

WHO CARES FOR THE CARERS?

PROMOTING APPLIED POLICIES FOR INFORMAL LONG-TERM CARE

- Policy Brief -

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EXECUTIVE SUMMARY

LONG-TERM CARE

Under the concept of long-term care, in this policy brief we refer to a system of activities undertaken in order to provide conditions for an as independent, as autonomous and as participative as possible practice of daily activities by people who are unable to do those activities on their own, over a longer period of time and in a manner which would ensure highest possible quality of life and guarantee to take their human dignity into account.

Long-term care consists of:

- a) The formal care provided by professionals paid for the services they offer on contractual basis.
- b) Informal care which is unpaid work done within the home, under the given family, friendly and neighborly relationships.

Source: OECD, 2005.

Within the system for long-term care in Macedonia, there are no policies for direct help and support of caregivers. Families are largely left on their own to carry the burden of caregiving, while the existing practices fail to recognize their needs. In conditions of an increasing need for long-term care as a result of the aging of the population, the low birth rates and the migration courses, it is of particular importance to design policies and measures for help and support of informal caregivers as a part of a comprehensive long-term care system.

This document focuses on informal caregivers, i.e. the family members, friends, neighbors, providing care to the elderly. To what extent do the existing measures and policies correspond to the needs and expectations of the informal caregivers and with the problems identified in practice, and what measures should be introduced in order to advance their status and position?

The aim of this policy brief is to provide an answer to this question and draw attention to the need of introduction of measures for help and support of people providing care within the home, thus recognizing and appreciating the contribution of home caregivers to the maintenance of the long-term care system, not only by supplementing the services from the formal care, but also by providing their financial sustainability, which would also contribute to an increase in the quality of the care provided by these people.

WHY IS IT NECESSARY TO DESIGN MEASURES FOR HELP AND SUPPORT OF INFORMAL CAREGIVERS?

The demographic trends indicate that the need for care will be on the increase.

Macedonia's population, similarly to the European one, is an aging one. According to the census from 2002, 15% of the population was over the age of 60.¹ According to the assessments of the State Statistical Office², in 2015, the percentage of population aged over 60 amounted to 18.7%. According to the forecasts of the United Nations, the population size will decrease from 2 078 000 in 2015 to 1 938 000 in 2050; the median age will increase - from 37.5 in 2015, to 47.2 in 2050. The life expectancy will also increase from 75.2 in 2010-2015, to 80.5 in 2045-2050³. The birth-rate will decrease - 12.91 in 2000 as opposed to the 11.1 from 2015⁴. The migration movements will also have their impact on this, including both the internal migration (the imbalance between the regions, with highest migration rate to the Skopje region; the Skopje region also has the highest population density according to the 2002 census), as well as the external migration (the rising trend of people moving out the country)⁵. In addition, based on the interviews, it became clear that in a large number of the municipalities, the number of people receiving welfare is already below the number of people using compensation for caregivers, as well as the fact that the number of people relying on caregivers is over 30,000 people, which is also quite indicative of the prevalence of caregiving, as well as its scope and significance.

1 Government of the Republic of Macedonia, *National Strategy for the Elderly 2010-2020* (June 2010)

2 Statistical overview Assessments of the Population on 30.06.2015 and 21.12.2015 According to Sex and Age, per Municipality and per Statistical Region no. 2.4.16.10 856 (Skopje, State Statistical Office, July 2016).

3 United Nations Department of Economic and Social Affairs/Population Division World Population Prospects: The 2015 Revision, Key Findings and Advance Tables

4 State Statistical Office, MakStat database, Birth rates, Mortality, Natural Growth, Marriages and Divorces, per Region, per Year

5 State Statistical Office, MakStat database, External Migration: people who have migrated abroad per sex and age, per region

Informal caretakers are the pillar of long-term care.

With the unpaid work they are doing, informal caregivers sustain the long-term care system. There is no quantitative data available, but the qualitative research that we conducted in Macedonia from 2014 to 2016, suggests that this system relies on the informal services provided by caregivers. In addition, the research conducted by the European Union in 2012 shows that even in the (then) 27 member-countries, long-term care was mainly provided by the families and close relatives of the people in need, and that a large part of it was informal.⁶ This research also highlights the existence of formal and informal care, as well as a type of semi-care which covers the measures that make it possible for the caregivers to have breaks, i.e. the so-called respite care.

