

Persons disabled since childhood with severe functional impairments: medical-social portrait

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Abstract

Aim. To study of medical and social characteristics of persons disabled since childhood of the first group, their needs for various types of rehabilitation and care for the development of a medical-social model of personal assistance.

Methods. A sample study of 194 persons disabled since childhood of the first group in eight regions of the Russian Federation was conducted using a specially developed methodology. The calculations were performed by using the IBM SPSS Statistics Viewer 23.

Results. The state of health of persons disabled since childhood of the first group is characterized by polymorphism and polymorbidity. 64.3% of people with disabilities have multiple dysfunctions of organs and systems. In this regard, there are pronounced restrictions on the main categories of life activity. Half of the caregivers (47.4%) spend more than 8 hours a day on organizing care for persons disabled since childhood of the first group; between 4 and 8 hours — 29.8%; between 2 and 3 hours — 12.9%; less than 2 hours — 4.1%. It was found that 32.7% of families spend more than half of their family budget on care (organization of medical and household care, transportation and relocation, organization of training, communication in accordance with age). At the same time, only 30.0% of caregivers work, the remaining 70.0% do not work (do not receive seniority) and will not be able to claim a labor pension. Persons disabled since childhood of the first group are characterized by pronounced restrictions on the main categories of life, the need for constant and regular care of all types, however, 28.4% of this group of people can self-service themselves or with little help from other people. With the presented medical-social portrait, state support for this category of citizens should be carried out in a differentiated manner. The “personal assistance” model allows parents/guardians of persons disabled since childhood of the first group not only to care for a family member but also to find employment as a personal assistant.

Conclusion. Families with persons disabled since childhood of the first group need differentiated support that will allow parents/guardians to care for their family members and work; the “personal assistance” model could solve these problems.

Keywords: people with disabilities, Convention on the Rights of Persons with Disabilities, persons disabled since childhood, severe disability, personal assistance, care.

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Background

In the Decree of the President of the Russian Federation of May 7, 2018, No. 204, reduction of poverty level by two times is determined as one of the national goals and strategic development objec-

tives of the Russian Federation for the period up to 2024 [1]. This means that the poverty rate should be reduced from 13.2% in 2017 to 6.6% in 2024. In 6 years, the population with incomes below the minimum subsistence level should decrease by 9.6

Table 1. Persistent disorders of organs and systems in patients with disability since childhood

Patients with disability since childhood (n = 194)			
Persistent body dysfunctions	Domains according to ICF	n	%
Mental dysfunctions	b110–b119	123	63.4
Sensory impairment	b210–b299	39	20.1
Disorders of neuromuscular, skeletal, and movement-related (statodynamic) functions	b710–b799	113	58.2
Language and speech disorders	b310–b399	51	26.3
Internal organ dysfunctions	b410–b699	107	55.2
Dysfunctions of the skin and related systems	b810–b899	2	1.0

Note: ICF, International Classification of Functioning, Disability and Health.

million people. Poverty eradication is one of the Sustainable Development Goals [2] adopted by the United Nations.

In the Russian Federation, Rosstat reported that 11.9 million people have disabilities, including 1.4 million (11.7%) people with disability since childhood [3]. According to the Federal Register of Persons with Disabilities, as of June 2020, slightly less than 1.2 million persons with disability since childhood live in the Russian Federation [4].

In 2012, the Russian Federation ratified the Convention on the Rights of Persons with Disabilities, which led to the reform of the social protection system in this field. Persons with disability since childhood, who have significant persistent impairments of functions and pronounced restrictions in life activities, need special care of the state. To develop the theoretical foundations of personal assistance to persons with disabilities and thus to implement Article 19 of the Convention on the Rights of Persons with Disabilities, a study of the main medical and social characteristics of persons with disability since childhood was conducted to draw up their “portrait” [5].

This study aimed to analyze the medical and social characteristics of persons with disability since childhood and their needs in various types of rehabilitation and care for the development of a medical and social model of personal assistance.

Material and methods of research

A sample medical and social study was conducted in eight constituent entities of the Russian Federation within the framework of the implementation of the Decree of the President of the Russian Federation of May 7, 2018, No. 204. According to the data of form 94 (pensions), 219,657 people with disability since childhood lived in the Russian Federation, and the sample population for this target group in medical and social institutions was 194.

Data were collected in the Main Bureau of Social and Medical Examination of the constituent

entities of the Russian Federation, namely, Ivanovo Region, Lipetsk Region, Novgorod Region, Kabardino-Balkar Republic, Republic of Tatarstan, Nizhny Novgorod Region, Tomsk Region, and Primorsky Territory.

