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ORGANIZATION AND CONTENT MODEL OF THE SYSTEM OF COMPLEX SUPPORT FOR CHILDREN WITH SEVERE MULTIPLE DEVELOPMENTAL DISORDERS

Abstract. The article describes an organization and content model of the system of complex support for children with severe multiple developmental disorders (SMDD). The model has been designed with the purpose of organization of the system of complex support for children with SMDD, enhancing socialization of the children of the given category via granting accessible and high quality complex rehabilitation and abilitation. The design of the model of the system of complex support for the children of the given category has been carried out within the pilot project of the Ministry of Labor and Social Protection of the Russian Federation aimed at specification of the approaches and formation of the system of complex rehabilitation and abilitation of persons with disabilities, including children. Organization of the system of complex rehabilitation and abilitation of children with SMDD presupposes the creation of principally important conditions: complex and systemic character of rehabilitation and abilitation activities, continuity of the process of complex support, constructive interaction and succession in the work of specialists and institutions, professionalism of the staff, and accessibility of rehabilitation and abilitation activities. The model of the system of complex support for children with SMDD includes the following interconnected blocs: normative-legal, administrative, systemic, and control and assessment blocs. The article contains recommendations on the development of the system of complex support for children with SMDD: unification of interdisciplinary and terminological apparatus; elaboration of regional legal documentation in the field of normative definition of the category of children with SMDD, creation of the coordinating council for the development of a detailed plan of implementation of the suggested model, etc.

Keywords: children with disabilities; children with disabilities; severe multiple developmental disorders; complex support.

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Approaches to the creation of a system of complex rehabilitation and abilitation of persons with disabilities, including children among whom researchers single out the category of children with severe multiple developmental disorders are being formed in Russia today.

Children with severe multiple developmental disorders (SMDD) are those with a combination of two or more severe psychophysical disabilities (severe impairments of vision, hearing, speech, intellectual development, etc.), for example: combination of deafness and poor vision, intellectual disability and blindness, severe musculoskeletal disorder and speech impairment (M. V. Zhigoreva, I. YU. Levchenko, N. M. Nazarova). Researchers note that children with SMDD have specific features of development and specific needs and ought to be granted obligatory complex support (T. A. Basilova, M. V. Zhigoreva, K. S. Lebedinskaya, I. YU. Levchenko, O. S. Nikol'skaya,

A. V. Khaustov and others) [4; 6; 8; 12; 13; 17].

Analysis of statistical information of medico-social expertise over the period 2014-2016 showed that about 1% of children in Sverdlovsk Oblast had the status of "child with disability". And the statistical information available does not allow singling out the target group of children with SMDD because disability is diagnosed on the basis of one disorder only. It has been revealed that in most cases the status of "child with disability" is established on the basis of the following groups of disorders:

- psychological and behavioral disorders (30% of the total number of cases of child disability);
- nervous system disorders (17% of children with disabilities);
- congenital defects (developmental disorders), deformations and chromosome abnormalities (15% of children with disabilities);
- endocrine diseases, nutrition and metabolic disorders (14 % of children).

We can make a supposition that among the most widespread groups of children with disabilities there are children, who do not only have a disease serving as a basis for certification of disability but also possess other developmental disorders that allow referring them to the category of children with SMDD.

These data have been confirmed by the statistics given by the State Public Inpatient Institution of social services “Ekaterinburg Children’s Boarding House for Children with Intellectual Disability”. Analysis of the nosological groups to which the inmates of the boarding house belong shows that the most widespread disorders are the following:

- psychological and behavioral disorders (2014 — 99,6 %; 2015 — 100 %; 2016 — 98,3 %), among which, intellectual disability prevails (2014 — 91,1 %; 2015 — 92,6 %; 2016 — 97,9 %);
- nervous system disorders (2014 — 71,6 %; 2015 — 84,8 %; 2016 — 82,2 %), including cerebral palsy and other paralytic syndromes (2014 — 27,9 %; 2015 — 33,7 %; 2016 — 35,1 %);
- diseases of the eye and its adnexa (2014 — 67,4 %; 2015 — 62,7 %; 2016 — 80,3 %);
- endocrine diseases, nutrition and metabolic disorders (2014 — 37,1 %; 2015 — 41 %; 2016 — 50,6 %);
- congenital defects (developmental disorders), deformations and chromosome abnormalities

(2014 — 39,4 %; 2015 — 38,3 %; 2016 — 35,9 %).

