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On Expanding the Opportunities for Disabled People to Lead an Independent Lifestyle in Their Chosen Place of Residence and Integration into the Local Community

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Abstract. The object of the study is social relations that determine the main approaches to the organization of an independent lifestyle of disabled people in the Russian Federation. The subject of the study is the rights of persons with disabilities to an independent lifestyle and the possibility of their implementation in Russia, taking into account the measures taken and the opinions of the disabled themselves. The purpose of the study is a scientific analysis of legislative and regulatory support, assessments by disabled people of the expansion of opportunities for disabled people to lead an independent lifestyle in their chosen place of residence and integration into the local community. Methodological basis of the work: comparative legal, logical, historical, statistical, sociological research methods. The paper analyzes international legal acts, federal and regional legislation on providing disabled people and disabled children with the opportunity to lead an independent lifestyle, statistical data on the number of disabled people living in stationary social service organizations. We have obtained unique results of the all-Russian survey of people with disabilities. The sample is stratified and not proportional according to the criteria: by place of residence (cities, rural

areas); by age: adult population (over 18 years old), children (from 0 to 17 years old); by gender (men, women, boys, girls) and by persistent functional disorders (disorders of the musculoskeletal system, functional disorders hearing, visual impairment, mental impairment, other disorders). As a result of the analysis, a non-comprehensive study was established in the legislation of the Russian Federation and the subjects of the Russian Federation of the issues of providing disabled people with the opportunity to lead an independent lifestyle. Normative and methodological acts have been developed that have made it possible to provide conditions and mechanisms for the implementation of an independent lifestyle of disabled people in their chosen place of residence. Within the framework of pilot projects in a number of subjects of the Russian Federation, positive dynamics of the introduction of new technologies for the preparation and organization of assisted living for disabled people has been established. Based on the received data obtained, a concept and a set of measures have been developed to expand the opportunities for disabled people to lead an independent lifestyle in their chosen place of residence.

Keywords: disabled people, independent lifestyle, legislative, regulatory and methodological support, disabled people's opinion about the readiness and possibility of leading an independent lifestyle.

Research area: social structure, social institutions and processes.

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О расширении способности людей с ограниченными возможностями вести независимый образ жизни в выбранном ими месте жительства и интеграции в местное сообщество

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Аннотация. Объект исследования – общественные отношения, определяющие основные подходы к организации самостоятельного образа жизни инвалидов в Российской Федерации. Предметом исследования являются права инвалидов на самостоятельный образ жизни и возможности их реализации в России с учетом принимаемых мер и мнения самих инвалидов. Цель исследования состоит в научном анализе законодательного и нормативного обеспечения, оценок инвалидами расширения возможностей ведения ими самостоятельного образа жизни в избранном месте жительства и интеграции в местное сообщество. Методологическая основа работы: сравнительно-правовой, логический, исторический, статистический, социологический методы исследования. В работе проведен анализ международных правовых актов, федерального и регионального законодательства по обеспечению инвалидам и детям-инвалидам возможности ведения самостоятельного образа жизни, статистических данных о численности инвалидов, проживающих в стационарных организациях социального обслуживания, их готовности к ведению самостоятельного образа жизни. Нами получены уникальные результаты всероссийского опроса людей с инвалидностью. Выборка стратифицированная, не пропорциональная по критериям: по месту проживания (города, сельские территории); по возрасту: взрослое население (старше 18 лет), дети (от 0 до 17 лет); по полу (мужчины, женщины, мальчики, девочки) и по наличию стойких нарушений функций организма (опорно-двигательного аппарата, слуха, зрения, психических функций, прочие нарушения). В результате анализа установлена некомплексная проработка в законодательстве

Российской Федерации и субъектов Российской Федерации вопросов обеспечения инвалидам возможности ведения самостоятельного образа жизни. Были разработаны нормативные и методические акты, позволившие обеспечить условия и механизмы реализации самостоятельного образа жизни инвалидов в избранном месте жительства. В рамках пилотных проектов в ряде субъектов Российской Федерации установлена положительная динамика внедрения новых технологий подготовки и организации сопровождаемого проживания инвалидов. На основании полученных результатов разработаны проекты Концепции и Комплекса мер по расширению возможностей ведения инвалидами самостоятельного образа жизни в избранном месте жительства.

