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# DEPRIVED OF RIGHTS OUT OF IGNORANCE

## Report on Monitoring of the Human Rights of Older People in Residential Care in Serbia

The Project is financed by the Delegation of the European Union to the Republic of Serbia under the EIDHR Programme

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Belgrade, September 2013

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## 1. ACRONYMS USED IN THE DOCUMENT

| | |
|---|---|
| AWC | Autonomous Women's Centre |
| BRA | Business Register Agency |
| CSW | Centre for Social Welfare |
| HC | Health Centre |
| EIDHR | European Instrument for Democracy and Human Rights |
| GC | Gerontology Centre |
| Ministry | Ministry of Labour, Employment and Social Policy |
| MIPAA | The Madrid International Plan of Action on Ageing |
| CSO | Civil Society Organization |
| PWD | Persons with Disability |
| PDI | Pension Disability Insurance |
| Rulebook | Rulebook on the Conditions and Standards for the Provision of Social Services |
| RHIF | Republic Health Insurance Fund |
| RS | Republic of Serbia |
| SIPRU | Social Inclusion and Poverty Reduction Unit of the Government of the Republic of Serbia |
| UN | United Nations |
| UNECE | United Nations Economic Commission for Europe |

## 2. INTRODUCTION

Monitoring of human rights of the older persons in residential care institutions in Serbia was carried out under the Project "For More Dignifying Life of the Elderly in Residential Care". The project is implemented by the Amity in partnership with the Autonomous Women's Centre (AWC) and in cooperation with the Social Inclusion and Poverty Reduction Unit of the Government of the Republic of Serbia, and with financial support from the Delegation of the European Union to the Republic of Serbia under the EIDHR Programme.

The objective of this Report is to determine the status of the human rights of the older persons in residential care institutions, which would serve as basis for creating the contents of educations on standards of the human rights of the elderly. Educations are intended for the members of civil society organizations (CSOs), older people in institutions and/or their guardians and the staff working most directly with the elderly.

Apart from that, it is foreseen this Report to serve as a foundation for creating recommendations for decision makers to establish and define standards on the rights of the beneficiaries accommodated in institutions, indicators of those standards and to ensure they are fully respected.

Monitoring of human rights was carried out in Jun-July 2013 with the approval of the Ministry of Labour, Employment and Social Policy (hereinafter referred to as: the Ministry). We chose the homes for the elderly for the monitoring visits[1] in cooperation with the Ministry.

During monitoring, the following methodology was used:

- Desk top analysis of the 2012 Synthesised Report on Work of Institutions for Accommodation of the Adults and the Elderly in Serbia from, as well as individual reports for five state-founded homes where monitoring was carried out;
- Desk top analysis of the international and national legal frame for respect for the human rights of the older people in residential care;
- Monitoring visits to 20 chosen homes for the elderly – 15 registered, privately-owned and 5 state-founded homes;
- Visits to two privately-owned homes which do not have the licence of the Ministry;
- Meetings with stakeholders (the representatives of the Ministry, Ombudsman, Republic/ Provincial Institute for Social Protection, Commissioner for Protection of Equality, Ministry of Health, UNDP and OEBS Mission to Serbia).

In May 2013, the basic monitoring team of three experts (for social aspect of the life of the older people in institutions, for medical aspect of human rights of the elderly and for women's rights and gender equality), was created. They visited all of the chosen institutions. The representatives of CSOs working with the elderly, persons with disabilities (PWD) or women, which were located in the same place where the homes were, joined the basic team.

At the beginning of June 2013, the letters of cooperation and visit announcement were sent to the managements of the homes. Cooperation was established with 17 out of 20 originally planned homes – two homes did not have the beneficiaries (Home "Zlatiborska dolina" of Cajetina and "Akvaten" of Alibunar), while the Home for the Elderly and Nursing of Older Persons "Dolce Vita Kej" of Zemun refused cooperation. We have included other three homes, two on Amity's invitation and one (Home for the Elderly "Gala" of Novi Slankamen) on the owner's invitation.

We announced the visit 24 hours ahead, and the on the occasion or the next day during the visit we distributed the Questionnaire in connection with the structure of the employees and beneficiaries of the institutions to the management, as well as the one about accommodation capacities, with the kind request to fill it in and return it to us.

1 Term homes (for the elderly) here includes both nursing homes and retirement homes

Visits to all 20 homes (the list in Annex 1 of the Report) were structured in similar manner. Team would, first meet with the management of the institution (usually the director/owner, social worker, medical doctor, chief medical technician). We have talked to total of 71 members of the management and staff of the institutions. During the short conversation, the Team Leader explained the objective and structure of the visit and announced the further steps. This time was also used for presentation of the instituion, employees and beneficiaries by the manager or other relevant person. Then the Team divided itself. The expert at social aspect, first talked to the manager/owner and social worker, and then had a tour around the home in order to gain direct insight in housing conditions and services and to discuss with some of the beneficiaries, as well as with visitors who were at the home at the time and who wanted to talk. The medical expert talked to the medical doctors and health workers, and then, in their company, visited the beneficiaries and the institution. The expert at the gender aspect talked to the female beneficiaries of the home, while the members of the CSOs talked to the beneficiaries of both gender. All interviews were carried out on the basis of previously prepared, semi-structured Questionnaires. We talked to 161 beneficiaries who wanted and were capable to talk to us.

At the end of our visit, the Project Team would meet with the management again, give short feedback on its impression and suggestions to the management, and asked for additional explanation for doubts, if any. In all of those homes, with the approval of the management, we made photo documents about conditions and moments of the life of the beneficiaries.

Visits to the privately-owned homes that do not have the licence issued by the Ministry were additionally included in the plan on the basis of information received during the planned monitoring visits. We have selected two out of 21 homes of Belgrade who advertised on the internet. We announced visits by phone, with the explanation that we were looking for the accommodation for older person.

The Report largely relies on the notes from monitoring visits to the registered homes and conversation with the managements, staff and beneficiaries, data received from the management of homes and notes from two homes that are not registered as social protection institutions.

The most important conclusions of monitoring visits to the registered homes are that the beneficiaries accept accommodation as ‘a necessary evil’, that even though they live in fairly good physical conditions, they are usually “isolated” from local community, the guarantees of their human rights are insufficient, and that their rights are neglected more out of ignorance of the staff, and the elderly themselves, rather than intentionally.
The conclusion of informal visits to two unregistered homes is that there are older people locked in there, who live in far worse conditions for insignificantly less money, without any guarantees of their human rights.

## 3. INTERNATIONAL LEGAL FRAMEWORK

We will focus on the most important documents and activities of international organizations (United Nations, the Council of Europe and the European Union), which are binding or are the recommendation to our country in connection to respect for the human rights of the elderly, with a particular focus on the human rights of the elderly who are in residential care in social care institutions.