The parameter values make it possible to draw a conclusion that almost every inmate has psychological and behavioral disorders, mostly in the form of intellectual disability, and other diseases (cerebral palsy, eye diseases, etc.), which lead to the emergence of the phenomenon of “severe multiple developmental disorders”.

The aim of our research consisted in design of a model of the system of complex support for children with severe multiple developmental disorders. The following *tasks* were accomplished in the course of the model design:

- to formulate a set of normative-legal provisions regulating the activity targeted at complex support for children of the abovementioned category in the field of health protection, education, social services, culture, sport, employment services and activity of nonprofit organizations on the basis of analysis of the normative-legal documentation of the international, federal, and regional levels;
- to study and analyze the methodological materials of the Ministry of Labor and Social Protection of the Russian Federation recommended for approbation and implementation within the pilot project on specification of the approaches to the formation of the system of complex rehabilitation and abilitation of per-

sons with disabilities, including children.;

- to work out suggestions for normative-legal regulation of inter-departmental interaction between organizations belonging to various departments and agencies ensuring succession in the work with children with SMDD;

- to work out and substantiate a model of the system of complex support for children with SMDD in Sverdlovsk Oblast;

- to describe the aspect of organization and content of the model of the system of complex support for children with SMDD and its functional content;

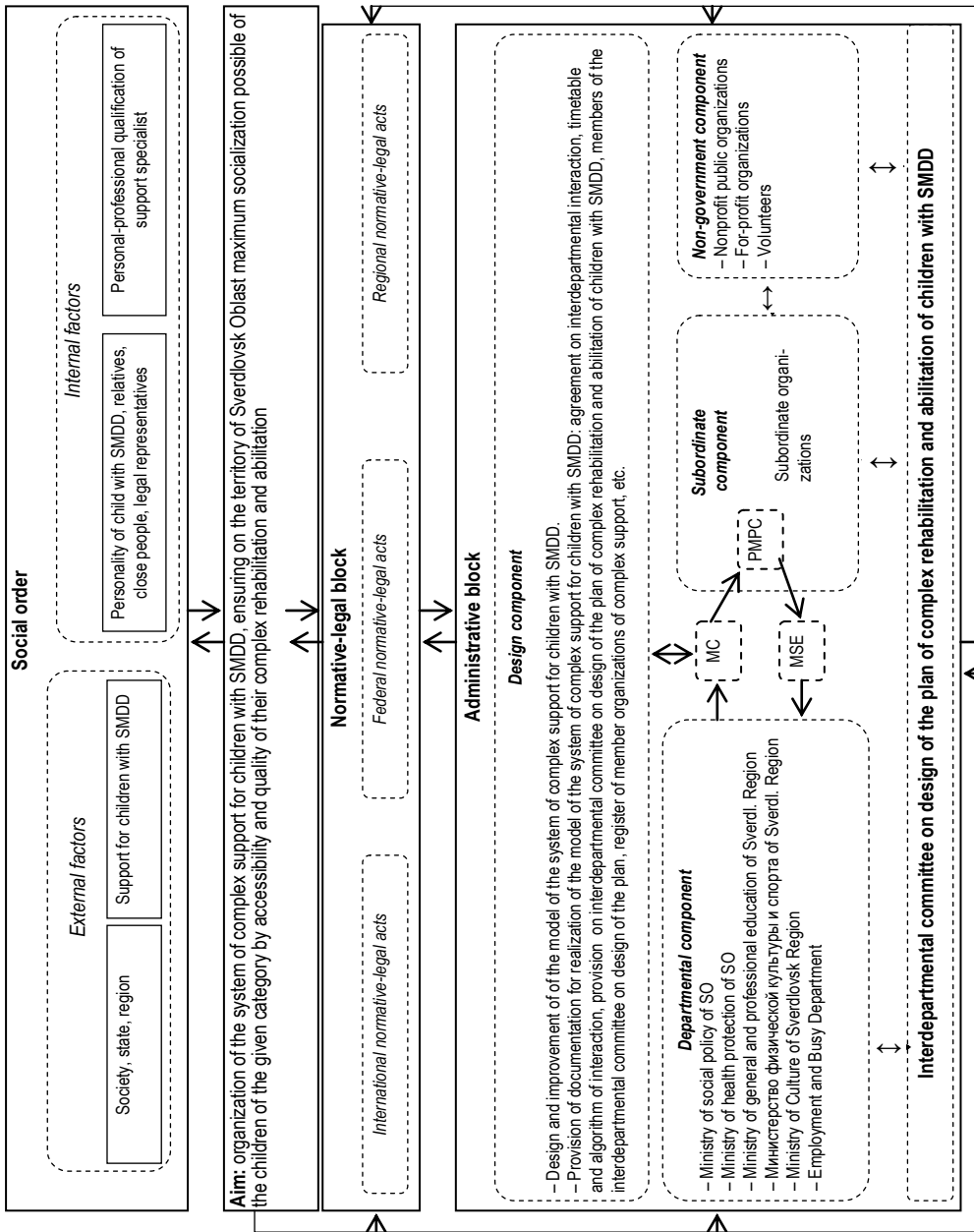
- to work out and present the system of management assessment of the quality of complex support for children with SMDD and quality control of this activity as part of the work towards formulation of requirements to the module of automated information-analytical system.