Ключевые слова: инвалиды, самостоятельный образ жизни, законодательное, нормативное и методическое обеспечение, мнение инвалидов о готовности и возможности ведения самостоятельного образа жизни.

Научная специальность: 5.4.4 – социальная структура, социальные институты и процессы.

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Introduction

To the study of social policy concerning disabled persons in Russia devoted the studies of the following authors: Tarasenko E. A. (2004); P. V. Romanov, Yarskaya-Smirnova E. R. (2006); A. V. Bronnikov (2007); Yu Bayushina L., (2009); Neberushkina E. (2017); Radchenko T. E., Yu Pestova M. (2019).

The full integration of disabled people into a diverse socio-economic and political space is a strategic goal of social policy that has been developed by the world community in recent decades (Maleva (red.), 2017: 247).

According to V. A. Bronnikov, “it is extremely important to legislate social policy that reduces the distance between the formally proclaimed goals of an open society for the disabled and their maximum involvement in all spheres of life and participation in social work and public life” (Bronnikov, 2007: 9).

A significant contribution to the definition of the goal of social policy was made by the research of P. V. Romanov, E. R. Yarskaya-Smirnova, which follows from the fact that “the ability of disabled people to be independent economic entities, to participate in the political, cultural and social life of society reflects

the level of realization of their rights as citizens of the welfare state” (Romanov, Yarskaya-Smirnova, 2006: 5–6). Consequently, the goal of the state policy in relation to this group of citizens becomes, first of all, “ensuring equal opportunities for disabled people with other citizens in implementation... rights and freedoms provided for by the Constitution of the Russian Federation” (Romanov, Yarskaya-Smirnova, 2006: 15).

The authors consider a new stage in the development of disability policy in Russia to be the dissemination and popularization of the concept (and even philosophy) of independent life, widely practiced in the West for more than a decade. This concept “implies control over one’s own affairs, participation in public life, fulfillment of certain social roles and decision-making leading to self-determination of the individual” (Romanov, Yarskaya-Smirnova, 2006: 26).

The ideology of independent living makes it possible to achieve optimal interaction of disabled people with the outside world and to integrate people with special needs most fully into the conditions of modern society (Drobot, 2011: 26).

Independent life as a scientific concept has two interrelated sides. On the one hand, in the socio-political aspect, these are guarantees of the realization of civil rights and freedoms of people with disabilities, and on the other hand, in personal terms, it implies the appropriate identification of a person who perceives himself as an equal person, setting himself the same tasks as any other person (Zhigunova, 2019: 2).

Personal readiness is associated with the assessment of the potential and possibilities of leading an independent life, which is actively studied by researchers. The factors that contribute to an increase in activity and the reasons that reduce it are highlighted. According to I.K. Svishcheva and T.N. Koneva, only a third of people with disabilities have a high level of integration potential. It is especially difficult for disabled people to lead an independent life at an older age. The authors popularize the social support system to increase the number of people with disabilities with high opportunities for integration into society. (Svishchyova, Koneva, 2018: 265). The concept of an independent lifestyle highlights the main components of the success of active social behavior: favorable social conditions – family, environment; active motivation of their chosen activities; competence; knowledge; level of education. This makes it possible to ensure equality of rights and opportunities for all socially unprotected groups of our society (Kefeli, Gorina, 2021: 90).

E.R. Yarskaya-Smirnova, V.N. Yarskaya note that the social vulnerability of people with disabilities, health limitations, arise due to the imperfection of social institutions, unsettled environment, intolerant social attitudes (Yarskaya-Smirnova, Yarskaya, 2021: 146).

The decrease in the activity of people with disabilities in the concept of subjective well-being is explained through the social and economic consequences of the unequal position of this group, and not through disability. Social isolation and financial situation make it possible to explain the differences in subjective well-being between people with and without disabilities (Nastina, 2019: 615).

Comparing the results of studies of disability problems of different years allowed E.K. Naberushkina to suggest that against the back-

ground of changes in social policy, “society’s readiness for changes in a non-discriminatory order is more noticeable in the development of the regulatory legal framework, in the aspect of the formation of infrastructural accessibility” (Neberushkina, 2017: 333), however, “the problems of employment, job placement and social inclusion of people with disabilities remain” (Neberushkina, 2017: 337).