There is no convention at the universal or the European level, which is entirely dedicated to human rights and dignity of the elderly. However, there is an initiative of the United Nations, under which, at the beginning of 2010, the Human Rights Council Advisory Committee prepared a working paper on "the necessity of introducing approaches based on human rights and the effective mechanism of the United Nations for human rights of the elderly," which suggests the international treaty, as a framework for standards and as a basis for reporting and supervision mechanisms.

In July 2011, the Secretary-General issued a report to the General Assembly, in which the focus is on the human rights of the elderly and four major challenges the elderly are facing in connection to their human rights (discrimination, poverty, violence and abuse, and lack of specific measures and services) were identified.

Despite the lack of specific convention, there are numerous obligations to older people and human rights instruments that apply to the elderly, in the same way as all to other people, providing them with protection of basic human rights, including the right to the enjoyment of the highest attainable standard of physical and mental health, freedom from torture or degrading treatment, and an adequate standard of living, without discrimination on any grounds.

The complete document presented selections from the following international instruments:

- The Universal Declaration of Human Rights (1948) , a binding document
- The United Nations Principles for Older People (1991) - Aneks/REZ/46/91
- The Basic Ethical Principles in Working with Older People with Mental Disorders of the World Psychiatric Organization
- The Convention on the Rights of Persons with Disabilities and its Optional Protocol (2006), a binding document
- The Political Declaration on Ageing and the Madrid International Plan of Action on Ageing (MIPAA)
- The Convention on the Elimination of All Forms of Discrimination against Women (1979), a binding document
- Extract from 57th Session of the UN Commission on the Status of Women (4-15th March 2013)
- The European Convention for the Protection of Human Rights and Fundamental Freedoms (1950)
- The European Social Charter - Revised (1996) - a binding document
- From the conclusions of the Council of Europe Commissioner for Human Rights from the Seminar on Human Rights and the Special Situation of Older People in Nursing Homes or Institutions (2001)
- From the 2012 Vienna Ministerial Declaration - Ensuring a society for all ages: Promoting quality of life and active ageing

## 4. NATIONAL LEGAL FRAMEWORK

The full report analyzed following national documents:

- The Constitution of the Republic of Serbia (2006 )
- The Anti-Discrimination Law (2009)
- The National Strategy for Improving the Position of Women and Promotion of Gender Equality (2008-2014)
- The National Strategy for Preventon and Fight against Domestic Violence and Intimate Partner Violence against Women
- The Law on Social Protection (2011)
- The Health Protection Law (2005 including amendments from 2009 to 2013)
- The Law on the Protection of Persons with Mental Illness (2013)
- The National Strategy on Ageing (2006-2015)
- The National Strategy for the Development of Mental Health (2007)
- The Strategy for Prevention and Protection from Discrimination (2013)
- The Rulebook on the Conditions and Standards for the Provision of Social Services (2013)
- The Rulebook on Prohibited Conduct of Employees in Social Protection (2012)
- The Regulation on the Network of Social Protection Institutions (2012)
- The Rulebook on Licensing Welfare Organization (2013)
- The Rulebook on Keeping Records of Users and Documentation of Professional Work in Social Care Institutions

## 5. BENEFICIARIES AND HOUSING CONDITIONS IN INSTITUTIONS

*Older people in Serbia*

Demographic statistics of many countries demonstrate already established tendency of society aging, particularly associated with the societies of European countries, among which Serbia is pointed out as one of the countries with the oldest population. Average age of population in Serbia is 42.2 years, which makes us demographically "old" country. According to 2011 Census, Serbia has 7,186,862 citizens, with 1,250,316 (17.40%) of them of 65 plus. Share of the older persons of 80 plus increased from 1.94% (2002 Census) to 3.59%, i.e., from 145.5 thousands to 258 thousands in 2011. It is indicative that according to 2011 Census, every ninth household is a single elderly household – 278,121, i.e. 11.2% of total number of households in Serbia.

Economic crisis our country is in, contributes additionally to annual increase of the number of older people entering the social welfare system. Therefore, in 2012, nearly 100,000 older persons of 65 plus were included in social welfare system. Out of that number, approx. 10,000 are those who use residential care services of 48 state-founded homes.

In Serbia, in 2013, there are 48 state-founded homes with the capacity of 8,837 beds for the adults and the elderly and 100 registered privately-owned homes with the housing capacity of approx. 3,000 for the elderly. There are numerous "illegal" homes for the elderly, which are not licensed as social protection institutions. We do not know their exact number or housing capacity.

Current capacities (of officially registered institutions) for accommodation of the adults of 26 to 65 and the elderly of 65 plus all together are approx. 12,000 beds. We do not know how many of those 12,000 are intended to the elderly exclusively, but even if we assume that all of the capacities are being used for the elderly, they do not cover even 1% of the population of the elderly. Institutions for the adults and the elderly established in this manner do not correspond to the institutions in European countries, where the institutions for the elderly of 65 plus are separated. All of the statistics and monitoring reports use uniform information; therefore, our data are not comparable. Anyhow, in European countries, capacities of residential care institutions cover 4-5% of the population of 65 plus, and are the highest in Netherlands and Switzerland (for 8, i.e. 7% of the elderly, respectively). Only Bulgaria, Romania and Armenia have lower accommodation capacities than Serbia.[2] Even though our cultural environment is completely different, and accommodation to social protection institution is the last option for older person or the family nowadays, current capacities for residential care are still insufficient.

For the needs of monitoring, we visited 20 institutions where 1,610 beneficiaries live, 950 of them in 5 state-founded and 660 in 15 privately-owned homes. The sample was representative (12% of the beneficiaries accommodated in state-founded institutions[3] and 22% in privately-owned homes).

During conversation with the beneficiaries and staff we confirmed previous findings that "the rule is that the elderly in Serbia go to the gerontology centres and homes for the elderly, only if and when they become unbearable burden to their families and when due to their health and general condition, no one can take care of them any more[4]". Unlike 30 years ago, when older people, mainly from urban areas came to homes, still relatively active, to solve their housing problem and enjoy with their peers if they did not receive the apartment while in service, today's story is totally different. People come to privately-owned homes due to illness or immobility, when all other home care options are exhausted. The elderly from rural areas also come, especially in cases when their relatives are living

2 Facts and Figures on Healthy Ageing and Long-term Care, Europe and North America, European Centre for Social Welfare Policy and Research, European Centre for Social Welfare Policy and Research, 2012, page 84

3 State-founded homes, according to the 2012 Synthesized Report on Work of Institutions for Accommodation of the Adults and the Elderly in Serbia, on December 31, 2012, there were 8,171 beneficiaries, Republic Institute for Social Protection, Belgrade, June 2013

4 Ombudsman's Report on Supervision in social care institutions for residential care of the elderly in 2010, page 72

and working abroad. State-founded homes accommodate significantly younger persons, mainly from psychiatric institutions, and there are the beneficiaries who are accommodated into the homes merely from social-economic endangerment (nearly 10% of them). In most cases, home is final solution, “a necessary evil”.