On the basis of the analysis of normative-legal documentation, scientific-methodological research and national and regional experience [1; 2; 3; 5; 7; 9; 11; 13; 14; 15; 17], we have worked out an organization and content model of the system of complex support for chil-

dren with SMDD *aimed at organization of the system of complex support for children with SMDD, enhancing socialization of the children of the given category via granting accessibility and high quality of their complex rehabilitation and abilitation.*

Complex rehabilitation and abilitation of children with SMDD includes medical, social, psychological, physical culture and sport, professional and other aspects which facilitate the realization of the main components of support: care, education, assistance and counseling. These four components make up the core of interaction with children with SMDD in the main spheres of life: board, education, work, spare time, etc. The actions of all people engaged in the work with the child should be coordinated. To this end, it is necessary to form a team of specialists taking into account the child's urgent needs, to discuss the activity of the members of the team, to determine the aims of rehabilitation work and its general and concrete tasks collectively.

The organization and content model includes the following interconnected blocks: normative-legal, administrative, system, and control and assessment blocks (see Fig. 1).



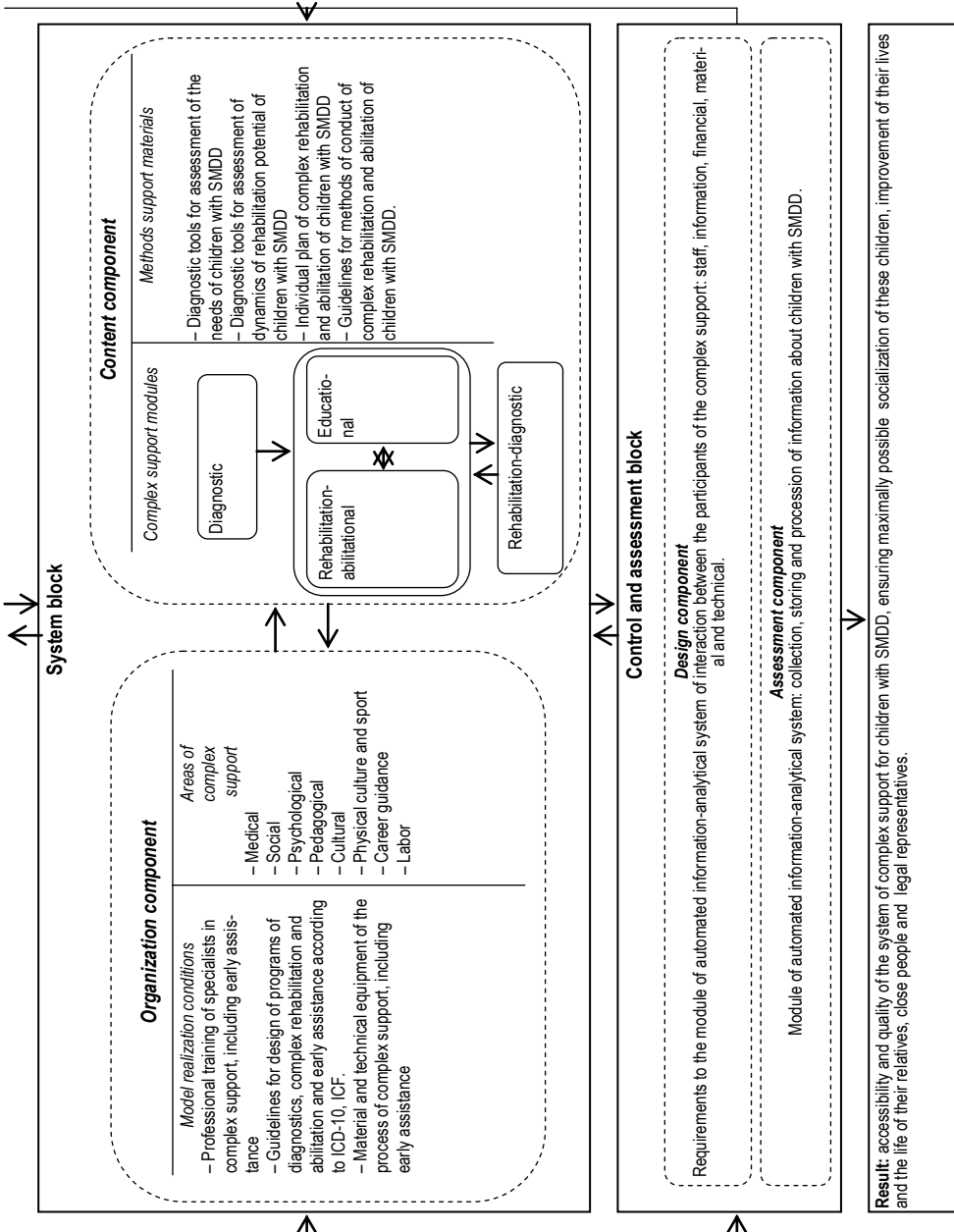


Figure 1. Organization and content model of the regional system of complex support for children with SMDD

The normative-legal block is based on the analysis of the normative-legal documentation of the international, federal, and regional levels.

The administrative block contains the following interconnected components:

- design component (design and improvement of the model of the system of complex support, provision of documentation for its realization);
- departmental component realized by the ministries of social policy, health protection, general and professional education, physical culture and sport, culture and the department for employment of the population;
- medical commission making decisions on issues of medical rehabilitation and referral to psychomedico-pedagogical commission (PMPC) and medico-social expertise (MSE);
- federal public institution “Chief Bureau of MSE”;
- subordinate component (PMPC, subordinate organizations providing services of complex rehabilitation and abilitation);
- non-government component (non-profit and public organizations, for-profit organizations, volunteers).

The block designates authorities and zones of responsibility of the institutions taking part in the complex support for children with com-

plex developmental disorders under the current legislation.

We have defined the main principles of interdepartmental interaction, which may include:

- the principle of complex and systemic approach to organization of the process of support for children with SMDD;
- the principle of voluntary participation in the processes of complex support for the children of the given category;
- the principle of confidentiality;
- the principle of granting equal opportunities of getting high quality rehabilitation and abilitation services.

