



## Review Article

## Children with Disabilities: A Review on Medical Care and Social Supports

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## ABSTRACT

Type 1 diabetes is one of the most common chronic diseases in children. The cause of this disease is the destruction of pancreatic beta cells and the consequent loss of insulin production in the body. The incidence of this disease varies according to the geographical area, age, sex, family history, and race. Parents play an important role in childhood diabetes. Certainly, children do not have the ability to diagnose and treat, and the parents must give them the necessary care. It is obvious that children with disabilities need more care. In general, children with special healthcare needs often require specialized medical care and support. This article analyzed the main directions of social protection of families raising children with disabilities. All types of payments and benefits for this category of the population in modern Russia were considered, i.e. prospects of social work technologies with such categories as families with disabled children, particularly at the residence. The directions of the considered technology between various subjects and objects with a given family were analyzed, that is the historical aspect of the study of intrafamilial relationships in a Mordovian family with a disabled child. An algorithm of intermediary social activity with a category of the considered type is proposed.

## GRAPHICAL ABSTRACT



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## Introduction

Global statistics confirm that the number of people with diabetes is steadily increasing. Russia ranks fourth in the world in terms of the number of people infected by the disease (about 8.5 million), and among them, children are increasingly found. In such circumstances, the government cannot be inactive and provide special benefits for diabetics, which vary depending on the type of disease and the child's disability, but generally provide equal rights for all minors [1, 2]. One of the reasons that children get diabetes is a kind of immune system reaction to insulin-producing cells in the pancreas, and the body recognizes these cells as annoying, attacking and destroying them. Although family history may play a role, researchers have not yet been able to identify the risk factors for childhood diabetes [3]. This type of diabetes is called insulin-dependent diabetes. Although it accounts for 5 to 10% of all cases of the disease, its control is very important [3, 4].

Type 2 diabetes is caused by poor nutrition, obesity, low activity, stress and sleep deprivation, smoking, high fat, and in short, everything that is harmful to a healthy life and is institutionalized in the mechanical life. In type 2 diabetes, many of the above symptoms cannot be attributed to children because children generally do not smoke, are not stressed, and are generally not prone to many of the above factors. In type 1 diabetes, the patient is not involved in the development of the disease and has more of a genetic aspect that interacts with external factors and impairs the secretion of the hormone insulin. Of course, there are theories about the effects of toxins and viruses on type 2 diabetes [5]. If your child has diabetes, his or her diabetes is most likely type 1 diabetes. But in general, there are two types of diabetes in children, as follows:

- Type 1 diabetes (or insulin-dependent diabetes): In this type of diabetes, the baby stops producing insulin and will need regular insulin injections to process glucose. Although type 1 diabetes accounts for only 5 to 10 percent of all cases of diabetes, it is the most common type of diabetes in children. In fact, 85% of the most recently diagnosed types of diabetes are in

children and young people under the age of 18, which is why it is also called juvenile diabetes

- Type 2 diabetes: This type of diabetes, formerly called adult-onset diabetes, occurs when the pancreas makes insulin, but the body cannot use it. This type of disease was more likely to occur after the age of 40. But it has recently appeared earlier than this age, probably because more children from the same age are underweight or even obese, and obesity puts pressure on the pancreas, which can be the beginning of type 2 diabetes.

Having health care benefits or insurance for children with disabilities or special health care needs helps you pay for essential medical care [6, 7]. A family with a disabled child is a family with a special status, the features and problems of which are determined not only by the personal characteristics of all its members and the nature of the relationship between them, but in greater employment in solving the child's problems, the family's closeness to the outside world, lack of communication, but most importantly, the specific situation in the family of a disabled child, which is due to his illness [8, 9]. The family, like a person, is the main value of the state. The decrease, due to one reason or another, of the social value of certain categories of families in a difficult situation limits the disclosure of a person's potential. In such a situation, a complex of problems arises, among which the most significant is that an individual does not realize his potential, and society is deprived of huge potential for its own development, unjustifiably reducing the social status of certain groups or categories of citizens. Unfortunately, this attitude towards citizens is observed on the part of society in relation to many categories of people with disabilities, including children with disabilities, which sets specific tasks for a thorough study of this phenomenon and finding ways to remove socially negative attitudes towards persons with abnormal development [10]. The interaction of the individual, family, educational institutions, and society is becoming a global, worldwide problem today. It also acquires a specific character in modern Russian society: The moral ill-being of society, the

psychological crisis of minors, and the minimization of the educational role of the family; this is however not a complete list of socio-economic conditions that affect the genesis of the family and the process of socialization of the younger generation.

Social protection is a system of economic, legal, organizational measures guaranteed by the state, providing conditions for overcoming a difficult life situation. These measures are aimed at creating equal opportunities with other citizens to participate in the life of society. Benefits for families with disabled children include: 1) housing and communal benefits. 2) transport benefits 3) medical and medical benefits. 4) labor and pension benefits (for parents of disabled children). 5) tax incentives [11].