The main goal of social policy is not to support certain social strata or groups, but to integrate society, to ensure the balance of the social system (Bayushina, 2009: 59).

E. Y. Sidelshchikova states that “one of the most important means of achieving the goals defined by law is prosecutorial supervision, at the same time, the uncertainty, inconsistency and lack of legislation in this area does not allow the full use of prosecutorial potential” (Sidel’shchikova, 2015: 57). Summing up, the author notes that “the regulatory legal framework in the Russian Federation in the field of social protection of disabled people is constantly developing and transforming. At the same time, in modern Russian society there is an objective need to improve the legal regulation of social protection of disabled people” (Sidel’shchikova, 2015: 59).

The relevance of the study is determined by the need to substantiate measures to create conditions for disabled people and disabled children to lead an independent lifestyle, on the basis of which appropriate legal regulations will be developed in the subjects of the Russian Federation.

The object of the study is social relations that determine the main approaches to the organization of an independent lifestyle of disabled people in the Russian Federation. The subject of the study is the rights of persons with disabilities to an independent lifestyle and the possibility of their implementation in Russia, taking into account the measures taken and the opinions of the disabled themselves.

The purpose of the study is a scientific analysis of the normative legal support and assessments by disabled people of the expansion of opportunities for disabled people to lead an independent lifestyle in their chosen place of residence and integration into the local community.

Material and methods of research. The paper analyzes international legal documents, federal and regional legislation on providing disabled people and disabled children with the opportunity to lead an independent lifestyle, statistical data on the number of disabled people living in stationary social service organizations according to Form No. 3-sobes, opinions of citizens with disabilities on the readiness and possibility of their independent lifestyle based on the results of all-Russian survey of people with disabilities. 7,775 respondents took part in the survey, 90 people were interviewed in each subject of the Russian Federation. The sample is stratified, not proportional by criteria: by place of residence (cities, rural areas); by age: adult population (over 18 years old), children (0 to 17 years old); by gender (men, women, boys, girls) and type of disability (disorders of the musculoskeletal system, hearing disorders, visual disorders, mental disorders, other disorders).

Methodological basis of the work: comparative legal, logical, historical, statistical and sociological research methods.

A. Structural and functional analysis of compliance of the legislation of the Russian Federation and the subjects of the Russian Federation with international acts on providing disabled people with conditions for independent lifestyle and involvement in the local community

In order to ensure and promote the full realization of all human rights and fundamental freedoms by persons with disabilities without any discrimination on the basis of disability, the Federal Law of the Russian Federation No. 46-FZ of May 3, 2012 ratified the UN Convention on the Rights of Persons with Disabilities (hereinafter referred to as the Convention).

Article 19 of the UN Convention on the Rights of Persons with Disabilities recognizes the equal right of all persons with disabilities to live in ordinary places of residence, to choose their place of residence on an equal basis with other people, to have equal access to services, including support services provided at home and at the place of residence, including person-

al assistance to support an independent lifestyle in the local community.

Social protection of persons with disabilities should promote active citizenship, social integration and participation in the life of the local community without paternalism, dependence and segregation. Consequently, its ultimate goal is to ensure the right to an independent lifestyle and involvement in the local community, enshrined in article 19 of the Convention (Zhavoronkov, 2020: 195).

According to paragraph 16a of the General Comment No. 5 (2017) of the UN Committee on the Rights of Persons with Disabilities, an independent lifestyle means that people with disabilities receive all the necessary means to allow them to make choices, exercise control over their lives and make all decisions concerning their lives. Personal autonomy and free expression of will are key elements of an independent lifestyle, which includes access to transport, information and communication facilities and personal assistance, place of residence, daily routine, habits, decent work, personal relationships, clothing, nutrition, hygiene and medical care, religious and cultural activities and rights to sexual and reproductive health.

In order for the Russian Federation to comply with the provisions of the Convention, it became necessary to amend a number of regulatory legal acts to ensure compliance with international norms. In this regard, on December 1, 2014, Federal Law No. 419-FZ was adopted, which amended 25 legislative acts of the Russian Federation and 750 legislative acts of the subjects of the Russian Federation on social protection of disabled people, assistance to them in the implementation of established civil rights. The results of the implementation of the Convention in the Russian Federation are reflected in the state report submitted to the UN Committee on the Rights of Persons with Disabilities in 2014 and 2018.