Beneficiaries of the homes can be divided in two basic groups: to those who came to the home of their own free will and by personal decision to continue their life in institution, because they realized they had no other choice while the other group of the beneficiaries are thosewho were talked into coming by their relatives, and in some cases they came without even being talked into, i.e. they were forced to come. The first group demonstrated positive attitude towards the life in institution. The other, not so small group of beneficiaries, who came against their will, and sometimes without approval, demonstrated totally different attitude towards the life in institution, they were mainly unsatisfied and would like to leave, but they were not able to or had nowhere to go to.

*„It was hard for me to accept life in Home... But when I compare it...My child left me, so how could I expect more here...“* (beneficiary, GC Sombor)

*„Accommodation was my daughter’s decision. I accepted it for my house was on sale, so there was no place for me there any more.“* (beneficiary, Home Vozdovac)

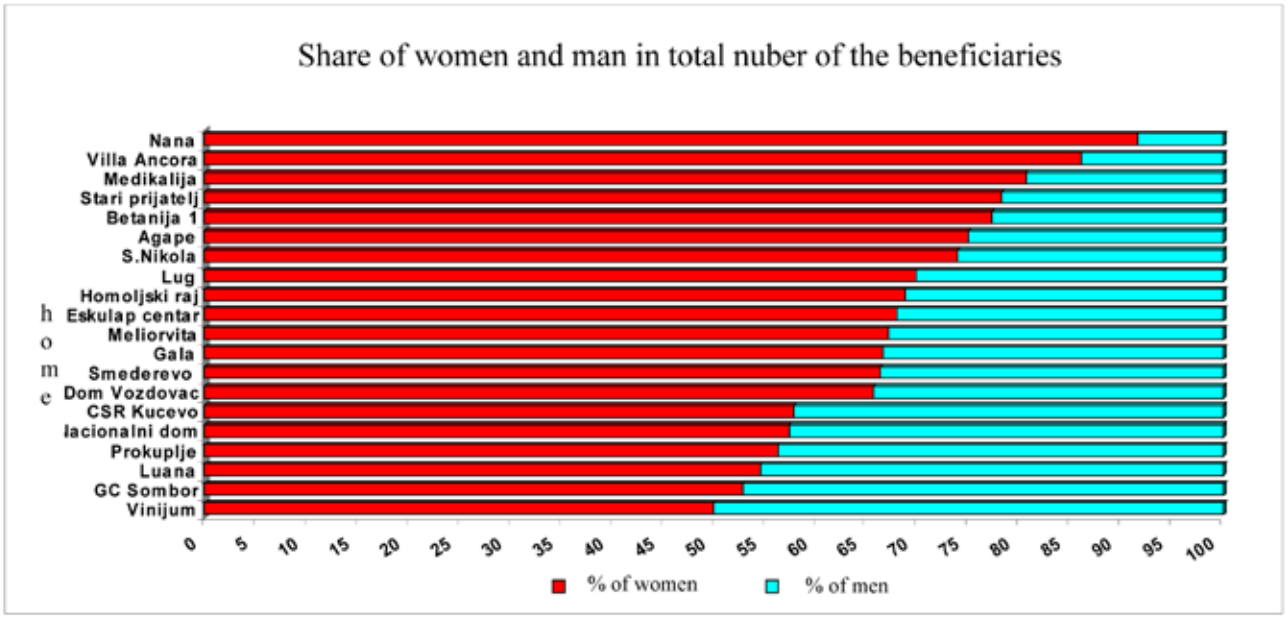
*„Yesterday, we found out that our son arranged with the owner for us to stay here permanently and we are still shocked. We want to go back home.“* (married couple, privately-owned home)

Mutual for all visited institutions is that their beneficiaries are mainly women (2/3 – 65%), most of them are widows/widowers (53%) and that they usually come to home from the elderly households (70% - out of which 57% lived alone, and 13% with the spouse).

What is not common for all homes but is characteristic is that nearly 50% of the beneficiaries are fully dependant on other persons care and help, almost a third are with dementia – over 50% are in privately-owned homes and approx. 15% in state-founded homes, a significant number of the beneficiaries has closest relatives abroad and many of them come from rural areas, especially in homes outside Belgrade area.

Share of women in visited homes varies from 50% in privately-owned Home Vinijum to over 90% in privately-owned Home Nana of Belgrade.

Graphic 1: Beneficiaries according to gender



Relation of the number of women and men in homes is not proportional to the share of women in general population of the elderly, where they make 58%[5]. One of the reasons for significantly larger number of women in institutions is their poorer health status comparing to their peers, caused by biological factors[6], which forces them to look for support in institutions for the elderly. Women come to homes more often because they "sacrifice more easily" for their children and grandchildren, they do not want to disturb them, they leave their apartments to them and accept "silent isolation" in institution.

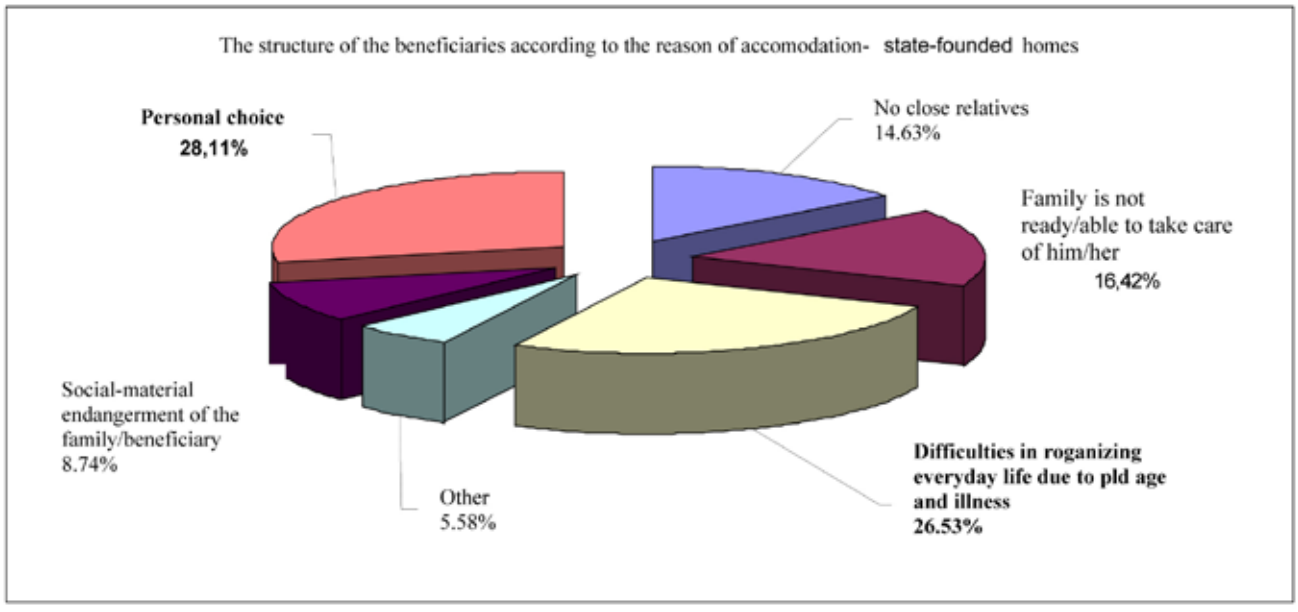
Majority of 119 women we talked to stated that it was not their desire to come to home, but it was usually the choice of their children and closest relatives, either for they could not get organized and provide needed support or they needed additional housing space or they wanted to sell the apartment for settling the material problems they were in.