Social services for families with disabled children entail: 1) provision of material assistance in the form of cash, food, hygiene products, clothes, shoes, etc.; 2) social services at home through the provision of various services; 3) semi-stationary social services; 4) social services in inpatient institutions when constant care is needed; and 5) provision of temporary shelter in specialized institutions for disabled children. Social protection of a family with a disabled child is focused not only on solving specific problems but also on strengthening and developing its own potential. In this process, the role of a social worker is important, who should help the family overcome daily difficulties and teach family members ways of self-help and mutual assistance [12, 13].

Social protection and support of disabled children are some of the components of the state socio-economic program to improve the welfare of the population. A disabled child is a person under the age of 18 with a persistent disorder of body functions caused by an illness, injury, or congenital deficiencies in mental or physical development, leading to the restriction of her normal life and the need for additional social assistance and protection [14].

#### *Children with Disabilities: Current Situation*

The "disabled child" status was first officially introduced in the USSR during the International Year of the Child, declared by the UN in 1979.

According to the order of the Ministry of Health of the USSR No. 1265 of December 14, 1979, "On the procedure for issuing a medical certificate for disabled children under the age of 16" in the USSR, the official presence of disabled children was recognized. Until 1979, disability was defined as "a permanent impairment (decrease or loss) of general or occupational disability due to illness or injury" [15–18]. Currently, there are five levels of legislative and regulatory documents that regulate the organization of social work with families raising a disabled child [19]:

1. Regulatory and recommendatory documents of the world community: constituent acts, declarations, pacts, conventions, recommendations and resolutions of the UN, WHO, UNESCO, etc.;

2. Domestic legal acts of federal significance: The Constitution of the Russian Federation, federal laws of the Russian Federation, decrees and orders of the President of the Russian Federation, decrees of the Government of the Russian Federation, orders of the Ministry of Labor and Social Protection of the Russian Federation, etc.;

3. Executive republican acts of regional significance: Decrees, orders of the Heads and Governments of the constituent entities of the Russian Federation;

4. Municipal acts of urban and regional significance: Decisions, orders of the heads of the administration of cities and districts; and,

5. Documents adopted on the basis of specific social institutions and their structural units.

International documents include: The World Program of Action for Persons with Disabilities, adopted by Resolution 37/52 of the UN General Assembly of 03.12.1982; Universal Declaration of Human Rights, adopted by the UN General Assembly on December 10, 1948; UN Declaration on the Rights of Persons with Disabilities, proclaimed by General Assembly Resolution 3447 (XXX) of 09.12.1975; The UN Convention on the Rights of the Child, adopted by Resolution 45/25 of the UN General Assembly of 20.11.1989 and others. For example, the Declaration of the Rights of the Child states that "a child who is physically, mentally and socially handicapped should be

provided, education and care necessary in view of his special condition."

Among the main laws of the Russian Federation concerning the social protection of families raising a disabled child are the following: The Constitution of the Russian Federation, the Family Code of the Russian Federation, the Labor Code of the Russian Federation, federal laws "On the basics of social services for citizens in the Russian Federation" (2013/2016), "On social protection Persons with Disabilities in the Russian Federation "(1995/2015)," On the Basic Guarantees of the Rights of the Child in the Russian Federation "(1998/2015)," On Education in the Russian Federation "(2012/2016), etc. [20–23].

According to Art. 7. Clause 2. of the Constitution of the Russian Federation in our country, everyone's social security is guaranteed by age, in case of illness, disability, perspiration of the breadwinner, for raising children, and in other cases established by law. These provisions also apply to families raising children with disabilities. The Federal Law "On the Social Protection of Disabled People in the Russian Federation" dated November 24, 1995 No. 181 - FZ (as amended on December 29, 2015) establishes the basic guarantees related to the provision of disabled children with medical care (Art. 13) and living space (Art. 17), with their upbringing and training (Art. 18), education (Art. 19), employment (Art. 20), material support (Art. 27), social services (Art. 28), health resort treatment (Art. 29) [24, 25].

### 3. Children with Disabilities: Family's Education

When considering family education among the Mordovians at the present stage, we analyzed 35 families raising a disabled child. We studied the presence of family composition (complete, incomplete, large, single mother, living with relatives), living conditions, financial situation, lifestyle, age, and disease. At present, the attitude towards disabled children in the Republic of Mordovia at the legislative level has changed. In addition to the main normative and legal acts regulating social and legal protection and support of disabled children, the republic has regional normative and legal acts, organizations, and

programs that consider the region's specifics. Among these, it is necessary to highlight Decree of the Head of the Republic of Mordovia dated June 15, 2009 No. 115 - UG "On the council under the head of the Republic of Mordovia for disabled people." [26]. According to this document, the Council carries out its activities on the affairs of persons with disabilities in order to increase the effectiveness of measures for social protection, rehabilitation, and social integration of persons with disabilities, which are carried out in accordance with the legislation of the Russian Federation and the legislation of the Republic of Mordovia [27]. In addition to the implementation of laws and targeted programs, a number of organizations operating in the republic carry out measures for social protection and support for disabled people. The public organization, "Torch in Mordovia," promotes the protection of economic, social, housing, cultural rights and legal interests of the disabled and disabled children, provides equal opportunities with other citizens, and supplies various types of assistance to them.