The Russian Federation recognizes the equal right of all persons with disabilities to an independent lifestyle and involvement in the life of the local community in accordance with the Constitution of the Russian Federation (Chapter 8, Articles 130 and 131) and the Fed-

eral Law “On General Principles of Organization of Local Self-Government in the Russian Federation” (Article 1). In accordance with the norms of the Constitution of the Russian Federation, everyone has the right to housing. No one may be arbitrarily deprived of a home (part 1 of Article 40).

The legislation of the Russian Federation provides that disabled persons and families with disabled children in need of improved housing conditions are provided with living quarters in accordance with housing legislation (Article 52 of the Housing Code of the Russian Federation, Article 17 of the Federal Law “On Social Protection of Disabled Persons in the Russian Federation”), they are provided with conditions for unhindered access to common property in apartment buildings, as well as the adaptation of living quarters taking into account the needs of disabled people (paragraph 5.1 of Article 2, paragraph 2 of Article 12 and part 3 of Article 15 of the Housing Code of the Russian Federation).

At the same time, the requirements for the provision of housing for disabled people, including in the case of recognition of the residential premises occupied by them as not subject to adaptation, are not fulfilled, since their effect is limited by the need to recognize a disabled person as poor and a number of other conditions that are not feasible in practice.

The main directions of improving social policy in order to ensure an independent lifestyle of disabled people in the local community are the development of innovative forms of social services, early assistance to children and their families, the expansion of the practice of placing disabled people in foster families, the development of hospital-substituting technologies and social support for disabled people, the introduction of public-private partnerships and the development of a competitive environment in the provision of social services to them.

In order to prepare children with disabilities of early age to lead an independent lifestyle when they reach the age of 18, Decree of the Government of the Russian Federation No. 1839-r of August 31, 2016 approved the Concept of Early Care Development in the Russian Federation for the period up to 2020.

The Order of the Ministry of Labour and Social Protection of the Russian Federation No. 847 dated December 14, 2017 approved methodological recommendations for the organization of various technologies for assisted living of disabled people, including such technology as assisted cohabitation of small groups of disabled people in separate residential premises.

The UN Committee on the Rights of Persons with Disabilities, in its concluding observations on the initial report of the Russian Federation, expressed concern about “the significant number of disabled people living in specialized institutions, as well as their limited opportunities, especially those with intellectual and/or psychosocial disorders, in terms of access to services and participation in the life of local communities, and also notes the lack of a deinstitutionalization strategy” (OON, 2018: 5, 6).

In order to expand the opportunities for disabled people to lead an independent lifestyle in their chosen place of residence, regional legislative acts are being adopted in the constituent entities of the Russian Federation to solve specific tasks, including providing housing for disabled people, providing services, tariffs and payment procedures to service providers, interdepartmental interaction and other issues. These documents have been adopted in 29 constituent entities of the Russian Federation, and are being prepared for adoption in another 29. In total, more than 100 legislative acts have been adopted in the subjects in the field of assisted living: on housing for disabled people – in 16 subjects of the Russian Federation; on the provision of services, tariffs and payment procedures to service providers – in 28 subjects; on interdepartmental interaction – in 25 subjects; on solving organizational issues of assisted living – in 29 subjects; on solving other social issues – in 11 subjects.

B. Analysis of the number of disabled people living in stationary social service organizations, assessment of the ability of disabled people to self-serve and lead an independent lifestyle

The number of children living in boarding houses for children with physical disabili-

ities in 2018 amounted to 16,101 people, including 13,352 people with mental disorders (82.93 %), 2749 people with physical disabilities (17.07 %).

The number of disabled children aged 16–17 years living in inpatient social service institutions of the social protection system in 2020 amounted to 21,785 people, including 5982 people in psychoneurological boarding schools, and 1919 in boarding houses for children, including for children with physical disabilities a person in other organizations that provide inpatient social services – 9738 people.

In the constituent entities of the Russian Federation, much attention is paid to the preparation of graduates of orphanages for assisted living. According to the data of the constituent entities of the Russian Federation, 1,515 people left orphanages in 2019, 304 of them were sent to hospital-substituting forms of residence, including 158 people (10.4 %) were assigned to assisted living and to a family, 146 people were assigned to assisted living in the structure of neuropsychiatric boarding schools.