The research methodology took into account the main provisions of the International Classification of Functioning, Disability and Health (ICF), recommended by the World Health Organization in 2001 [6].

An expert assessment of the medical and social characteristics of a person with disability since childhood was used, which was performed based on the protocol for conducting a medical and social examination of a citizen by interviewing guardians. The assessment was carried out to investigate the need for additional social protection measures (19 items), analysis and generalization of data, and general scientific methods. Descriptive statistics were also used (absolute, relative, mean values, and mean error). Statistical processing was performed using the Viewer IBM SPSS Statistics 23.

The sample was composed of persons with disability since childhood with an average age of 27.3 ± 0.9 (range, 18–81) years.

Results

The health status of persons with disability since childhood is characterized by polymorphism and polymorbidity (Table 1). Mental dysfunctions were found in 63.4% of the subjects, sensory dysfunctions in 20.1%; neuromuscular, skeletal, and movement-related (statodynamic) dysfunctions in 58.2%; language and speech dysfunctions in 26.3%; persistent dysfunctions of internal organs (including cardiovascular, respiratory, digestive, endocrine and metabolism, hemic, immune, and urinary systems) in 55.2%; and dysfunctions of the skin and related systems in 1.0%. Multiple dysfunctions of organs and systems were found in 64.3% of the subjects.

Given the significant dysfunctions, persons with disability since childhood have pronounced restric-

Table 2. Medical care needs of persons with disability since childhood

Activities/services	Total		Frequency of need for medical care (n = 194)									
			Daily		2–3 times a week		1–3 times a month		1–3 times a year		Others	
	n	%	n	%	n	%	n	%	n	%	n	%
Clinical nutrition	49	34.2	29	14.9	8	4.1	5	2.6	5	2.6	2	1.0
Tube feeding	3	1.5	2	1.0	0	0	0	0	0	0	1	0.5
Injections	94	48.5	8	4.1	11	5.7	19	9.8	33	17.0	23	11.9
Treatment of wound surfaces	33	17.0	14	7.2	7	3.6	5	2.6	5	2.6	2	1.0
Exercise therapy	94	48.5	28	14.4	18	9.3	25	12.9	8	4.1	15	7.7
Massage	105	54.1	11	5.7	14	7.2	29	14.9	28	14.4	23	11.9
Taking off/putting on prosthetic devices	26	13.2	8	4.1	9	4.6	1	0.5	7	3.6	1	0.5
Speech therapy assistance	27	14.0	6	3.1	5	2.6	4	2.1	5	2.6	7	3.6
Processing of medical documents	158	81.4	2	1.0	14	7.2	53	27.3	58	29.9	31	16.0
Others	9	4.5	2	1.0	3	1.5	3	1.5	0	0	1	0.5
Total of persons requiring care	189	97.4	69	35.6	58	29.9	87	44.8	93	47.9	57	29.4

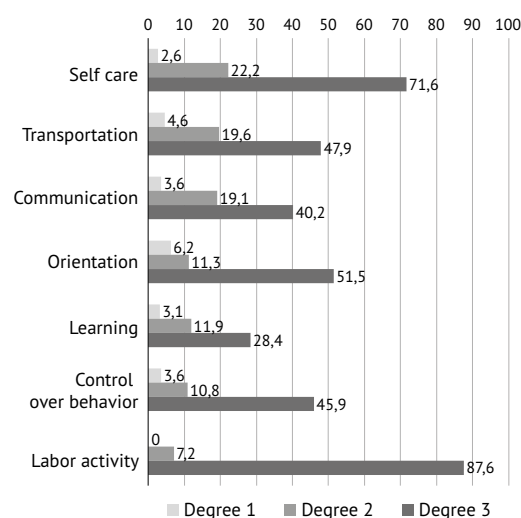
tions on the main categories of life activity (Fig. 1) [7]. Third degree of severity of restriction of labor activity was established in 87.6%, self-service in 71.6%, orientation in 51.5%, movement in 47.9%, control over their behavior in 45.9%, communication in 40.2%, and learning in 28.4% of the subjects. At the same time, 28.4% of the subjects can take care of themselves.

In this study, medical rehabilitation was required in 91.8%, social rehabilitation in 79.4%, technical means of rehabilitation in 66.5%, occupational rehabilitation in 19.6%, physical culture and sports rehabilitation in 10.8%, and psychological and pedagogical rehabilitation in 7.7% of the subjects.

Moreover, 97.4% of the subjects required medical interventions (Table 2). As regards the implementation of one or several medical measures, 35.6% of the subjects need daily assistance, 29.9% need assistance at 2–3 times a week, and 44.8% need assistance at 1–3 times a month.