The Mordovian republican organization of the All-Russian public organization "All-Russian Society of Disabled People" has its own goals in the field of protecting the rights and interests of disabled people and disabled children, as well as providing them with equal opportunities to participate in all spheres of society and their integration into society [28–30].

Thus, the above documents recognize the equal rights of disabled children with other members of society, guarantee for them a wide range of types of social security and social services, enshrine their right to family education, education in general institutions, or at home, and determine social assistance to families.

### 4. Children with Disabilities: Social Work

The importance of the development of technologies for social work with families with disabled children in Russia is that many of them are vital because the social worker "connects" and restores many of the deformed, destroyed relationships of such families [28, 29]. It is technologies that make it possible to eliminate social, administrative, managerial, moral, and

psychological barriers between families with disabled children and various institutions, social institutions, and specialists providing assistance, confirmed by the results of both theoretical and applied sociological research.

It is promising to intensify the development of the use of the technology of social mediation in social work with families with disabled children, in all its areas, namely in the relationship between [31]:

- family members with a disabled child;
- a family raising a disabled child and the closest social environment (relatives, neighbors, teachers, friends, etc.);
- different families with disabled children to provide self-and mutual assistance;
- families with disabled children and self-help and self-help organizations;
- families with disabled children and institutions of social protection, education, health care, culture, sports, the media, and other subjects of assistance;
- families with disabled children and social institutions, institutions - subjects of assistance;
- organizations and institutions - subjects of social work with families with disabled children;
- families with disabled children and various specialists involved in solving their problems; and,
- other specialists involved in solving the problems of families with disabled children

Social mediation in social work with families with disabled children is undoubtedly one of the promising technologies [29, 30]. Among the measures that could help to optimize the use of social mediation technology in social work with families raising children with disabilities are as follows:

- increasing the professional level and level of responsibility in the work of specialists in the social sphere;
- moral and material stimulation of professionalism in social work with families with disabled children;

- expanding opportunities for advanced training of specialists in social work, with an emphasis on the importance of using the technology of social mediation in social work in general and with families with disabled children, in particular;
- promoting the optimization of interagency and inter-organizational interaction in social work with families with disabled children;
- the introduction of the positions of a specialist in social work and a psychologist in all structures working with families with disabled children;
- optimization of social work with families with disabled children at the local, republican, and federal levels [32].

Also, work with families with disabled children at the residence can be carried out according to a certain algorithm of intermediary social activity. From our point of view, it might include:

- Research by a specialist in social work of the problem of a family with a disabled child, understanding the problem situation, identifying the problem, and determining the root cause (if necessary, independently collect and evaluate additional information about the problem) [33–35].
- Determination of the possibility of solving the problem of a family with a disabled child on the basis of a social protection institution in which a specialist in social work operates.
- Considering the possibility of involving other specialists, organizations, and institutions to solve the problem of a family with a disabled child.
- Organization of interaction between a specialist in social work and other specialists involved in solving the problem of a family with a disabled child.
- Extract for a family with a disabled child the most necessary information about the organization or institution: address and telephone number, name of the specialist (if possible), explanation of the route, and suitable transport. This technique is

- constantly used when referring children with disabilities to general health institutions, social assistance centers, boarding schools, rehabilitation centers, etc. The initiative to establish contact with the institution, the appointment, and the meeting itself remains with the family.
- Writing by a social work professional a cover letter for an institution to which a family or disabled child is sent. In this case, the family has on hand a clear description of the reasons for and how they went to the institution, and the institution has a clear idea of what the family expects from it.
  - Telling the family the name of the person to whom they should contact in a particular institution.
  - Before sending a family with a disabled child to an institution, you should first call there and provide the necessary information about it.
  - Control over the result of mediation, whether the problem of a family with a disabled child has been resolved.