The number of disabled people aged 18 years and older living in inpatient social service institutions of the social protection system in 2020 amounted to 251,754 people, including 154,591 people in psychoneurological boarding schools, and 9738 people in other organizations providing inpatient social services. 13,602 people live in inpatient departments for adults that were not established in inpatient social service organizations, of which 320 people live permanently in neuropsychiatric departments, 61 people temporarily.

Of the recipients of social services, 409 people were employed in stationary social service organizations in 2020, 167 people were sent for training, and 30594 people were sent home.

Thus, a significant number of disabled people, including children with disabilities, are forced to live in specialized residential institutions and are limited in the possibilities of exercising their rights to lead an independent lifestyle. Many disabled people living in families do not have such an opportunity either.

At the same time, the country has launched the implementation of a new hospital-

substituting technology of social services and technology of assisted living for people with disabilities. In this regard, since 2018, the Federal State Budgetary Institution “Federal Scientific Centre of Rehabilitation of the Disabled n.a. G. A. Albrecht” of the Ministry of Labour and Social Protection of the Russian Federation has been conducting annual monitoring studies to assess the accessibility of life arrangements for people with disabilities in the form of assisted living technology.

In order to expand the opportunities for disabled people to lead an independent lifestyle in their chosen place of residence, regional legislative acts are being adopted in the constituent entities of the Russian Federation to solve specific tasks, including providing housing for disabled people, providing services, tariffs and payment procedures to service providers, interdepartmental interaction and other issues. These documents have been adopted in 29 constituent entities of the Russian Federation, and are being prepared for adoption in another 29. In total, more than 100 legislative acts have been adopted in the subjects in the field of assisted living: on housing for disabled people – in 16 subjects of the Russian Federation; on the provision of services, tariffs and payment procedures to service providers – in 28 subjects; on interdepartmental interaction – in 25 subjects; on solving organizational issues of assisted living – in 29 subjects; on solving other social issues – in 11 subjects.

According to the results presented by the executive authorities of 85 subjects of the Russian Federation, as of 01.10.2020, this form is being implemented in 75 subjects of the Russian Federation. This is 36 (48 %) more subjects compared to the data for 2018. In 2020, 1,923 people were sent for assisted living, including 1,365 people from inpatient social service institutions (987 people from psychoneurological boarding schools, 252 people from orphanages for the disabled and 126 from other institutions) and 558 people living in families.

The total number of disabled people who receive services within the framework of assisted living amounted to 5,056 people in 2020. This is almost twice as much as in 2018 (there were 2,545 people). Of these, 2,776 people are

on educational (training) assisted living, 2,280 people are on permanent assisted living.

The main contingent of disabled people receiving services within the framework of assisted living – 3317 people (65.6 %) are disabled people with mental disabilities, of which 732 people live independently with periodic support in a separate apartment or in a house, 2585 people live in apartments in small groups.

C. Analysis of the readiness and assessment of the ability of persons with disabilities to lead an independent lifestyle

Disability has always been considered a problem of a person with a disability who needs to change himself, or specialists would help him change through treatment or rehabilitation (Yaotova, 2015: 57).

In 2019, according to the conclusion of the Federal Bureau of Medical and Social Expertise, based on the assessment of persistent disorders of the body's functions, it was found that 11.9 % of disabled people living in psychoneurological boarding schools, aged 18 years and older, can carry out self-care and lead an independent lifestyle, with the regular help of other persons – 15.7 % of disabled people. 30.8 % of adults with disabilities cannot carry out self-care and lead an independent lifestyle. The ability to lead an independent lifestyle has not been determined for the rest of the disabled people living in the psychoneurological boarding schools (41.6 %).

In this regard, it is of considerable interest to study the opinions of people with disabilities themselves and parents of disabled children about their readiness and ability to lead an independent lifestyle.

The analysis of the readiness and opportunities of disabled people to lead an independent lifestyle is based on the results of an all-Russian study conducted by the Federal State Budgetary Institution “Federal Scientific Centre of Rehabilitation of the Disabled n.a. G. A. Albrecht” of the Ministry of Labour and Social Protection of the Russian Federation.