In this study, 99.5% of the subjects need one or several types of care at home (Table 3). Moreover, 95.9% required daily assistance in the implementation of one or several elements of self-care, 69.6% required assistance at 2–3 times a week, and 23.2% required assistance 1–3 times a month.

As regards marital status, 80.9% of the subjects lived with their families, which include several family members. The remaining 19.1% of the respondents indicated that their family consists of

**Fig. 1.** Restrictions on the life of persons with disability since childhood (%)

only one parent/guardian and the subjects herself/himself. In addition, 50% of the subjects have a full family, and 29.9% of the families have young children. As regards the number of children, 17.5% of the respondents had one child, 9.8% had two children, 2.1% had three children, and 0.5% had four children. Moreover, 32.5% of the subjects live together with other relatives, and 6.2% indicated the presence of a different family composition.

In terms of employment, since the subjects required daily assistance, 70.0% of the guardians

Table 3. Home care need of persons with disability since childhood

Activities/services	ICF domain characterizing life activities difficulty	Total		Frequency of need for medical care (n=194)									
				Daily		2–3 times a week		1–3 times a month		1–3 times a year		Others	
		n	%	n	%	n	%	n	%	n	%	n	%
Washing	d510	178	91.8	103	53.1	62	32.0	11	5.7	0	0	2	1.0
Skin care	d5200	179	92.2	145	74.7	28	14.4	6	3.1	0	0	0	0
Hygienic procedures	d530	170	87.6	160	82.5	6	3.1	2	1.0	1	0.5	1	0.5
Putting on and taking off clothes	d540	175	90.2	167	86.1	4	2.1	3	1.5	0	0	1	0.5
Assistance with eating and drinking	d550. d560	169	87.1	167	86.1	0	0	1	0.5	0	0	1	0.5
Assistance with health care (diet, regimen)	d570	176	90.7	126	64.9	20	10.3	19	9.8	6	3.1	5	2.6
Help with purchases and services	d620	171	88.1	72	37.1	76	39.2	14	7.2	2	1.0	7	3.6
Cooking food	d630	175	90.2	166	85.6	7	3.6	2	1.0	0	0	0	0
Others	d599	3	1.5	3	1.5	0	0	0	0	0	0	0	0
Total of persons requiring care		193	99.5	186	95.9	135	69.6	45	23.2	9	4.6	14	7.2

Note: ICF, International Classification of Functioning, Disability and Health.

were not employed, and the remaining 30.0% of the guardians/caregivers, along with caregiving, perform labor activities; thus, 16.0% were working full time, 8.3% were working part time, and 5.7% had other types of work.

Persons caring for study subjects need some external help to organize care; therefore, 79.9% of the caregivers asked their relatives for help, 65.3% sought specialists, 51.5% turned to friends, and 18.0% asked strangers for help.

In 47.4% of the respondents, the average income per family member was <10 thousand rubles, 40.2% reported 11–20 thousand rubles, 9.3% reported 21–30 thousand rubles, and only 3.1% reported >31 thousand rubles. At the same time, the majority of the guardians could not improve their financial situation independently, since they did not have the opportunity to find a job because they need to take care of a family member with a disability. Caregivers of people with disability since childhood spent a significant amount of time on care activities (47.4% spent >8 h, 29.8% spent 4–8 h, 12.9% 2–3 h, and 4.1% spent <2 h). The financial costs of caring for a family member with a disability have a significant effect on the material condition of these families.

If we consider the share of family budget expenditures on care, 26.8% of the respondents in-

dicated that they spend more than half of their family budget on organizing care for a family member with disability since childhood (including medical and household care, transportation and travel, organization of training, and communication in accordance with age). Among families with a family member having a monthly income <10 thousand rubles, 17.4% spent more than half of their budget on care, and among families with a family member having a monthly income of 10–20 thousand rubles, 35.9% spent more than half of the family budget on care.

Discussion

The health status of persons with disability since childhood is characterized by polymorphism, which is confirmed by the variety of persistent static-dynamic dysfunctions, mental dysfunctions, sensory dysfunctions, internal organs dysfunctions, etc. Polymorbidity is typical for 64.3% of the subjects who have persistent disorders of two or more body functions, which can aggravate the severity of each other. Because of severe pathology, manifested by persistent pronounced dysfunctions of organs and systems, i.e., third degree of restrictions of self-care ability, 71.6% of the subjects are constantly dependent on other people and

require assistance, while the remaining 28.4% are able to take care of themselves independently, despite some difficulties. Medical rehabilitation is required in 91.6% of the subjects, social rehabilitation is required in 79.4%, and technical rehabilitation is needed in 66.5%.