This algorithm makes it possible for a family with a disabled child to quickly contact the necessary institutions at the place of residence, facilitates the search for the necessary structural unit of the social service, and also facilitates, in some cases, the receipt of social services. In this case, as an intermediary, the social worker is obliged to make sure that the contact has taken place and that the family has been assisted [36]. For the effective implementation of technologies of social work with families with disabled children by specialists of social services, it is important to fulfill certain conditions:

- understanding the problems of families with disabled children, his ability to totally get used to such families, the meaning of their problems;
- the ability to adequately express and present (represent) the life problems of families with disabled children;
- the specialist's knowledge of the social resources available to their institution;

- knowledge of the instrumental capabilities of related professions, whose representatives are involved in solving the problems of families with disabled children;
- the presence of a common language that ensures mutual understanding of different specialists and their effective cooperation, the willingness of a social worker to become a translator, if necessary;
- delegation of representative powers by families with disabled children to a social worker;
- delegation of appropriate powers to the social worker by state institutions and organizations;
- recognition of the right of a social worker to the partial representation of related professions; and,
- the trust of the parties in the specialist that has been achieved thanks to his professionalism and is supported by impeccable work.

It is also important to overcome the lack of organizational, material, personnel, software, information resources necessary for the development of technologies for social work with families with disabled children. Interdepartmental and intersectoral interaction in this activity should be developed more actively. Within the framework of refresher courses and other forms, it is also important to raise awareness among social services specialists about the essence and significance of using technologies of social work with families with disabled children. It is also necessary to increase the motivation of specialists in social work at a high professional level, including raising wages, overcoming the syndrome of professional combustion, etc. The expansion of both contact and remote via the Internet, mass media, telephone communication forms of technologies of social work with families with disabled children [37].

##### *5. Socio-Cultural Skills and Interpersonal Relationships*

According to studies of the family system with an atypical child, among the functions of the family, as pointed out by AP Turnbull & HR Turnbull, should be considered not only economical, housekeeping, and health care, but also recreational (for example, hobbies and other activities, both family and individual), socializing (for example, the development of socio-cultural skills and interpersonal relationships), self-identification (for example, recognition of strengths and weaknesses, the formation of a sense of belonging), affective (for example, the development of intimacy and the ability to educate), educational and professional.

Efforts, therefore, should be aimed at the social rehabilitation of the family. On the other hand, it is necessary to create conditions to support the initiative of the family itself in the rehabilitation of a disabled child. In the family, the social role that he will play in society is formed, and this can be the role of the sick person or the role of the healthy one, assuming the denial of the very fact of his disability. Both roles are negative. From a psychological point of view, only in the family can the only correct attitude be developed - to adequately consider the mental or physical deviation in the development of the child. Parents should strive to ensure that the child does not feel lonely and helpless among people so that he can independently make contacts. And first of all, this applies to those who are closer to him in age and interests, i.e., children. Unfortunately, there are families where the very fact of a child's disability is hidden not only from others but also from the child himself. This indicates how low the level of public consciousness regulating attitudes towards child disability is. And it is very difficult to organize a child's participation from such a family in socialization activities; parents simply "close in their world," thereby preventing the child from even trying to fully participate in the life of their peers [38].

Another important area of work on the socialization of a disabled child and the socio-psychological rehabilitation of his family is the unification coordination of the efforts of various social institutions included in the system of rehabilitation of disabled people. All this

actualizes the need to integrate these categories of families in need of comprehensive state support into the beneficiary system (system of benefits, benefits), as well as to ensure close cooperation of educational institutions with socio-psychological and social rehabilitation institutions anti-crisis centers since at present well-coordinated, coordinated work of these social structures is extremely rare [39].

The unfavorable socio-cultural situation of the development of a disabled child, determined by the peculiarities of the socio-demographic characteristics of their parental families, actualizes the need to develop a network of complex socio-cultural and psychological-pedagogical support for the family. Currently, the development and activation of targeted state support for children with disabilities and their families, the orientation of social policy in accordance with the principles of "supporting children through the family" [40] and "well-being of children through the well-being of their parents (family)," which should become the focus of all social activities of the Russian state. In addition, the family should be sovereign within the framework of socio-cultural relations. The intervention of the state and society in its world should be reduced to zero against the background of the high activity and vitality of the family itself. In this context, the emphasis of modern social policy can be shifted to stimulating the internal reserves of the family: Demographic, economic, educational, recreational [41, 42].

### Conclusion

It is advisable to improve the technology of social work with families with disabled children, and now this is the technology of social mediation because it is a vital necessity for many families. Without it, it is impossible to effectively use the technologies of social support, social adaptation, social rehabilitation, social insurance, etc., in social work with these families. A social worker in the role of an intermediary combines in his work the functions of a lawyer, social therapist, and coordinator of all services necessary for families with children having disabilities. In many cases, the intermediary activity of a social worker is associated with ensuring confidentiality, that is,

he, being the confidant of a family with a disabled child, firstly defends its interests and the interests of the child, and secondly, creates a favorable social and socio-psychological climate for adaptation and rehabilitation, participation in joint work, thirdly, and monitors the activities of those specialists and social structures that directly or indirectly participate in the process of providing assistance, etc.

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We have no conflicts of interest to disclose.

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