The existing legal and policy frameworks contain the grounds for introduction of this kind of measures.

The existing legal framework locates the responsibility for caregiving within the family, although this takes place under circumstances burdened by a lack, i.e. restricted access and quality of services, whereby the informal caregivers most frequently do not have another choice but to take care of their relatives. The existing policy papers⁷ recognize the need to reform the long-term care system due to the access to and quality of services, as well as the demographic trends which point to the increase in the volume of required caregiving in the (near) future.

The care provided by informal caregivers is not structurally recognized and aided.

The previous research by the European Policy Institute - Skopje (EPI) showed that all the efforts made by the caregivers are not recognized by the state, not even in cases when they are the ones providing most

6 European Commission, European Economy (Economic papers 469, November 2012)

7 Such as the National Strategy for Reducing Poverty and Social Exclusion in the Republic of Macedonia for the period 2010-2020.

of the care.⁸ Even more so, the respondents point out that “children” (caregivers) are regarded as people who are obliged to take care of the elderly. The care itself, especially when it is related to a disability, is prone to be stigmatized. The stigmatization in cases like these is either already lived, or expected. It is a multitude of financial, physical, mental and emotional factors and their consequences that affect the well-being of caregivers, thus affecting the quality of care.⁹ The caregivers have their own needs, such as domestic services, daycare centers which would be geographically available etc. which are not recognized/or are completely ignored by the present system.¹⁰

There are no measures supporting or aiding caretakers and making it possible for them to have a better quality of life

There is no sustainable framework for long-term care which would recognize and respond to the social risk that caregivers are exposed to, as well as leave it up to them to outline and implement the activities necessary for them to be able to provide the required care and support.¹¹ The needs, interests and expectations of the people who need care and the persons providing it, are frequently equated. For example, the person who requires care may wish to stay at home and be taken care of in the home, while the person providing the care may wish/have to join the labour market. Therefore, the services and measures must be organized to meet the needs and expectations of both - the people requiring care, as well the informal caregivers. The introduction of support measures and assistance will help the caregivers to maintain or upgrade their health status, join the labour market or the educational process and fulfill their full personal potential, while at the same time contributing towards improved quality of

8 Biljana Kotevska, Elena Anchevska and Simonida Kacarska, *The Art of Survival: Intersectional Inequalities in the Social Protection in Macedonia - Results from an Empirical Research, working paper* (Skopje: European Policy Institute, 2016) [http://www.epi.org.mk/docs/Country_paper\[MK\]\[DTP\].pdf](http://www.epi.org.mk/docs/Country_paper[MK][DTP].pdf).

9 Biljana Kotevska, Elena Anchevska and Simonida Kacaska, *The Art of Survival: Intersectional Inequality in the Social Care in Macedonia – Results of an Empirical Research, working paper* (Skopje: European Policy Institute, 2016), [http://www.epi.org.mk/docs/Country_paper\[MK\]\[DTP\].pdf](http://www.epi.org.mk/docs/Country_paper[MK][DTP].pdf).

10 Ibid.

11 Ibid, pp. 90, 137

the care they are providing. Taking into consideration the fact that it is mainly women who take care of the elderly people with a disability, the weak and chronically ill, special attention should be paid to creating gender-sensitive services and measures.

THE NEEDS OF THE INFORMAL CAREGIVERS

The care provided by informal caregivers does not only require time, dedication and self-sacrifice. It is also physically and psychologically exhausting, which, in turn leads to increased implications on the possibility for inclusion or participation in the labour market on the part of the informal caregivers, as well as their general well-being (both physical and psychological) and quality of life. The respondents who participated in our previous research faced a series of challenges, three of which are singled out here.

Barriers to participation in the labour market

The every-day care which takes a significant portion of the caregivers' time limits their possibilities for participation in the labour market. The needs for care are unpredictable and often vary from “passive forms of care involving routine tasks and urgent interventions for crisis prevention or management”.¹² The intensity of care also varies, ranging from very intensive and exhausting activities to easier ones. In addition, apart from taking care of a disabled child, some of the informal caregivers also take care of a parent. This leads to inability to join the labour market on the one hand, and a tendency to engage in informal economic activities on the other, due to the increased time flexibility in the completion of the tasks, as well as the time-saving aspect, as time is one of the resources that caregivers severely lack.