*„My son tricked me. He didn't tell me where I was going, brought me here. I didn't even know. They keep me for nothing, they are only taking my money for nothing."* (beneficiary, privately-owned home)

*„The social worker brought me here when my sister died. Made me crazy and loony. I did not sign anywhere and did not want to go to any homes..."* (beneficiary, state-founded home)

*„I did not want to come, I wanted a woman to take care of me, but my son-in-law brought me here, his parents were in a home..."* (beneficiary, privately-owned home)

Graphic 2 Reason for accommodation – state-founded homes

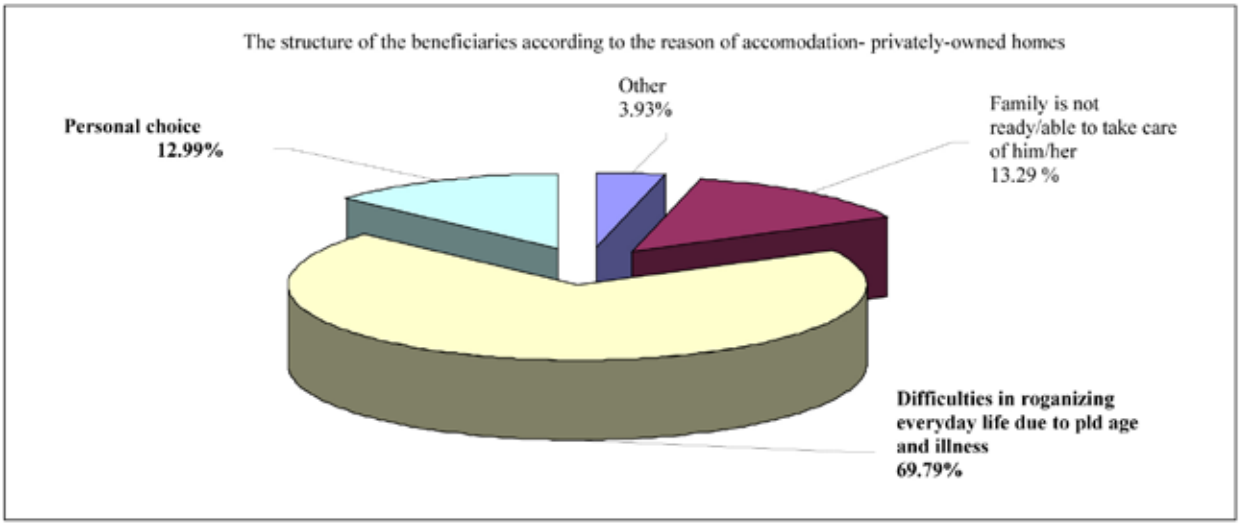



As the most frequent reason of accommodation to state-founded homes, employees stated the difficulties in organizing everyday functioning due to old age and illness (approx. 26%). In addition, it was said that for only 28% of the beneficiaries coming to home was a personal choice. It is alarming that beneficiaries come to home due to social-material endangerment of the family (almost every tenth). Centres for Social Welfare in cooperation with the beneficiary should try to find other solutions for support to those persons in local community.

5 Total number of older people is 1,250,316, out of which 723,249 are women, according to the Census in Serbia from October 2011.

6 Non-institutional Care for the Elderly in Serbia – Gap between needs and options, N. Sataric, M. Rasevic, Belgrade, 2007, page 29

Graphic 3 Reason for accommodation – privately-owned homes

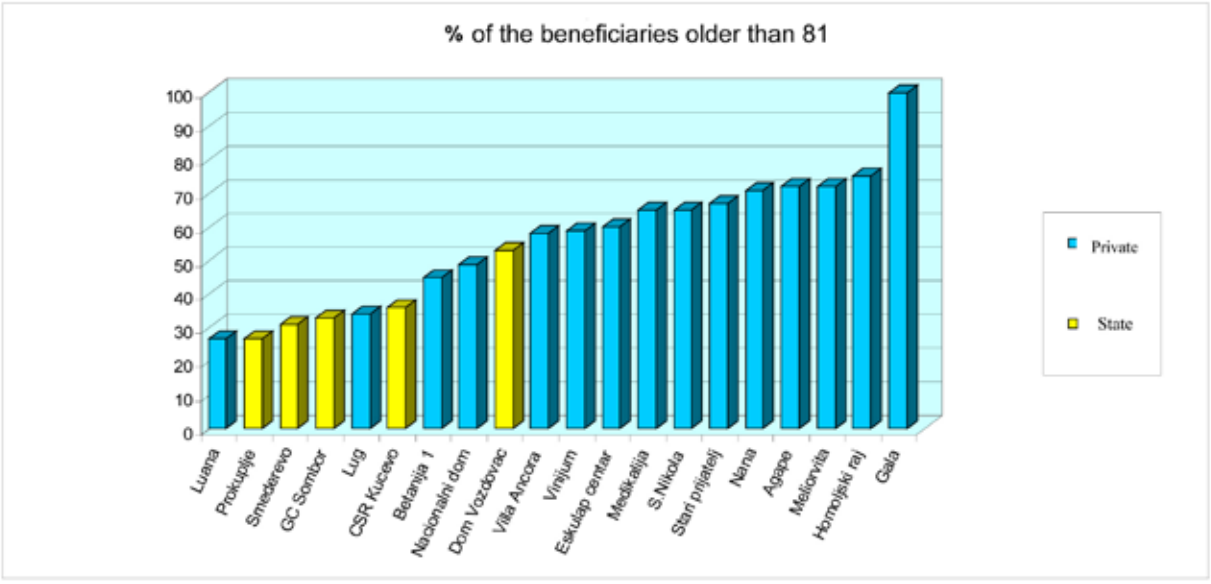



People are accommodated to privately-owned homes in 70% of the cases due to the difficulties in everyday functioning caused by old age and illness. This was confirmed by situation we encountered in the visited homes – persons accommodated there were those who would hardly be able to function without constant care and supervision by others.

We are concerned by the fact that accommodation to the privately-owned home was a personal choice of merely 13% of the beneficiaries, according to information provided by the staff. This could be justified partially by the fact that privately-owned homes accommodate large number of the beneficiaries with dementia, but it should be considered that those persons, depending on the degree of the progress of their illness can make ecisions (mental illness itself does not mean full lack of capacity of making decisions).