According to the results obtained, 31.7 % can lead an independent lifestyle, 26.2 % can lead an independent lifestyle with the help of other persons, 22.5 % cannot lead an indepen-

dent lifestyle, 4.9 % have no interest or desire. The number of people with disabilities surveyed who would like to lead an independent lifestyle if accessibility was provided facilities and services, transport, accounted for 8.4 %, 6.4 % found it difficult to give an answer about the possibility / impossibility of leading an independent lifestyle. The number of respondents included people with disabilities who live in a psychoneurological boarding schools, a orphanages for the disabled, disabled homes, their number was 11.8 %, 43.8 % live in an apartment.

Among those who can lead an independent lifestyle, people are mainly of working age (18–29 years – 41.8 % and 30–49 years – 44.6 %), with a basic general education – 38.3 %, secondary vocational education – 38.2 %, or higher vocational education – 46.2 %. The financial situation of disabled people with an active position in relation to an independent lifestyle rated higher than the rest. Respondents more often note such characteristics describing the financial situation as “good” – 40.8 % – or “average” – 34.0 %, “provided with everything” 36.7 %. Among those who can lead an independent lifestyle, there are respondents who have hearing impairments – 42.8 % – or who have a common disease – 44.9 %. 21.8 % live in psychoneurological boarding schools, orphanages for the disabled, disabled homes.

Parents of disabled children aged 8–14 years – 37.5 %, 4–7 years – 38.4 %, 15–17 years – 36.2 % and a third of disabled people of working age (18–29 years – 33.6 %) choose to lead an independent lifestyle with the help of others. The majority of respondents have primary general education – 39.6 %, basic general education – 26.7 %, secondary general education – 25.9 %. A third of respondents (31.4 %) noted the lack of education, which is primarily due to age. In this group, the assessment of the financial situation is diverse and is represented by such characteristics as: “we live hard” – 27.4 %, “average” – 28.1 %, “good” 26.5 % and “provided with everything” – 25.5 %. According to the types of disability, disabled people with disorders of the musculoskeletal system – 30.1 %, mental health – 32.9 %, vision – 32.4 % – can partially lead an independent

lifestyle. 30.4 % live in psychoneurological boarding schools, orphanages for the disabled, disabled homes.

They would be able to lead an independent lifestyle in case of accessibility of facilities, services and transport: disabled people aged 15–17 years – 11.1 %, 30–49 years – 11.6 %, mainly with higher education – 10.8 % – and general secondary education – 10.6 %. The financial situation in this group is estimated as low. 13.5 % of respondents described it as difficult, 14.4 % – as “we live poorly”. Depending on the limitations of life, the choice was made by respondents with visual impairments – 10.6 % – and musculoskeletal system – 13.8 %. For those who care about the availability of facilities and services, 4.7 % live in psychoneurological boarding schools, orphanages for the disabled, disabled homes.

Among those who cannot lead an independent lifestyle due to age and health status – persons with disabilities older than able-bodied (from 70 years and older – 55.1 %, 50–69 years – 28.8 %) and children aged 0–3 years – 23.0 %, 4–7 years – 21.0 %, 8–14 years – 19.7 %. The level of education of the respondents: secondary vocational – 28.0 %, secondary general – 19.3 %, or basic general – 22.9 %, or none (including due to age) – 28.7 %. In this group, the assessment of the financial situation is described as low in the judgments “we live hard” – 26.9 %, “poor” – 31.7 %. However, some of the respondents noted that “they live on average” – 22.4 %, “the financial situation is good” – 20.6 %, “provided with everything” – 25.4 %. According to the type of disability, disabled people with disorders of the musculoskeletal system – 30.6 %, general disease – 24.3 % – and visual impairments – 22.7 % cannot lead an independent lifestyle. Passive attitude is especially common among those living in the psychoneurological boarding schools, orphanages for the disabled, disabled homes (31.2 % of the respondents).

Every tenth respondent has no interest in an independent lifestyle. Among them, respondents aged 50–69 years – 6.1 % – and 70 years and older – 7.6 %, with secondary general education – 5.9 % – or basic general – 7.4 %. In this group, the financial situation is estimated

by respondents as “we live poorly” – 8.6 % – and “the financial situation is difficult” – 6.0 %. Depending on the limitations of life, the respondents with mental health disorders most often chose a lack of interest in an independent lifestyle – 7.6 %. 7.2 % of those living in the psychoneurological boarding schools, orphanages for the disabled, disabled homes.