Women are particularly affected because in conditions of lack of publicly available services combined with the still dominant traditional gender division of roles in society, women are the ones who mainly carry the burden of care. Out of the total female population in Macedo-

12 Julia Twigg, “Clashing Temporalities: Time, Home and the Bodywork of Care,” in *Aging and Caring at the Intersection of Work and Home Life*, ed. Anne Martin Matthews and Judith Philips (New York: Lawrence Erlbaum Associates, 2008)..

nia, 64% of the women are economically inactive, while 39% are employed.¹³ Out of the average 2.25 hours spent in unpaid, domestic activities, 3.38 hours fall on women, in contrast to the 1.11 hours of work done by men.¹⁴ If it is taken into consideration that the average hours spent in such activities in the urban environment (2,08 hours) is less than the average hours spent in a rural environment (2.48 hours), it can be concluded that women in rural environments are the ones who spend the most time doing unpaid, domestic chores. In addition, 94% of the unemployed who have left their last job in order to take care of children of adults with a disability are women.¹⁵ Due to the flaws in the care services for adults who need care, 81.5% of women (18.5% of men) do not work or work only part-time.¹⁶ Previous research also reveals that 42% of the respondents believe that if there are children or adults who need care in the family, it is not worthwhile for the woman to work.¹⁷ The absence from the labour market affects women's financial security, both current, as well as future. Therefore, we can draw a conclusion that female caretakers are more susceptible to poverty.

Need of healthcare

The people caring for members of the family neglect their own personal needs at the expense of the needs of their children/protégées/parents. They face significant levels of stress and worry on daily basis related to the successful completion of the chores and the provision of financial means to satisfy their basic need. There is an omnipresent fear about the future of their children/protégés, after their death.

The entire engagement around the care they give, including the constant exposure to stress and uncertain future, also generates a need for care provided to the caregivers themselves, which is often based on the physical inability to carry out all of the caregiving ac-

tivities. This finding is based on what the respondents from our previous research stated. However, if we take into account that mental health is often overlooked and stigmatized, the respondents often did not comment on it, and consequently we do not have findings on the extent and type of care the caregivers need as a result of deteriorated mental health.

Inclusion in social life

Due to the activities which take up a large proportion of their time, engaging in any kind of social activity usually comes last for caregivers. They face solitude and isolation, by both, their extended and closer family, as well as friends. It can be said that neither they, nor the people they provide care for, live as autonomous self-sufficient individuals. Although they have different needs and realities compared to the people they provide care for, caretakers cease to have a life of their own.

Getting accustomed to the place of residence and the environment

Caregivers do the necessary adjustments to their habitat on their own. These may be minor undertakings in a lot of cases, such as, for example, moving people who have decreased physical mobility one floor down. However, these sometimes are undertakings of a larger scope. For example, a caregiver has adjusted all the electricity and water-supply outlets in a house (sockets and taps), in order to provide a safe environment for the person he takes care of, as well as the rest of the family. He did the adjustments after the person he cared for caused a flood and an electricity outbreak in the house.

However, these adjustments should not only be aimed at creating better conditions for the caregivers to do their care-related chores. In fact, depending on the level and type of care necessary, it is also possible to conduct adjustment for the purpose of creating conditions for the cared person to be able to live as independently as possible, including the aspect of protection of his/her dignity.

13 Data from the MakStat Basis, <http://makstat.stat.gov.mk>. Last accessed: 29.11.2016 r.

14 Ibid.

15 State Statistical Office, Workforce Survey (Skopje, 2016)

16 State Statistical Office of the Republic of Macedonia, Men and Women in the Republic of Macedonia (Skopje 2015)

17 Reaktor - Research in Action, Finding the Key to the Glass Door: Demystification of the Reasons for Low Participation of Women in the Labour Market (Skopje, 2012) 30.

No availability, accessibility, acceptability and quality of the state institutions and services

The time necessary to run the administrative errands, the limited physical and sensory accessibility of the state institutions and services and the geographical remoteness affect the inability of caregivers to do their own administrative chores in a timely and uninterrupted manner. These are oftentimes related to the use of healthcare services in order to preserve one's own health, such as the "My Time" service. The unexpected events which often crop up related to the care they provide may render them unable to show up as scheduled, without it being their fault (see below - invasive and punitive system).