Based on the presented medical and social portrait of persons with disability since childhood, the need for help from close and distant relatives (domains e310 and e315 according to ICF) are determined by the following factors:

- Regularity of services (frequency of the provision of services from 1 time per week to several times a day)
- Volume of services (from unregulated up to ≥ 6 h per day)
- Type of support
- Nature and content of the services that require caregiver training

The data presented indicate the need for a differentiated approach in the development of state programs aimed at social protection of persons with disability since childhood and their caregivers. Caregivers of persons with disability cannot work fully in accordance with the Labor Code of the Russian Federation since they need to spend time on supporting self-service, mobility, and other main categories of the life of persons with disability since childhood.

These tasks could be solved by the “personal assistance” model existing in other countries, for example, in the Kingdom of Sweden, Republic of Moldova, and Kyrgyz Republic [8–10]. In this model, the caregiver concludes an employment contract with the social protection authorities for the provision of social services, that is, he/she is employed as a personal assistant to care for his family member with a fixed salary. Accordingly, for the caregiver, a human rights-based approach of a different level is implemented, namely, possibility of formalization of an employment record book, work experience for obtaining a pension, paying taxes, and social guarantees of a working citizen.

The elaboration of models for financing personal assistance is required, taking into account the factors that determine the need for assistance of close and distant relatives (domains e310 and e315 according to ICF). The COVID-19 pandemic situation showed that a personal assistant could support not only his family member (a person with disability since childhood) but also other people with disability in the area of residence.

CONCLUSIONS

1. Persons with disability since childhood are characterized by pronounced limitations of the

main categories of life activity and need for constant and regular care of all types (medical and household care, transportation and movement, organization of training, and communication in accordance with age). However, 28.4% of people with disabilities are able care for themselves or asked little help from others. Consequently, state support for this category of citizens should be implemented in a differentiated manner.

2. The financial costs of caring for a family member with disability have a significant effect on the financial situation of these families. Moreover, 70% of the parents or guardians do not have the opportunity to work. The “personal assistance” model enables parents or guardians of patients with disability only to care for a family member but also to find employment as a personal assistant.

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REFERENCES

1. Decree of the President of the Russian Federation №204 of 07.05.2018 “On national goals and strategic objectives for the development of the Russian Federation for the period up to 2024”. (In Russ.)
2. Goal 1: End poverty in all its forms everywhere. The Sustainable Development Goals UN. <https://www.un.org/sustainabledevelopment/poverty/> (access date: 01.08.2020). (In Russ.)
3. The total number of people with disabilities by disability group. Official website of the Federal State Statistics Service. <https://www.gks.ru/folder/13964> (access date: 01.08.2020). (In Russ.)
4. Number of people with disabilities due to disability reasons. Federal Register of Persons with Disabilities. <https://sfri.ru/analitika/chislennost/chislennost-po-prichinam/territory=1> (access date: 01.08.2020). (In Russ.)
5. Article 19 of the UN Convention on the Rights of Persons with Disabilities. Adopted by the General Assembly at the Sixty-first Session, resolution 61/106, A/RES/61/106, 13 December 2006. (In Russ.)
6. International classification of functioning, disabilities and health (ICF, WHO, 2001). Online reference book of health care and medicine ZdravMedInform. <https://zdravmedinform.ru/icf.html> (access date: 01.08.2020). (In Russ.)
7. Order of the Ministry of Labor and Social Protection of the Russian Federation from August 27, 2019 №585n “On the classifications and criteria used in the implementation of the medical and social examination of citizens by federal state institutions of the medical and social examination”. <https://www.garant.ru/products/ipo/prime/doc/72921006/> (access date: 01.08.2020). (In Russ.)
8. Bakk A., Gryundeval'd K. *Zabota i uhod: kniga o lyudyah s zaderzhkoj umstvennogo razvitiya*. (Concern and care: A book about people with mental retardation.) Translation from Swedish. Ed. by Yu.Kolesovoj. SPb.: IRAY. 2001; 177–178. (In Russ.)

9. Decree of the Government of the Republic of Moldova from 23.05.2012 №314 “*On approval of the Model Regulations on the Organization and Functioning of the Social Service "Personal Assistant" and the Minimum Quality Standards*”. State register of legal acts of the Republic of Moldova. https://www.legis.md/cautare/getResults?doc_id=84693&lang=ru (access date: 01.08.2020) (In Russ.)

10. Last step. How can parents get funds to care for children with disabilities. *IA “24.kg” — Novosti Kyrgystana*. https://24.kg/obschestvo/102534_posledniy_shag_kak_roditelyam_poluchit_sredstva_pouhodu_zadetmi_sovz_/ (access date: 01.08.2020). (In Russ.)