (RF Government, 1995). In this regard, the adoption of a new standard by the World Health Organization has exacerbated the problem of improving state standards for rehabilitation assistance to children with disabilities and people with disabilities since childhood. Also, the adoption of a new standard by the World Health Organization made it obvious the need to create regional rehabilitation services. These priorities of state policy in the field of protecting the rights of children with disabilities and ensuring their livelihoods are reflected in the Concept for improving the medical, social, and psychological rehabilitation of children with disabilities and invalids from childhood and the Action Plan for its implementation (RF Ministry of Health, 2003).

Since 2003, the Russian Federation has created a service for medical-social and psychological-pedagogical rehabilitation of children with disabilities and invalids from childhood in the course of the implementation of this Concept. As a result, by the beginning of the second decade of the 2000s, 768 social rehabilitation centers for minors, 286 social shelters for children and adolescents, 282 rehabilitation centers for children and adolescents with disabilities, 17 centers for helping children left without parental care were functioning in Russia. One hundred thirty-two children's inpatient social service institutions, including 122 boarding homes for mentally disabled children and ten boarding homes for children with disabilities (RF Ministry of Labor, 2014).

One of the fundamental principles of the work of federal and regional rehabilitation centers was the inclusion of their families in the systemic work on the rehabilitation of disabled children, for which the structure of the centers provided schools for parents, guardianship (public) councils of parents of children with disabilities and children with disabilities from childhood. Besides, in the 2000s, citizens' compulsory preparation for the admission of orphans and children left without parental care for upbringing in a family was legislatively enshrined in Russia. In the future, the norm on the need for an agreement with the parents of any medical service provided to a child in a medical institution was enshrined in federal legislation (RF Government, 2011).

During this period, the state priorities for ensuring the rights of children with disabilities were supplemented by the solution of the task of introducing patronage services (support) for families raising children with disabilities and children with disabilities by the services of district social workers (RF President, 2012b). A new priority in the state policy for protecting the rights of children with disabilities has become protection from information that is harmful to their health or development (RF Government, 2010).

The Concept of improving the medical, social, and psychological rehabilitation of children with disabilities and invalids from childhood fixed the main directions of rehabilitating children with disabilities traditionally established in Russia: medical, social, psychological, and pedagogical. In connection with the ratification of the Convention on the Rights of Persons with Disabilities", a new concept was introduced into the legislation – habilitation, i.e., the system and process of forming the abilities of disabled people for every day, social, professional, and other activities (RF Government, 2014).

Thus, the state policy's goal concerning children with disabilities was the elimination or the fullest possible compensation for their life activity limitations for their integration into society. In the development of the beginning process of the formation in the Russian Federation of a consolidated, interdepartmental approach to the organization of the process of rehabilitation and habilitation of disabled people, focused on the elimination of the complete compensation for the limitations of their life in all spheres. Since 2017, the implementation of a related pilot project has begun in two regions. Since 2019, as part of the implementation of the subprogram "Improving the system of comprehensive rehabilitation of disabled people" of the state program of the Russian Federation "Accessible Environment", the formation of a system of comprehensive rehabilitation and habilitation of disabled people began in 18 constituent entities of the Russian Federation (in 2020, in 39 regions) (FSUE STANDARDINFORM, 2020).

According to federal legislation, the main mechanism for realizing the right of disabled people to state-guaranteed rehabilitation and habilitation was the individual program of rehabilitation or habilitation of a disabled person being developed by federal institutions of medical and social expertise (MSE). Promising in terms of implementing the main directions of state policy on protecting the rights of children with disabilities was the solution to the problem of financing an individual rehabilitation or habilitation program for a disabled person: the allocation of funds for the provision of disabled people with technical means of rehabilitation was centrally organized; otherwise the financial support of rehabilitation and habilitation measures was departmental. In this regard, in the Russian Federation, about 29 thousand organizations of various departmental subordination were involved in the number of organizations that carry out, in one form or another, measures for the rehabilitation and habilitation of disabled people.