Poverty

In circumstances of a high unemployment rate, unavailability of flexible jobs, as well as lack of services and measures for daily care and support, caregivers are prevented from entering the labour market, which often results in worsened economic standing and falling, or danger of falling into poverty, or below the poverty line. In the struggle for existence, this leads to them undertaking informal economic activities, where there is a lower investment of time, and a higher flexibility.

In this kind of a situation, the financial assistance for care they get is more than important. However, they face the problem of insufficient and late assistance, similarly to the other kinds of financial assistance. This, in turn, creates a problem when it comes to the payment of the overheads and other bills, which puts this people in contact with bailiffs, which further leads to additional costs for unblocking accounts, as well as huge investments of time, which is a luxury that these people do not possess.

The system is invasive, punitive and discriminatory

Caregivers face administrative procedures which do not take into account the unpredictability of their daily lives. Moreover, it seems that the state has no understanding for missed deadlines or scheduled meetings due to unpredictable obligations related to the provision of care. The absence of adjustment on the part

of the state when it comes to the peculiar situation of caregivers, results in a systemic discriminatory attitude. The lack of a separate form of discrimination by association through which the personal characteristic or status (disability in particular) could also apply to caregivers, as it is stipulated under the law of the European Union, places an additional barrier on the path to protection against discrimination on the already relatively new, and hardly functioning equality body.

PROBLEMS IN THE EXISTING SYSTEM IDENTIFIED BY THE PRACTITIONERS

"We are a welfare country, but have no social awareness."

Respondent from CSW (22.09.2016 r.)

The following problems in the existing long-term care system have been identified by our respondents - employees in the centers for social work, relevant parts of the executive, local governments, as well as the civil sector and international organizations. The following part was drafted based on the data we obtained from the interviews; the authors from the research team summarized these findings.

Not understanding the notion of long-term care, lack of needs assessment, or a system that would enable problem identification

There is general agreement among the employees from CSW that we interviewed that the need for long-term care is not adequately recognized as a social risk. Moreover, the informal caregivers are not featured in the legal and policy frameworks. There is only limited understanding on the part of several crucial stakeholders, including those who could occur in the role of caregivers, on what long-term care is and the scope of measures and services that can be introduced within this policy. Also, there is no recognition of the social risk that the caregivers are exposed to. There is lack of knowledge about the complex network of relations and factors which cause a certain person to require care, as well as the set of relations that caregivers are susceptible to, and that determine their lived experiences.

Limited resources and capacity

There is no balanced quality and access to resources among the various CSW. Among the respondents working in centers which are in charge of major rural areas there is consent that there is a lack of professionals who would work on field with the end users. In addition, civil society organizations are trying to respond to this need, but the needs are vast and their resources limited. For example, 500 families in Kumanovo need to use the Center “Our Message”, but it can only accommodate 21 people.

The employees of CSW sometime visit the people who need care more frequently, and sometimes they don't. The geographical position plays a large role in where and how often these people will be visited. The accessibility of certain areas often depends on the weather. For example, in winter, when there is snow on the mountains, the employees of CSW wait for spring to arrive in order to get in touch with the people who live in higher places, or wait for them to climb down alone. They do not have the necessary vehicles which would give them mobility under any weather circumstances. In addition, the number of people that a single person within CSW is in charge of, is also a problem. For example, in some of the municipalities, a single person is in charge of all of the users of care by a third person (thus, for example, in the Municipality of Kichevo, a single person is in charge of 800 people).

The financial assistance related to caring for other people is low (from 3,800 to 4,200 MKD) and there is a constant lack of the basic means of survival. This leads to the conclusion that these people either live on the brink of poverty, or under the brink of poverty. Therefore, the practitioners report that most of these funds are used up to satisfy the needs of the users for procurement of food, medicines, hygiene products, which leaves them with very little money, most often a symbolic amount, insufficient to cover any other costs which may be real costs of the caregivers.