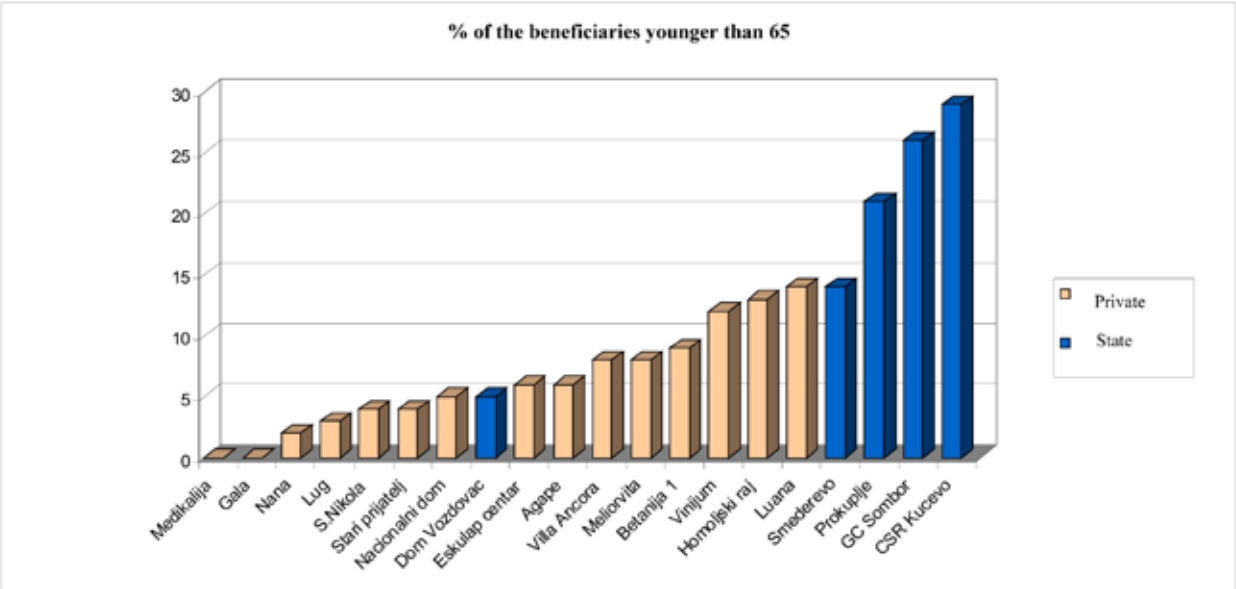
When it comes to age, dominant among the beneficiaries are those of very old age, with the larger number of them in privately-owned homes, where the average age of the beneficiaries is 80 plus (up to 56% of them are 81 or older). In state-founded homes, the average is bellow 80 years of age, with only 38% of the beneficiaries older than 81.

Graphic 4 Beneficiaries older than 81



Every fifth beneficiary of the state-founded institutions is younger than 65. The largest number is in Kucevo, where every third beneficiary is younger than 65, while in privately-owned homes, only every twentieth beneficiary is in that age category.

Graphic 5 Beneficiaries younger than 65




The reason of this large number of younger beneficiaries in state-founded institutions is in legislation, i.e. in the Social Protection Law (article 63 – The Network) and the Directive on the Network of Social Care Institutions from 2012. Those documents regulate that the homes for the adults and the elderly accommodate the adults (of 26 to 65) and older people of 65 plus. In practice, it means that the number of younger persons significantly increased in state-founded homes, because they "are forced to accommodate" significantly younger beneficiaries, including those with psychiatric disorders. As a part of deinstitutionalization of the institutions for the children and the young, a number of adult beneficiaries who can not be provided with more adequate accommodation is being transferred to the home for the elderly – they move from one institution to another. Additional problem is that in some regions there are no psychiatric institutions, so the patients are sent to the home for elderly, as in case of GC Sombor.

> *"Those are psychiatric patients, 50% of them, many are alcoholics, those who could not be accommodated in psychiatric institutions, for there aren't any in the region, so everyone presses us to accommodate them. Those beneficiaries get injection of Moditen depot, once a month, "not to be aggressive". The youngest beneficiary on the inpatient care unit is 31 and the oldest one is 92."*[7]

> *"The biggest problem in Home's operation is that there are practically no contraindications for accommodation. We accommodate persons with psychiatric diagnosis as well as those completely mentally preserved, those very young, as well as those who are old. Later, it becomes a problem, because the staff is not trained in treatment of psychiatric patients or working with the young who have completely different needs comparing to the elderly. The youngest beneficiary of Home in Smederevo was born in 1962 and the oldest in 1919."*[8]

7 Interviewee from the Gerontology centre Sombor
8 Interviewee from the Home for the elderly and pensioners Smederevo

The representatives of the state-founded homes of Prokuplje and Kucevo pointed out those problems, too. Situation is such that it leads to 'burnout syndrome' among employees, because they are doing their best to hold everything under control in the institutions, but it is often impossible. They consider it necessary to separate age categories, especially those who are psychiatric patients.

The largest number of the homes' beneficiaries belong to the group of pensioners (81%), and out of the financially supported persons, every fourth beneficiary lives in state-founded and every 16th in privately-owned homes.

The recommendation to the Ministry is to make supplements and addenda to the Law on Social Protection in a manner to addend current regulations of the article 63. The Network, which in paragraph 2 stipulates that "Social protection institutions which provide residential care services – home care services are established as institutions for the children and young or as institutions for the adults and older persons", which should be altered in a manner to regulate that Institutions for residential care of the elderly are established as institutions which cover only this target group.

In connection to educational status, every fourth beneficiary of the homes is without official education (school), with the significantly larger number in state-founded homes (37%), unlike the privately owned ones, where there are less than 6% of them. This is important for the institutions to bear this in mind when they work on informing the beneficiaries, because they most often do it by posting information on notice boards, usually with insufficiently large letters. It is necessary to establish availability of information in form and manner suitable to communication abilities of the beneficiaries.

Almost every third beneficiary has dementia, with the significantly larger number of them in privately-owned homes (over 50%), unlike state-founded ones, where the percentage is 15%. There are much more women among the beneficiaries with dementia.

Every 20th beneficiary has made an Agreement on lifetime support - the larger number of the beneficiaries in privately-owned homes, out of which, some have signed the agreements with the owners of the homes. Managements of some privately-owned homes promote signing agreements on lifetime support with the beneficiaries on their websites. We are concerned about indications that there are elements of exploitation of the beneficiaries, because the beneficiaries in subordinate position comparing to the position of the owners of the institutions and that misuse of trust and power can occur, i.e. use of the financial and other funds of the beneficiaries for personal gain.

The Recommendation to the Ministry is to addend the Rulebook on Forbidden Actions of the Employees in Social Protection in a manner to rename the document to the Rulebook on Forbidden Actions of the Institutions and the Employees in Social Protection. In addition: article 10, which refers to forbidding exploitation, should be supplemented in the first paragraph, which is: "Employee is forbidden to exploit the beneficiary" in a manner to say "Institutions and employees are forbidden to exploit the beneficiary".

It is necessary to increase supervision in homes in order to prevent exploitation of the beneficiaries. This can be done in a manner to clearly define mechanisms of control and to envisage independent monitoring in order to enable full respect of the rights of the beneficiaries.