An important direction in developing the system of comprehensive rehabilitation and habilitation of disabled people was creating a federal state information system, i.e., Federal Register of Disabled Persons, to record information about people with disabilities, including children with disabilities. Following Article 5.1 of Federal Law No. 181-FZ, the operator of the Federal Register of Disabled Persons was the Pension Fund of the Russian Federation (RF Government, 2016).

One of the main directions of state policy in the 2000s was the prevention of child disability and the organization of early assistance. This trend was reflected in the National Strategy of Action for Children for 2012–2017, the Concept of State Family Policy in the Russian Federation for the Period up to 2025, the Concept for the Development of Early Care in the Russian Federation for the Period until 2020 and other documents (RF President, 2012b). At the same time, the issues of early assistance to disabled children and their families were still insufficiently linked with the issues of their comprehensive rehabilitation in terms of consistency and continuity. This circumstance determined the prospects for their development for the next decades.

One of the most important directions of state policy has traditionally been to ensure the implementation of the right of disabled children to education. Since 2012, the fundamental legislative act regulating the education of disabled children in the Russian Federation is the Federal Law of December 29, 2012, N 273-FZ "On Education in the Russian Federation." This law regulates the right of children with disabilities to education. It obliges federal state bodies, state authorities of the constituent entities of the Russian Federation, and local self-government bodies to create the necessary conditions for obtaining a quality education by persons of these categories. One of the main directions of state policy in the Russian Federation was determined to increase the effectiveness of state support for families. In particular, this process concerned the creation of a rehabilitation system for children with disabilities, providing comprehensive psychological, pedagogical and medical, and social support for the individual development of a child with disabilities, regardless of the form of his upbringing (RF Government, 2008). The implementation of this direction involved a set of measures and measures of a federal and regional scale (RF Government, 2017).

Besides, in order to promptly assist the regions in 2018, the Federal Center for Comprehensive Rehabilitation and Habilitation of Disabled People and Children with Disabilities was established in the structure of the Federal Bureau of Medical and Social Expertise (RF Ministry of Labor, 2018).

During the period under review, a special place in the formation of state policy was occupied by the advisory bodies under the President of the Russian Federation: since 1994 – the Coordination Committee for Disabled Persons under the President of the Russian Federation, from 1996 to 2012 – the Council for Disabled Persons under the President of the Russian Federation, since 2012 – the Commission under the President of the Russian Federation for the disabled (RF President, 2012a). Their special role was to ensure effective interaction between federal government bodies, government bodies of the constituent entities of the Russian Federation, local government bodies, public associations, scientific and other organizations when considering issues related to solving disability and disabled people.

The goal was to increase the effectiveness of state social support for disabled children and other persons with disabilities and their families. In connection with this goal, in 2009, the Russian Federation established the position of the Commissioner under the President of the Russian Federation for the Rights of the Child, ensuring the protection of the rights, freedoms, and legitimate interests of children, including children with disabilities (RF President, 2009).

Thus, during this period, the state and society paid serious attention to the legal support and organization of the multi-vector process of solving the problems of disabled children in the 1990s–2000s.

7. Conclusion

The Russian Federation has ratified the Convention on the Rights of Persons with Disabilities. Thus, the Russian Federation has demonstrated the country's readiness to create conditions aimed at observing international standards of economic, social, legal, and other rights of children with disabilities, as a heterogeneous group of persons with different needs, by strengthening and expanding comprehensive rehabilitation and habilitation services for this category of the population, including medical, educational and social aspects. In the Russian Federation, children with disabilities from birth belong and are guaranteed human rights and freedoms to create legal, socio-economic conditions for the realization of the child's rights and legitimate interests.

There are issues of further improvement of legislative and regulatory legal regulation of the complex rehabilitation and habilitation of disabled people, institutional, scientific, methodological, and information technology development of this system. In connection with these needs, the following directions of state policy are of priority: improving the system of comprehensive prevention of child disability; development of early assistance services for children with disabilities; development of technologies for interactive support of disabled children in the organization of their education, upbringing, socialization; development of technologies for supporting families of disabled children, aimed at keeping disabled children in families; active inclusion of families of disabled children in the habilitation process; conducting a systematic mass information campaign aimed at the diversified inclusion of children with disabilities into society.

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