Insurmountable, expensive and irrational bureaucratic barriers and reaching for temporary solutions

Although efforts are made by the practitioners working in this area to do systemic changes which would result in a more permanent solution for this problems, they most often face the obstacles inherent to the existing system. Thus, for example, the qualities of care-

givers are not evaluated, i.e. there are no efforts to try and keep the people who are trained and have some experience in providing long-term care.

The procedures to use the measures available at the moment, for the people who need care, are expensive. Unlike before, a large part of the documents that are to be taken out (an opinion of a primary care doctor, consultative opinion, ambulance or other transportation costs, proof of income) are now financially burdening the people in need themselves.

Furthermore, for some of the people who take financial assistance due to a social risk or a social need related to permanent impairment of health, disability or old age, different conditions apply when it comes to the uninterrupted use of this kind of assistance. In fact, some are given permanent right to this benefit, while others need to be evaluated by a committee every two years. This was illustrated by two of our respondents, with an example of a person with an amputated leg, who was given the right to assistance within the duration of one year. They both wondered whether this maybe means that the person would grow a new leg within that year, so that it would become necessary to re-evaluate the situation.

Lack of information

There is a lack of information on both, who is in need of care, as well as who provides it. When it comes to what people need care, the respondents from CSW who cover several villages, say that they are in charge for a lot of old people that no one in the family wants to provide care for. Yet, CSW finds about those cases only after the people are dead. Furthermore, on one occasion CSW found out about a person in need of specific help, only after it was revealed that the person had been subjected to inhumane treatment (for example kept locked at home, when everyone else from the household was out).

When it comes to who provides them with care - not even the people working CSW know who exactly provides the care, unless the people who are cared for tell them so; According to one person at a managing position, CSW does not even pay attention to who gets the money as long as everything is done in accordance with the law. This seriously clashes with what the people CSW say, i.e. that the state must keep records and that the people who claim that they are able, or willing to perform the role of a caregiver need to submit

a medical certificate for their psycho-physical ability. All of this makes it impossible to map the needs to train these people, as well as approach them in a comprehensive and systemic way, in order to provide as high quality and timely care as possible. In addition, it seems that there is an opinion held by the people working CSW that when female caregivers are in question, they know how to do the job, which is not the case with male caregivers.

Not using the possibilities already given under the legal framework and policy framework

Some of the possibilities which already exist under the legal and policy frameworks are not sufficiently taken advantage of. Thus, the possibility for lifelong support by the country is insufficiently used, according to which any property belonging to the person that care is provided for, would be left to the state after the cared person's death. Next, the category of foster families is also not used every often in practice, and is facing extinction.

Furthermore, there is no developed awareness about the nature and importance of long-term care. The motivation to provide care, among those who are not family with or related to the people who need care, are mainly finances. However, the employees of CSW notice that sometimes even the finances are not a sufficient motive for some people to take on a caregiving engagement.

Insufficient utilization of the potential on a local level

The local government is of utmost significance due to its good (systemic) position, closeness to the people and knowledge of the need, and this renders it an unutilized resources for both mapping the problems, as well as finding solutions and implementation of adequate measures.

Unequal distribution of services and institutions

There is unequal distribution of services and institution on the entire territory of the country, which disproportionately affects the people from rural environments. It seems that, just like when it comes the other services, when it comes to long-term care, the

farther the person who needs care lives from the big urban centers, the lower the probability is that he/she will have adequate resources to satisfy his/her needs institutionally. We are mentioning this, because it directly affects both the male and female caregivers and their ability to adequately respond to the needs of the people.

No one takes care of the caregivers

It seems that the visibility, recognition and help for the work of caregivers remains virtually non-existent. The needs that they are talking about, and which we mentioned in the previous part, only come second. All the discussions related to long-term care revolve around the people who need care and around how to provide this care. There are no specific measures for help and support of informal caregivers which would be directed aimed at promoting their status and increasing the quality of their life. In addition, the civil organizations are focusing on people who need care, and thus also fail to pay attention to the needs of the caregivers. There are no civil society organizations which advocate improvement of the quality of life and status of caregivers in an organized manner and in large numbers (such as advocacy groups).

BRIEF OVERVIEW: WHAT POLICIES RELATED TO INFORMAL CARE ARE THERE IN OTHER COUNTRIES?