The surveyed disabled people only in 33 % of cases note an active position regarding the readiness and availability of opportunities to lead an independent lifestyle. 26.7 % say there are partial opportunities. The key factors that influenced this choice were: younger or able-bodied age, type of disability, education and a positive assessment of the financial situation. The passive position in the assessments of the respondents is associated with low estimates of the financial situation and low level of education, as well as older age and type of disability. Respondents with mental health disorders and living in psychoneurological boarding schools, orphanages for the disabled, disabled homes for the more often choose a passive position in assessing their readiness to lead an independent lifestyle and, as a result, the subsequent low potential.

D. Measures for the development of normative and methodological acts, which allowed to start working out issues of ensuring the possibility of disabled people to lead an independent lifestyle within the framework of pilot projects

In accordance with General Comment No. 5, the Committee on the Rights of Persons with Disabilities recommends “adopting a strategy aimed at: promoting the rights of persons with disabilities to independent living and involvement in the local community” (OON, 2017: 2).

In accordance with the state program “Accessible Environment” for 2011–2020, a number of measures have been carried out to develop normative and methodological acts that made it possible to begin working on these issues within the framework of pilot projects and other measures, including support for young people with disabilities in employment, the formation of regional programs for the compre-

hensive rehabilitation of disabled children, the organization of assisted living together with disabled people, providing early rehabilitation assistance to disabled children and supporting families with disabled children, on the organization of the activities of multidisciplinary rehabilitation centers.

At the same time, the work carried out in these areas in 2016–2018 did not lead to results that make it possible to form a system of measures to assist disabled people in exercising their rights to choose and lead an independent lifestyle. In particular, the following tasks have not been solved:

- strategic goals (expected results) and a system of measures to achieve them that comply with the norms of article 19 of the Convention on the Rights of Persons with Disabilities have not been defined;
- the drafts of the prepared acts have not passed state registration and do not have a regulatory status;
- the lists of support services provided to disabled people for their independent lifestyle, mechanisms, including regulations and standards of their provision are not defined in a normative way;
- the norms obliging state authorities and local self-government bodies to train disabled children in specialized institutions to lead an independent lifestyle after the age of 18 have not been defined, including the formation of a reserve of necessary living quarters, the creation of vacancies for employment, the allocation of assistants in social institutions to assist them in transition period of adaptation;
- there are no statistics on the number of people who are able, but not able to switch to an independent lifestyle;
- predictive indicators of their socialization have not been determined, as well as calculations of the funds necessary to provide them with support services and individual assistance (social support);
- the legislation has not been amended to determine the legal status and mechanisms for providing early assistance, assisted living and other forms of personal assistance to disabled people at the stage of transition to an independent lifestyle and independent living;

- the problems of providing housing to disabled people who have the right to receive extraordinary living quarters, including in exchange for living quarters recognized as not subject to adaptation, taking into account their needs, have not been solved;

- the issues of support and comprehensive support for families raising disabled children and disabled people have not been resolved;

- there are no normative-methodological, organizational and material-technical conditions for ensuring assisted social and labor employment of people with mental disabilities and mental disorders outside of inpatient institutions;

- there is no legal regulation of interdepartmental co-ordination in order to assist disabled people in realizing the right to lead an independent lifestyle.

In the process of research on the introduction of assisted living technologies in the subjects of the Russian Federation, conducted at the Federal State Budgetary Institution “Federal Scientific Centre of Rehabilitation of the Disabled n.a. G.A. Albrecht” of the Ministry of Labour and Social Protection of the Russian Federation. The following problems were identified that hinder the introduction of this technology of assisted living for disabled people: lack of living quarters – in 65 % of subjects, trained personnel – in 58 % of subjects, insufficient funding – in 55 % of subjects, insufficient regulatory framework at the federal level – in 43 % of subjects, regulatory framework at the regional level – in 35 % of the subjects from all the studied subjects of the Russian Federation.

Due to the lack of comprehensive study of the above issues, there are currently no regulatory and planning and administrative decisions defining step-by-step indicators (tasks) for preparing disabled people and disabled children for an independent lifestyle and for their socialization outside specialized institutions in accordance with their choice, as well as mandatory measures for the implementation by state authorities of legal regulation, financing, staffing of this work.