Out of the beneficiaries in visited homes who were accommodated in homes during the first six months of 2013, according to information received from the persons we talked to, for one third the accommodation has been terminated. Every fifth beneficiary died, and among other reasons are return to the family/home or transfer to another home.

## Procedure of Admission into the Social Protection Institution

*Oriented towards Interest*

State-owned homes have highly bureaucratic admission procedure, unlike the privately-owned where everything is much simpler and sometimes without respecting the standards.

Privately-owned homes act in very pragmatic way, require much less documents, even though the rules vary from home to home. For some nursing homes, you need to provide two, three documents with the request (copy of ID card and health insurance card) and, possibly, the current medical history/ records. Some ask for the Extract from the Birth Registry or Marriage Registry, neuro-psychiatrist's findings, while some ask for the pension check, Agreement on Lifetime Supporting and Certificate on Deprivation of Legal Capacity, if the beneficiaries are with dementia.

Documents are submitted directly to Home, where usually the relative simultaneously gains insight in conditions and talk about the accommodation with the person in charge. In significant number of cases, older person is accommodated without previously even seeing neither Home nor conditions where he/she will live. It is done for him/her by one of the relatives, guardians or the third person. If there are available capacities, admission will be carried out on the same day or the next day, as previously agreed.

Documents needed for applying for accommodation in state-founded home is significantly larger. It is necessary to collect at least 13 documents[9] which are submitted to the Centre for Social Welfare (CSW) in the municipality where the potential beneficiary has residence. The deadline for CSW to make decision on referral of the beneficiaries to social protection institutions is a month if the referral is on official request, and two months[10], if the request is filed by the beneficiary or someone on his/ her behalf, with the obligation of the older person to come to CSW to an interview in the meantime. Then, complete documentation is referred to the institution, where expert associates are obligated to carry out admission/initial assessment in the period of 15 days after receiving the request. After that, care provider is obligated in 7 day period to inform the applier on the outcome of the procedure, which includes information on the beginning of the service, registering on waiting list or reasons for possible refusal of accommodation.[11]

This large and long-lasting administrative procedure is one of the reasons why relatives or guardians prefer accommodation of their elderly in privately-owned homes. This is specially common in cases where the relatives live and work abroad, and they come to Serbia only for few days in order to take

9 Request of the Party; copy of personal ID card – 2 copies; copy of the Extract from the Birth Registry -2 copies; Citizenship; pension check, if he/she is pensioner or certificate from PDI Fund that he/she is not a beneficiary of the pension; certificate on property; health certificate; neuro-psychiatry findings; infective diseases test results, including Wasserman despite the opinion of the Batut Institute that it is not needed for the elderly; X-ray of the lungs with description; copy of health insurance card; Statement of Consent of the older person for accommodation to nursing home, and if the request is submitted by the person under custody, it is necessary to submit the Decision on Custody and Guardian's consent; copy of relative's ID card and income sertificate for the previous three months for the relatives who participate in accommodation costs

10 In practice, CSW counts two months from the moment of submitting the complete documentation, not from the moment of submitting the request when someone comes for the first time, as stipulated by the Law (personal example od accommodation via City CSW of Belgrade – Department of Surcin)

11 Rulebook on the Conditions and Standards for the Provision of Social Services, Article 12 – Admission of the beneficiaries.

care what is necessary to accommodate older person in home. But, not only for them, but for all of those who personally pay from their own funds and where no additional payment made by the State is required. We received confirmation of this from the relatives/guardians of older people themselves, whom we talked to during out visits to homes for the elderly.

*"...I did not understand why I had to go to CSW, when we pay for our mother completely. But the second reason was that when I heard what I needed of documents, I gave up immediately, because I came from Vienna for only two weeks. I went to see three privately-owned homes, and I preferred this one." – the daughter of the beneficiary of the privately-owned home in Belgrade.*

The other reason why people chose privately-owned home is longer waiting period for accommodation in state-founded homes, and problems when accommodating persons with dementia, somewhere they do not accommodate the persons who can move, and somewhere you have to wait long like at Home on Bezanijska kosa, which is the only home in Belgrade that accommodates persons with dementia. There are too many patients on one location and they are separated from other beneficiaries, which is not good because inclusion and spending time with those who are not with dementia helps slower development of dementia.

"*They asked for lot of documents, and it was difficult for me to deal with it... and the other reason why we decided to go to the private Home was that my daughter went to Bezanija (home) where persons with dementia were, and she saw a lot of them in the basement premises and did not like it." – the spouse of the beneficiary of the privately-owned home in Belgrade.*

The recommendation to the Ministry is to suggest supplementing and amendments of the Law on Administrative Procedure in a way to shorten the period of solving requests by CSW in cases when the beneficiary requires accommodation from two months to maximum duration of one month.

The second recommendation is to reduce administrative procedure (number of documents needed for admission, especially in cases when state's participation in the costs is not needed) and that the potential beneficiaries who pay full amount, without participation of the budget funds, sign Agreements on Accommodation with the home directly not with CSW.

The recommendation to the owners of private homes is to enable that the future beneficiary, unless he is deprived of legal capacity, surely visits the institution before the final decision on his/her accommodation is made. If the future beneficiary is in hospital or bed-rodden at his/her home, and cannot come to visit the institution, it should be enabled that someone of institution's staff to visits the beneficiary and discusses with him in details about the long-term care transit.

Emergency accommodation should be avoided as much as possible.

The recommendation is, actually to always carry out the initial assessment of the beneficiary in accordance with the article 12 – Admission (Joint structural minimal standards of the Rulebook)

## Accommodation Conditions in Visited Social Protection Institutions

*Extremely polarized*

From the aspect of respect for the human rights of the elderly, it is important that in institutions the older people are accommodated to, their safety and security is ensured, that everything is available to the persons with disabilities (PWD), that the rooms are wide enough, light and not overcrowded, that domestic atmosphere is present, that the furniture is comfortable and adapted to the needs of older persons, that heating is adequate, that water supplying is constant, that there is enough space for day-care centres and working-recreational activities of the beneficiaries, that there is enough green space and walking paths and that the object is located in the residential area with the developed infrastructure.

There are important differences in accommodation conditions in the homes we visited.

Some homes have very good housing conditions. Quality of the equipment, beds and other furniture in the rooms is adapted in accordance with the needs of the elderly; inpatient care units have modern medical beds, which are adequate both for the beneficiaries and for the staff providing care. Each room has television and phone, signal device for calling the staff on duty, bathroom is in every room where the independent beneficiaries are, heating is good, and homes Villa Ancora and Medikalija have floor heating, etc. Rooms, studios or apartments are mainly single or double-bed rooms, except from the stationary units, where three/four beneficiaries are in one room. Number of toilets and sinks are sufficient. Objects are painted in various, light colours, premises are available to the persons with disabilities (there are handrails, ramps, elevator, etc.), corridors are wide, as well as the doors leading into rooms, no doorsteps on entrance to room or exit to the balcony. There is equipment for serving food in bed, grab rails above beds and screening is provided for care in the rooms where persons with physical impairments are accommodated. There are large, light and well-equipped common premises, as well as occupational therapy and physical therapy provided to, with all necessary materials and devices. Our impression is that, among the visited Homes, the best accommodation conditions are at: Villa Ancora, then Medikalija, Nacionalni dom, Agape and Vinijum.

