**Abstract**

**TR-136**

Title: "Analyzing health status of clients of the long-term care system for citizens with autonomy deficit (LTCS) and developing financial and organizational mechanisms of LTCS"

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1. **The object** is represented by characteristics of Russian long-term care system (LTCS) clients, living conditions of relatives caring for them, financial and organizational tools of LTCS, tools for regulating activities of care providers and for protecting rights of recipients of long-term care.
2. **The aim** of the project is to develop proposals on the financial and organizational tools of the LTCS created within the national project "Demography", having considered health status of the LTCS clients, tools used in the pilot project to assess eligibility for care and quality of the services provided, and data on the contribution of relative care in total demand for care.
3. **Methodology:** desk research methods (analysis of scientific and expert publications, departmental statistics, regulatory documents), multivariate statistical analysis of sample survey data (including regression analysis)? modeling techniques.
4. **Empirical base of research:** (a) normative legal acts of the Russian Federation and subjects of the Russian Federation on the topic of social services and LTCS; (b) data of Federal State Statistics Service; (c) microdata from various sample surveys: Quality and Availability of Services in the Spheres of Education, Health Care and Social Services, Promotion of Employment of the Population (QAS) – 2015-2019; Sample Survey on the of the Use of the Daily Time Fund by the Population (SSUDTF) – 2019; Russian Longitudinal Monitoring Survey, Higher School of Economics (RLMS, HSE) – 2019; Comprehensive Survey of Living Conditions (CSLC) – 2020; sample survey "Reproductive and Self-Preserving Behavior of the Population of the Republic of Tatarstan" (RSPBP RT) – 2020, "Epidemiological Survey of the Prevalence of Geriatric Syndromes and Age-Associated Diseases of the Elderly in Regions of the Russian Federation with Different Climatic, Economic and Demographic Characteristics" (EUCALYPTUS), conducted by Russian Gerontological Research and Clinical Center of the Ministry of Health of the Russian Federation with the participation of ISP NRU HSE in 2018-2019.
5. **Results of research:**

The analysis of the normative legal acts showed that the pilot project for the creation of the LTCS is not only focused on improving the quality of services for people with a self-service deficit, but also contributes to the introduction of modern principles of needs assessment into Russian practice. The implemented method of typing (functional diagnostics) makes it possible to consider the need for care not only in disabled people but in elderly too. The pilot project contributes to the transition to a formalized procedure of needs assessment, providing equal chances of access to care for residents of all the regions of the country, but it has not been fully implemented yet due to differences in regional norms of care for each individual care group. In this regard, it is necessary to consider the experience of the developed countries of the world, in which, in the distribution of care, as well as medical care, the principle of equal access to services is used (as in health sector), but not the principle of the specific needs of certain vulnerable social groups (as in the social systems support).

 The data of the QAS 2015-2019 shows significant differences between urban and rural settlements in the accessibility of social services, in forms of the services, in possibilities of obtaining them for a fee and in co-financing. At the same time, there is a lack of public data on the long-term care services provided by form of social services: on material and technical base, personnel.

The comparative assessments of the legal regulation of consumer protection of LTC in Russia and countries with LTCS showed that the Russian legislation establishes the basic rights of recipients of social services. At the same time, there are no tools and mechanisms for realizing the rights of recipients of long-term care services – standards that include characteristics and indicators of services.

In connection with the organization of regulation of the practices of care providers in Russia at the regional level, including through quality control of care, monitoring of the social package of care, this study identified the risks of regional differences and inequality in care for recipients.

According to the obtained estimates, relative care remains the main channel for providing care to people with care deficits in all countries, including Russia. Therefore, home-based care from relatives and friends is the most common way to receive assistance of medical or sanitary and hygienic services - 64.9%. A specially hired person cares after only 6.3% of respondents.

The share of people providing relative care for people aged 50 and over is 21.3% according to CSLC-2020 and 16% according to the RSPBP RT. The involvement in relative care in Russia is slightly higher than in the OECD countries. In OECD countries, about 10% of the population aged 50 and over is engaged in informal care for people with functional limitations.

The assessment of the socio-demographic characteristics of relative care donors according to CSLC-2020 shows that care these care providers are more often represented by women, middle-aged people (30-54 years old), those who live in rural areas and have higher education. Also, among donors of care, there are more often poor categories of population. The largest share of unemployed donors are women aged 55 and over with a relatively lower level of education.

The results of the study showed a nonlinear relationship between the frequency of care and the labor market activity: care on weekends or at an intensity less than 1-2 times a week can stimulates employment (perhaps to pay for related medical costs), but the higher intensity of related care leads to the less involving in labor activity. Intensive daily care over 28 hours a week is hardly compatible with work activities. For this category of the population the development of LTCS and the partial replacement of hours of related care by professional care could help.

The study indicates that the provision of relative care negatively affects the household income of care providers. Almost every fifth unemployed relative care provider notes that his family has enough money only for food and utility bills. Employed care donors are in a much more comfortable financial situation. At the same time, those included in relative care receive, on average, less income from employment compared to those who do not care after relatives.

According to the forecast of the Institute for Social Policy of the Higher School of Economics, the total number of people with self-service deficits will increase from 4.1 million in 2020 to 6.8 million by 2040. In Russia as a whole, the current average cost of care is estimated for inpatient care at 47.4 thousand rubles / month per bed, for home care – at 6 thousand rubles / month per recipient, at semi-stationary care at 0.8 thousand rubles / month per recipient. Based on the simulation results, households' current expenditures on care are at least 86.5 billion rubles per year. Without considering inflation and development of the social service system, households' expenditures may grow by 168% to 143 billion rubles by 2040.

Based on the results of the study, the following proposals and recommendations were formulated. To overcome significant interregional differentiation in social services and long-term care, it is proposed to introduce regulatory procedures that reinforce methodologies, comparable infrastructural, financial and personnel provision of LTCS in the regions of the country. Based on the Russian and international experience in regulating the activities of service providers, summarized in the study, it is proposed to introduce a licensing mechanism for the activities of stationary social service organizations, including the establishment of licensing requirements for material and technical support, personnel qualifications, and special conditions for the provision of social services to persons with disabilities. To improve the system of accounting and reporting in social services, the principles of data generation based on state digital services, including direct interface between the information system of a social service provider and of the Unified State Information System of Social Security, are proposed.

1. **Level of implementation, recommendations on implementation or outcomes of the implementation of the results:**

The work was carried out for of the Apparatus of the Government of the Russian Federation. Within the project, 4 analytical notes were prepared. Separate materials of the project are represented by the results of expert work on behalf of the Ministry of Labor and Social Protection of the Russian Federation. The project materials were also used in the work of the following agencies: the Council under the Government of the Russian Federation on the issues of guardianship in the social sphere (on the development of a network of inpatient social service organizations), the Government of the Russian Federation (on the design of the initiative for the socio-economic development of the Russian Federation “Medical rehabilitation optimal for health restoration"). The results of the project were discussed at the sessions of the regular seminar of the Institute of Social Policy "Politics of active longevity and pension reforms: Russian and international experience", The 24th St. Petersburg International Economic Forum, the 4rth Forum of Social Innovations of the Regions, the Moscow Financial Forum, the 5th All-Russian Congress on Gerontology and Geriatrics with international participation "Preventing Falls - Saving Life".

1. **Field of application:** the results of the study can be used in the work of federal and regional government bodies to improve existing or emerging legislation in the field of social services and the development of a long-term care system to increase their effectiveness.