Bulgaria: The unemployed family members (who need to meet specific conditions and undergo a short training) are hired to provide care to the people who need it, for which they are awarded with a minimal compensation, designed, above all, for the people facing a high risk of social exclusion and institutionalization. The services for introduced at the start of 2009, as part of the National Program "Social Services in a Domestic Environment"¹⁸.

18 Ludmila Mincheva and Galina Kanazireva, The Long-term Care System for the Elderly in Bulgaria, report, European Network of Economic Policy Research Institutes, ENPRI Research Report No.71 (2010), 2.

Slovenia: The unprofessional care for relatives and family members is paid. The amount of the fee is low, but it serves as a compensation for the effort and work invested in the long-term care for the relative. Such “family helpers” are also introduced in the schemes for pension and disability insurance. They also qualify for social benefits and receive the minimum wage as compensation for the lost income they could otherwise earn.¹⁹

Serbia: There are no specific measures for informal caregivers. However, the National Aging Strategy defines providing support for informal care as one of its strategic goals. In fact, it states that flexible working hours are to be introduced for the families and/or relatives who provide care, help the adjustment of the living space and physical environment, provide training and education of caregivers of seriously ill people, provide organized psychological and social support, counseling, information as well as other types of help and support. Moreover, they are also planning to introduce a support system for the relatives, friends and neighbors, along with coordination and more intense collaboration between the various instruments of the long-term care system.²⁰

Croatia: There is a separate status parent-caregiver, or caregiver which entails a financial compensation, health and pension insurance, as well as the right to an annual holiday (up to four weeks), under certain criteria. This right is recognized to one parent, if the child does not spend more than four hours in some of the daycare centers. If there are two or more disabled children in the family, then the right can also be recognized to both of the parents. Moreover, this kind of right may also be recognized to close relatives who occur as caregivers.²¹

HOW TO IMPROVE THE STATUS AND QUALITY OF LIFE OF THE INFORMAL CARETAKERS: POLICY RECOMMENDATIONS

The policies contained here were generated through a research process consisting of several stages. The draft recommendations were prepared based on the findings of the previous research, an overview of the existing literature on long-term care, as well as the existing statistical data, including the demographic trends. Next, these recommendations were discussed with selected respondents - employees in the centers for social work, relevant part of the executive authority, the local authorities, as well as the civil sector and the international organizations. The recommendations were also tested on two focus groups with the same respondents, in order to identify possible changes in the findings which would emerge from the group dynamics of the focus groups. After this, the recommendations were reviewed and opened for discussion at a round table. In accordance with the remarks of the participants at the round table, the recommendations were reviewed once again, whereby the following list ensued:

General recommendations

» To prepare a comprehensive analysis in order to determine the number, profile (characteristics), as well as the needs and expectations of informal caregivers. The process of drafting this analysis should also be taken advantage of in order to carry out a holistic review of the problem in order to generate evidence for well-grounded policies, where in the preparatory stage, the data and databases of MLSP can be combined with the data from the local self-governments and the centers for social work, the Ministry of Health, the international and non-governmental organizations, as well as strengthening of the collaboration between the relevant stakeholders.

- It is recommended that in the process of drafting this analysis a base of the existing literature, or at least a bibliography be generated, which would contain the existing analysis. A step like this would facilitate any future research in this area, as well as the drafting of this comprehensive analysis. Such research might have already been done by international organizations (UNDP, for example), as well as state bodies and institutions (for example, the Institute for Social Affairs), or the civil society organizations (for example, EPI, or the Association for Emancipation, Solidarity and Equality of Women). Furthermore, it is of exceptional importance for this

19 Valentina Prevolnik Rupel and Marko Ogorevic, The Long-term Care System in Slovenia, report, European Network of Economic Policy Research Institutes, ENEPRI Research Report No.71 (2010), 2
20 Gordana Matkovic, Who Cares? The Institutional Framework for Long-Term Social Care Benefits, National Report Serbia, March 2011,29

21 Pravo Na Status Roditelja Njegovatelja Ili Status Njegovatelja, Vlada Republike Hrvatske, last accessed November 29, 2016, <https://gov.hr/moja-uprava/obitelj-i-zivot/socijalna-skrb/prava-i-usluge-za-osobe-s-invaliditetom-iz-sustava-socijalne-skrbi/pravo-na-status-roditelja-njegovatelja-ili-status-njegovatelja/1804>.

activity to involve the previously carried out mapping (for example, the one by MLSP from 2008), as well as the findings from projects for development and standardization of services and financing (for example, the SOS Children's Village) and the experiences from projects on provision of services (for example by UNDP and the Red Cross). It is of the utmost importance for this activity to involve the civil organizations and all the other relevant stakeholders which could aid in generating statistics related to disability which would be helpful in the drafting of this analysis.