Accommodation conditions in other visited institutions are, in most cases, in accordance with the minimum of standards, but the equipment and furniture in state-founded homes are old, as well as the facilities, which were built in the second half of the 20$^{th}$ century, unlike in those purpose-built, privately-owned homes which were built in past 10 years or so.

We have noticed that some of the privately-owned homes have small rooms for the number of beds in them (such as Betanija 1 – four-bed rooms are overcrowded by furniture so that the beneficiaries can hardly pass between beds, Gala – some rooms are small, all in ceramic tiles, windows of non-standard size, i.e. too small, Eskulap centar, with small two-bed rooms, as well as Nana and Meliorvita). Standard is that muliple-bed rooms should have at least 5m$^2$ per beneficiary, and single-bed rooms at least 10m$^2$ (Article 34 of the Rulebook). Lack of common premises, premises for visits and work therapy is also evident (e.g. in Luana where the only common room is the dining room of the ground floor, without TV or any other adequate contents and where the beneficiaries do not dwell apart from having meal; then Betanija 1, where only common room is the dining room with the table and chairs with one sofa, which is insufficient for the number of the beneficiaries; Eskulap centar, where common rooms on each floor are small but the balcony on the ground floor is adequate).

Some homes do not have chairs for each beneficiary accommodated in the room, and some have small storage space for personal belongings.

Some of the rooms in privately-owned homes have appearance of temporary not the of permanent housing, which is not good, because older people are neither in the hospital nor hotel, nor just passing through, most of them should spend the rest of their lives there, and regardless of their age, they have the right to enjoy domestic atmosphere and it is necessary to enable it to them.

*"Same room from the beginning, but small for three of us. But I wouldn't like to change my room." (the beneficiary from the privately-owned home)*

*"I constantly pray to get better and go home. There's no place like home." (the beneficiary from the privately-owned home)*

*"I cannot go anywhere. Nobody comes, but I do not invite them to, the room is small, you see, there is nowhere to sit..." (the beneficiary from the privately-owned home)*

In some homes, availability is not adequatly provided for the persons with disabilities (e.g. Homoljski raj, where the house has 3 floors, no elevator, and stairs are narrow and steep and not adequate for the beneficiaries who have serious moving difficulties; or S. Nikola where bed-ridden beneficiaries are accommodated on the upper floor, and it is impossible to transport them in the wheelchair across the rails set on the staircase; or Nana, where is no elevator in the house, staircase is steep, so that semi-mobile and bed-ridden beneficiaries are not able to come down to the garden and spend time there). Some of the beneficiaries have not left their rooms since the moment of admission – year and a half.

> *"I'm bed-ridden and when there is no elevator, it's impossible..."* (answer to the question whether she leaves the Home or not)
>
> Heating is not always adequate.
>
> *"Heating is not always good here, and I'm sometimes cold."*
> *"When the weather became better, but still was cold in the room, I turned the heater on, but the housekeeper came and took my heater. It hurt me..."*

There is no screening for care and personal hygiene of the bed-ridden beneficiaries, no grab rails above bed, no equipment for serving food in the rooms where the beneficiaries with physical impairments are accommodated.

All visited homes have visible evacuation plans in case of fire, and according to persons we talked to, fire protection educations for staff are being organized.

Hygiene is very good in some of the visited homes, correct in others and you can rarely smell urine.

All of the visited homes have gardens with green areas[12], but they are in some cases large and very nicely decorated, with a lot of greenery, flowers and benches for sitting, as in Villa Ancora, Lug, Meliorvita, Homoljski raj, Nacionalni dom, Home department of CSW Kucevo, that enables independant beneficiaries to spend a part of their time enjoying nature. Home Smederevo has very nicely arranged garden but it is too small for the large number of the beneficiaries. Home Eskulap centar apart from their garden, has part with domestic animals (peacocks, ducks, turkeys, chickens, dog, etc.). Homes Kucevo, Homoljski raj, S. Nikola have gardens in their yards where the beneficiaries, who want to and are able to, to raise vegetables.

12 Except from GC Sombor, which does not have yard, but there is the Public Park behind the facility.

When it comes to accommodation capacities, the smallest capacities are of Home “Gala” (15 beneficiaries) and the largest capacities are of GC Sombor (310 beneficiaries). Capacities of state-founded homes are larger - from 150 beneficiaries up, while those in privately-owned homes are 50 beneficiaries in average, and the largest capacity, and the only one with more than 100 beneficiaries has Home Lug (150 beneficiaries). Law on Social Protection stipulates that the institution for accommodation of the adults and elderly cannot have the capacity larger than 100 beneficiaries. The Government of the Republic of Serbia did not obey the Law in its 2012 Decision on the Network of institutions where it determined the maximum of allowed capacities for each institution, where in significant number of cases, they are far over the stipulated and go up to 550 beneficiaries in Home Bezanijska kosa.

Institutions with larger number of the beneficiaries are mainly considered less human than those of smaller capacity. However, it does not always have to be like that, it all depends on the quality of service, organization of work of the staff and life of the beneficiaries, the way the staff deals with the beneficiaries, their relation with the beneficiaries. Bigger problem is accommodation of the larger number of the beneficiaries in the rooms of insufficient space or insufficient number of toilets. Overcrowded are homes where the beneficiaries are accommodated in five-bed rooms, such as in inpatient care units of GC Sombor (13 five-bed rooms) and Home Prokuplje (2 five-bed rooms) as well as in Home Smederevo, which also has 2 five-bed rooms. Current standards determine that rooms cannot have more than four beds, so those homes will have to reduce the number of beds in those rooms. The significant problem represents the fact that in some homes there are not enough showers for all beneficiaries. The standard is one shower per 10 beneficiaries (Article 43 of the Rulebook).

The recommendation to the managements of the state-founded homes for accommodation of the adults and elderly is that if they have inpatient care units in their setting, to re-register them as special organizational units such as social-health care institutions as stipulated by the Law on Social Protection (Article 60) in cases when: “For the needs of the beneficiaries who due to their specific social and health status have need for social accommodation and continuous health protection or supervision (institution) can be founded as social-health institutions.“

For other parts of institutions which are not of inpatient care or semi-inpatient care type, but have the capacity of more than 100 beneficiaries, the recommendation is that organizations divide themselves into separate units in accordance with the categories of the beneficiaries to fulfil the social protection regulation that the institution for accommodation of the adults and elderly cannot have the capacity over 100 beneficiaries.

It is necessary to join efforts of the Ministry of Labour, Employment and Social Policy and the Ministry of Health, to pass separate Rulebook on Special Criteria and Standards for Providing Services in Social-Health Care Institutions. The reason for this is the fact that the beneficiaries of those institutions require larger number of nursing staff and other employees, especially health workers for providing services comparing to the number stipulated for social care institutions.