The system block of the model is represented by interconnected components:

- organization component determining the conditions of model realization (professional training of specialists in complex support, including early assistance, presence of guidelines for design of programs of diagnostics, complex rehabilitation and abilitation and early assistance) and complex support areas (medical, social, psychological, pedagogical, physical culture and sport, cultural, career and employment);
- content component, based on distinction of the complex support modules (diagnostic, rehabilitation-abilitational, educational, rehabilitation-diagnostic) and their methods support materials (diagnostic tools for assessment of the needs of chil-

dren with SMDD, diagnostic tools for assessment of dynamics of rehabilitation potential of children with SMDD, individual plan of complex rehabilitation and abilitation of children with SMDD);

- guidelines for methods of conduct of complex rehabilitation and abilitation of children with SMDD.

The control and assessment block of the organization and content model of the system of complex support for children with SMDD contains:

- design component (requirements to the module of automated information-analytical system of interaction between the participants of the complex support);

- assessment component (module of automated information-analytical system ensuring interaction between the complex support participants, collection, storing and procession of information about children with SMDD).

The experience of design and testing of the organization and content model of the system of complex support for children with SMDD allowed us to formulate recommendations on its implementation in the following aspects:

- unification of terminological apparatus used by representatives of different departments and organizations;

- elaboration of regional legal documentation in the field of normative definition of the category of

children with SMDD with the purpose of granting these children the rights to accessible and high quality complex support and legal regulation of interdepartmental interaction;

- enhancement of the educational mission targeted at translation of value-based attitude to the children of the given category into socio-cultural environment, at prevention and propedeutics of severe developmental disorders among the population, and children's orphanhood by joint effort of the specialists, public organizations, parents, mass media, etc.;

- creation of the coordinating council for the development of a detailed plan of implementation of the suggested model and control of its execution;

- design and implementation of requirements to the organization of statistical registration of children with SMDD and computer-based systems of collection and control of information about these children;

- standardization and unification of the services of complex support for children with SMDD;

- preferential development of the systems of early complex support for children with developmental disorders;

- organization of an interdisciplinary scientific-methodological center for consolidation of effort and accumulation of information in the field of perfection of the methods of

differential diagnostics, rehabilitation and abilitation of children with complex disorders, specifically at an early age;

– intensification of activity of public organizations and charitable foundations for the benefit of children with SMDD and their parents (legal representatives).

References

1. Alekhina, S. V. Mezhdovedstvennoe vzaimodeystvie kak mekhanizm razvitiya psikhologicheskoy sluzhby v obrazovanii / S. V. Alekhina, L. P. Fal'kovskaya // Psikhologo-pedagogicheskoe issledovaniya. — 2017. — T. 9, № 3. — S. 116—128.
2. Alekhina, S. V. Sozdanie sistemy kompleksnoy pomoshchi detyam s rasstroystvami autisticheskogo spektra v Rossii: opyt odnogo proekta / S. V. Alekhina // Autizm i narusheniya razvitiya. — 2016. — T. 14, № 4. — S. 10—13.
3. Antropova, Yu. Yu. Organizatsiya mediko-sotsial'noy pomoshchi sem'e i detyam v regione: prakticheskie vyzovy i metodologicheskie podkhody / Yu. Yu. Antropova, E. E. Laykovskaya // Otechestvennyy zhurnal sotsial'noy raboty. — M. : Sotsial'noe obsluzhivanie. — 2013. — № 2. — S. 151—158.
4. Bogdashina, O. Autizm: opredelenie i diagnostika / O. Bogdashina. — Donetsk, 1999. — 304 s.
5. Zhavoronkov, R. N. Metodicheskoe posobie dlya obucheniya (instruktirovaniya) sotrudnikov uchrezhdeniy MSE i drugih organizatsiy po voprosam obespecheniya dostupnosti dlya invalidov uslug i ob"ektov, na kotorykh oni predostavlyayutsya, okazaniya pri etom neobkhodimoy pomoshchi : v 2 ch. / R. N. Zhavoronkov, N. V. Putilo, O. N. Vladimirova [i dr.]. — M. : Min-vo truda i sotsial'noy zashchity naseleniya Rossiyskoy Federatsii, 2015. — 555 s.
6. Zhigoreva, M. V. Deti s kompleksnymi narusheniyami razvitiya: diagnostika i soprovozhdenie / M. V. Zhigoreva, I. Yu. Lev-

chenko. — M. : Natsional'nyy knizhnyy tsentr, 2016. — 208 s.