» Based on this analysis, a comprehensive and sustainable long-term care system is to be maintained which:

- Will recognize and value the contribution and significance of informal caregivers when it comes caring for people who need care on the long-term;
- Will provide the introduction of new, or adjustment of the existing measures based on the findings of the comprehensive analysis, including financial compensation given to the informal caregivers, as well as introduction of a pension and health insurance for caregivers. In the course of this process, it is necessary to take into consideration the experiences of the previously conducted projects, such as, for example, UNDP's project on Community Service; and
- Will envisage providing greater visibility of informal care and the informal caregivers within the existing legal and policy frameworks, as well as pre-conditions for improved integration of caregivers in the existing system of social protection, as well as the new system of long-term care.

» To comply with the principle of equality and non-discrimination of caregivers. Above all, it is necessary to adjust the legal framework for equality and non-discrimination in such a way that:

- It will introduce a form of discrimination - "discrimination by association", with the aid of which caregivers will be able to call on discrimination related to the personal characteristics or status of the people that they provide care for; and
- It will extend the application of the provisions for reasonable accommodation based on disability to also apply to caregivers, i.e. it will envisage that the prohibition of discrimination seen as the absence of reasonable accommodation should also

apply on caregivers by association. It is necessary to provide conditions for the obligation for reasonable accommodation to be considered activated from the moment when this need is reported by the caregivers (*rationale temporis*) to the employers, service-providers, civil services, or any other potential holder of this obligation, laid down within the comprehensive analysis (*ratione personae*). It is expected that within the framework of reasonable accommodation provided in this way, it is possible to introduce measures, such as, for example, flexible working arrangements, including the guarantee for a possibility to work part-time, work from home, and other compensations, e.g. compensation to a part-time job for caring for a child with a disability.

» To increase the visibility of the implemented activities related to long-term care, both in order to increase the awareness of the entire population in general, as well as in order to provide direct insight of the public into the data related to the implemented and planned activities and strategic goals. For example, respondents report the conducting of activities and measures for implementation of the national strategy for the elderly, along with regular drafting of reports, but these are not published, which impedes the monitoring of this area, including the implementation of scientific projects.

» To work on increasing the level of information about the possibilities offered by the system, as it is at present, about the existing possibilities – for example, that according to the law, a natural person may have a contract with the Center for Social Work to provide caregiving services or that the users of welfare may get activated and starting earning as caregivers in order to compensate for the lack of staff.

Ministry of Labour and Social Policy:

» To take the lead in the process of reviewing the legal and policy frameworks. Within this activity, apart from the implementation of the comprehensive analysis based on which the measures for improvement of the status of informal caregivers will be designed, according to the findings from our research, we would like to point out that it is necessary:

- To increase the financial compensation for assistance and care;
- To consider reviewing the documents necessary to exercise this right, as well as place the burden of their payment back to the state. It is also necessary to consider introduction of other benefits to these people, for example, exemption from payment of the broadcasting service, parking etc.;