The preparation of conceptual solutions on these issues is planned by the Ministry of Labour and Social Protection of the Russian Fed-

eration as part of the development of a Concept and a set of measures to expand the opportunities for people with disabilities to lead an independent lifestyle (hereinafter – the Concept of Independent Lifestyle) and is entrusted to the Federal State Budgetary Institution “Federal Scientific Centre of Rehabilitation of the Disabled n.a. G. A. Albrecht” of the Ministry of Labour and Social Protection of the Russian Federation.

The development of the Concept of Independent Lifestyle is carried out on the basis of the provisions of international instruments in the field of the realization of the rights of persons with disabilities (the World Programme of Action for Persons with Disabilities of December 3, 1982, the Standard Rules for Ensuring Equal Opportunities for Persons with Disabilities of December 20, 1993, the Convention on the Rights of Persons with Disabilities of December 13, 2006, General Comment No. 5 (Zamechaniye obshchego poryadka, 2017) on Independent Lifestyle and Involvement in the Local Community of October 25, 2017, Concluding Observations of the UN Committee on the Rights of Persons with Disabilities on the Initial Report of the Russian Federation dated April 9, 2018), federal legislative acts (“On the Right of Citizens of the Russian Federation to Freedom of Movement, Choice of Place of Stay and Residence within the Russian Federation” dated June 25, 1993 No. 5242-1, “On Social Protection of Disabled Persons in the Russian Federation” dated November 24, 1995, No. 181-FZ), the experience of foreign countries and subjects of the Russian Federation.

The Concept of Independent Lifestyle is aimed at forming a human rights model of disability, achieving deinstitutionalization of disabled people with all types of impaired functions and disabilities, with their consent and by creating a barrier-free environment and providing them with the necessary assistance, taking into account their available opportunities, socialization and integration into the family and local community.

The basis for the development of the Concept of Independent Lifestyle is the philosophy of “independent life”, which considers the

human right to be an integral part of society and to take an active part in social, political and economic processes as freedom of choice and freedom of access to residential and public buildings, transport, communications, insurance, labour and education, as an opportunity to determine and to choose, make decisions and manage life situations as a way of thinking, psychological orientation of a person, which depends on its relationship with other personalities, its physical capabilities, the support services system and the environment.

The expansion of opportunities for disabled people to lead an independent lifestyle in their chosen place of residence, justified by the Concept, is based on the implementation of the requirements of the following principles:

- humanism, from the standpoint of which disability is a situation in which the normal functioning and quality of human life is possible due to compensation mechanisms and the construction of special conditions, assistance and support;

- interiorization, which assumes that the formation of the internal structures of the human psyche occurs through the assimilation of external social activities, the appropriation of life experience, the formation of mental functions and development in general, and this applies, among other things, to the capabilities of people with disabilities;

- normalizing the lives of people with disabilities in various places of residence and stay, stimulating their active participation in solving their own life tasks and developing their independence;

- an integrated approach, which consists in assessing not only the degree of severity of mental function, but also vital signs in the household, social and professional spheres, as well as the mutual influence of factors of functioning and the environment on the individual;

- an individual approach involving the provision of assistance commensurate with the needs of the person;

- orientation to the development of independence of people with disabilities;

- independent choice of place of residence;

- continuous/lifelong support for people with mental disabilities, including them in var-

ious activities in order to constantly support the acquired skills.

The strategic goal of the developed Concept is to create legal, economic and institutional conditions conducive to a gradual increase in the number of disabled people and disabled children who, as a result of the development of a system of continuous comprehensive support – early care, education, habilitation and rehabilitation, assisted living and assisted employment/labour activity – conditions will be created for self-selection of the place of residence, leading an independent lifestyle in the chosen place of residence for their full inclusion and involvement in the local community.

In conclusion, it should be noted that the implementation of a Set of Measures of the Concept is the most effective mechanism for promoting an independent lifestyle of disabled people in their chosen place of residence, developing a network of support services necessary for this, increasing the role of family, social services, civil society institutions in their provision, as well as the integrated use of social support methods, early assistance, assisted living, support with the assistance of employment and work activities of disabled people.

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