7. Kompleksnaya mediko-sotsial'naya i psikhologo-pedagogicheskaya pomoshch' detyam s rasstroystvami autisticheskogo spektra : inform.-metod. sb. — Smolensk : Smolenskaya gorodskaya tip, 2016. — 168 s.

8. Lebedinskaya, K. S. Deti s narusheniyami obshcheniya: ranniy detskiy autizm / K. S. Lebedinskaya, O. S. Nikol'skaya, E. R. Baenskaya. — M. : Prosveshchenie, 2007. — 95 s.

9. Mikhaylova, O. V. Kompleksnaya reabilitatsiya invalidov s tyazhelymi ogranicheniyami zhiznedeyatel'nosti / O. V. Mikhaylova // Sotsial'naya rabota. — 2014. — № 4. — S. 32—35.

10. Model' kompleksnogo soprovozhdeniya detey s tyazhelymi mnozhestvennymi narusheniyami razvitiya, v tom chisle s rasstroystvami autisticheskogo spektra : metod. posobie / Ural. gos. ped. un-t ; avt.-sost. I. A. Filatova, E. V. Karakulova. — Ekaterinburg, 2017. — 287 s.

11. Model' psikhologo-pedagogicheskoy pomoshchi detyam doskol'nogo vozrasta s tyazhelymi i mnozhestvennymi narusheniyami razvitiya / pod red. A. V. Ryazanovoy, D. V. Ermolaeva. — M. : Terevinf, 2015. — 82 s.

12. Pedagogika inklyuzivnogo obrazovaniya : ucheb. dlya stud. vyssh. ucheb. zaved. / T. G. Bogdanova, A. M. Guseynova, N. M. Nazarova [i dr.] ; pod red. N. M. Nazarovoy. — M. : INFRA-M, 2017. — 335 s.

13. Psikhologo-pedagogicheskoe soprovozhdenie detey s tyazhelymi i mnozhestvennymi narusheniyami razvitiya v usloviyakh detskogo doma-internata : metod. posobie. — M. : RBOO «Tsentr lechebnoy pedagogiki», 2015. — 68 s.

14. Sluzhba ranney pomoshchi : sprav.-metod. materialy po organizatsii sluzhby ranney pomoshchi / otv. red. M. M. Tsapenko. — M. : MGPPU, 2011. — 220 s.

15. Sotsial'noe soprovozhdenie semey s det'mi : inform.-metod. sb. dlya spetsialistov. — M. : IDPO DTZN, 2015. — 242 s.

16. Filatova, I. A. Psikhologo-pedagogicheskoe soprovozhdenie detey s tyazhelymi mnozhestvennymi narusheniyami razvitiya :

ucheb.-metod. posobie / I. A. Filatova, E. V. Karakulova ; Ural. gos. ped. un-t. — Ekaterinburg, 2018. — 158 s.

17. Khaustov, A. V. Psikhologo-pedagogicheskoe soprovozhdenie obuchayushchikhsya s rasstroystvami autisticheskogo spektra : metod. posobie / A. V. Khaustov, P. L. Bogorad, O. V. Zagumennaya, A. I. Kozorez, S. N. Pantsyr', Yu. V. Nikitina, O. V. Stal'-

makhovich ; pod obshch. red. A. V. Khaustova. — M. : FRTs FGBOU VO MGPPU, 2016. — 125 s.

18. Diagnostic and Statistical Manual of Mental Disorders / American Psychiatric Association. — 5th Ed. — Washington, DC ; London : American Psychiatric Association, 2013. — 970 p.