- To work on moving away from the medical and towards the social model of understanding disability, in accordance with the obligations undertaken after the ratification of the International Convention on the Rights of People with a Disability. In addition, it is necessary to work on transferring the international classification of functioning from the office of UNICEF and the new assessments should be carried out in accordance with the remaining ability of the persons. Moreover, in relation to this, the comprehensive analysis should make it clear whether it would be useful to introduce levels in-between the presents ones to a higher or lesser extent;
 - To consider a possible revision of the existing limit to the monthly income in order to fulfill the right to a financial compensation for care and assistance from another person in order to minimize the possibility of depriving those people who need this from the fulfillment of this right. At the same time, it is necessary to revise the manner and calculation of income, from, for example, the mobility allowance, the blindness allowance, etc., which are money received in order to satisfy a specific social need. In addition, it is necessary to review the time-frame for assessment, i.e. now there is insight into the income for the past year, although it would be better to have insight into the past three months;
 - To introduce mandatory assistance by formal caregivers during the mornings, while the informal ones could take over the afternoons. This will make it possible for the informal caregivers to have a job;
 - To introduce respite care periods by using adequate comparative practices from other European Countries; and
 - To introduce the possibility to get the right to pension and health insurance for caregivers, as well as the right to an annual holiday.
- » To monitor and encourage the use of the legal possibilities in practice, among other things, also by means of an analysis of the obstacles and recommendations for their overcoming. For example, by providing care within the home;
- » It is necessary to expand the network of daycare centers in the municipalities in order to achieve equitable and increased geographical coverage of the entire territory of the state, by getting some of these institutions closer to the people who need their services. This will directly alleviate the work of caregivers;
- » To allocate an annual budget for the implementation of activities for elderly people and disabled people;
- » To receive information from the CSW about possible ways for permanent solution of some of the current challenges, to use their potential and knowledge from the local level and to support their efforts for increased action on a local level related to the help and support for caregivers, by means of introducing counseling services as one of the modes.

Centers for Social Work

» To have a key on-field role in the drafting of the comprehensive analysis, especially in the part of conducting the assessment of needs of both, the people who need care, and those who provide it. This should be done in a manner leading to the building of the capacities of CSWs so that after the assessment is completed, they will continue with the regular monitoring of the situation on field, which means that the implementation of this activity should be used to strengthen the human resources in CSRs;

» To reorganize the service-providers and service, on the basis of the needs and expectations of the informal caregivers and the people who need care and assistance;

» To conduct activities for the purpose of informing the informal caregivers and the people who need care about the existing measures and services, by means of extending the existing efforts to introduce counseling or by organizing open days;

» To design and conducts trainings for informal caregivers on providing care in the home in accordance with the findings of the conducted comprehensive analysis, alone or in collaboration with the centers specializing in providing care in the home;

» To work on developing measures for monitoring of the homes of the elderly, the daycare centers and other institutions where people who need care reside. This is of particular importance if we take into consideration the vulnerability of these people.

Centers providing assistance in the home

» In collaboration with the Ministry of Health, to take into consideration the past experiences with the health visitor teams visiting the people at risk and the elderly people, the experiences with the rural doctors, in order to design measures to provide care by medical persons in the home (focusing on the scope and quality). In

addition, it is necessary to take into consideration the possibilities to adapt “My Time” according to the needs of the caregivers in order avoid the limitation or prevention to the use of their right to healthcare, exactly because of the unpredictable nature of the responsibilities related to providing care; and

» To improve the access and quality of services, on a local level, to strengthen the capacities for long-term care by means of adjusting the services to the modern lifestyles, as well as by using the advantages offered by the modern technologies and social networks in order to achieve the goals of long-term care.

Institute for Social Affairs

» In accordance with the findings of the comprehensive analysis and the conducted analysis of comparative experiences, a special program to be drafted, including a code of ethics and work, as well as training modules. Within this, to lay down the points necessitating inter-sectoral collation, especially in collaboration with the Ministry of Health, so that this activity can be carried out with joint efforts; and

» In collaboration with CSW, to advertise the trainings and recruit the people.

Homes for the Elderly

» In collaboration with MLSP and other relevant institutions, to:

- Take part in the development and implementation of trainings for the elderly, among other things, also by means of enabling continual education of their employees who had not previously attended a training of this kind;
- Develop protocols for standardization of homes for the elderly; and
- Open info-centers for the elderly.

Civil Sector

» To encourage self-recognition of the caregivers and stimulate participation, both by self-representation, as well as by forming groups who will advocate the improvement of their position and rights (e.g. Association of Caregivers of the United Kingdom);

» To establish or help the establishing of support groups, web-sites, hotlines;

» To strengthen the connections and communication with CSW in order to take advantage of the full potential for joint work and activities, as well as implementation of projects;

» To monitor the current situation, the implementation of the legal and policy frameworks, as well as provide adequate information by correcting the information launched in public so that the citizens can be informed about what exactly has been done; and

» To inform about the existing measures and services and the access to them.