General impression is that privately-owned homes, in most cases, resemble more to health institutions and they are, practically more focused to providing care, health care and palliative care services, where the cancer patients and other dieing patients are nursed (care of the dieing). In most of those homes, despite high level of hygiene, there is no personal touch of the beneficiaries, so everything looks “sterile” and hospital like. There are no life-meaning details important to the beneficiary on night cabinets – photos, details, souvenirs from travels, etc. Walls have no paintings, etc. Not enough attention is paid to the individual preferences and desires of the beneficiaries.

Recommendation to the owners of private institutions, focused on nursing, medical care and health protection, to re-register themselves to social-health institutions, as stipulated by the Law on Social Protection (Article 60).

In connection to providing appropriate decoration and "personal touch" of the beneficiaries to respect Article 30 of the Rulebook – Activities intended towards meeting the basic needs and insuring the safe and pleasant environment, paragraph 1, point 13 - provision of adequate decoration that reflects individual preferences and wishes of the beneficiaries and point 14 – provision of enough space and equipment which enable privacy to the beneficiary.

When it comes to standards for care provision, it is necessary to point out that the current Rulebook is insufficiently readable, especially for someone who is not from social welfare area or law. Namely, most social care providers, registering the institution for accommodation of the adults and elderly, will have difficulties in finding: which standards of personal hygiene and spatial hygiene are set forth for his activity, i.e. institution? Those from Article 7 of the Rulebook – Personal and Spatial Hygiene Maintenance; those from Article 37 – Hygiene Maintenance or those from the Article 43 - Personal and Spatial Hygiene Maintenance? Is the answer all three?
This is only the example, there are more insufficiently understandable Articles (location – Article 6 or

Recommendation to the Ministry is to amend the Rulebook on the Conditions and Standards for the Provision of Social Services in a way to regroup the standards according to the types of services.

Article 46?), etc.
This is very important to carry out in order to make it easier to private and CSO care providers to apply standards as well as to those who work in and/or monitor institutions of public sector.

## Nutrition of the Beneficiaries

*Main occupation of the beneficiaries in some homes*

The largest number of the beneficiaries' complaints is in connection to nutrition. It is somehow expected, especially in those homes where the meals are main daily activity of the beneficiaries. They complain that the food is unsalted, tasteless, always the same for breakfast and supper, etc.

In most privately-owned homes, beneficiaries do not participate in creating the menu (good practice examples are Eskulap centar, where the beneficiary is included in the Commission for Menu, Vinijum, where the main nurse during the breakfast on Mondays usually asks all beneficiaries what their suggestions are for the meals during the week or Home Meliorvita where the beneficiaries are consulted). In state-founded homes there are commissions for menus and the menu is created for 15 days, and the representatives of the beneficiaries participate, except from the beneficiaries of the Home Vozdovac, who do not have that option, because the menu is created at the GC Belgrade level for all four homes, and where the representatives of the beneficiaries of Home Bezanijska kosa participate in the commission's work.

Menus are posted in dinning rooms or on notice boards in most of the visited homes, but they are usually typed in small fonts, which are not visible enough to older people who have sight impairments. However, the beneficiaries do have option to find out what is for lunch, because those who are interested in, usually ask.

Many of the beneficiaries we talked to told us they did not know what is for lunch, but that they were not particularly interested in finding out. They would eat what is served.

*"Breakfast and supper are not cooked meals. They just put something on bread. Lunch is so-so, soup, main course, salad and desert, bread. They do not ask for our opinion. However, nutrition is various. I don't know today's menu. I'll go and see."*

*"It is getting worse and worse as more people are coming. They reduce our food, and we have no stores nearby... What your family brings you, that's what you'll eat.."*

*"Do not ask me for food, I am a child of war, grew up on messroom food, modest in eating and everything. I do not know what I shall eat until they bring me."*

*"Food is good, we get three meatloaves, who ever cooks, does a good job. I did not try to influence the menu."*

*"Food is average, there are different dishes... potatoes, beans, I do not influence it, do not choose, one ate a lot, he died, he is not alive any more."*

The representative of the monitoring team was able to try lunch in almost all of the visited homes, and several members of the team were able to monitor the lunch process. There was enough food and it usually was tasteful. Some dinning rooms have small tables with insufficient space, which results in serving the salad in small plates or together with the main course. In some homes, food is nicely decorated, served in rostfrei of arcopal dishes, somewhere with tablecloths and somewhere without them. We would like to point out very nice food serving in Villa Ancora and Vinijum. Food in Home Homoljski raj also caught our attention for it was served with unusual combination of spices (nutmeg, lovage, etc. – the cook is really trying to make dishes without salt somehow tasteful by adding spices). In inpatient care units, some beneficiaries eat alone, and some need support from staff. We have noticed that some homes do not have adequate equipment for serving food in bed so that the beneficiaries and staff have to manage somehow.

## Locations of the Homes

*Sidelined from the heartbeat of life*

Locations of the homes are usually remote from the town's centre, as well as from any other "stronger beat of urban life" (away from stores, marketplace, church, library, etc.). This could be justified by better ecology environment for the elderly and cheaper infrastructure, which is basically true, but it neglects social dimension. In practice, when those institutions are "sidelined" to outskirts of urban places, their beneficiaries are usually deprived of participation in any of community's activities.

"It is unfounded presumption that homes should be located away from urban life, on the contrary, theatres, cinemas, health centres, marketplace, stores, urban life in general (with all negative aspects of the centre, noise and air pollution) influence the residents of the homes to feel independent (more free) from necessary and inevitable life in home. It all affects them being active, which is very important for their physical and mental health.

Mental and other impairments of older people which are usually used as an argument against locating the home for pensioners in urban centres, are less significant than presented. We certainly need to fight the feeling of isolation and inequality which could be caused by apparently idle location of the home near the forest, in green areas."[13]

13 Kostić Aleksandar, architecture engineer, "Structural-Architectural Aspects of Housing in Old Age", Gerontology Corpus 79, page 321

Out of the visited homes, the most remote ones are Home Vinijum, which is several kilometres away from urban area, Home Lug, which is also located away from the residential area (there are meadows, fields, no houses). According to the current standards, the facility where the services are provided should be located in populated area. However, the Rulebook did not specify in more details what does the populated area mean.

*"I do not go out of Home, we are far away from the city."* (the beneficiary of the privately-owned home).

The best location among the visited homes is of the luxury part of the GC Sombor, which is located in the downtown and Villa Ancora, which is in the most tranquil street in Palic.

When we discus the location of homes, it is important to mention that homes do not exist in two thirds of municipalities. Almost a third of the beneficiaries of the visited homes came from the territory of other municipalities/towns (32%). Their possible integration in local community's life is made even more difficult by the fact that they are moved far away from their previous place of residence.

### Prices and Payment Schedules

*Significantly over the average pension*

Service prices very a lot from home to home, as well as within the institution itself, depending of accommodation capacities as well as the category of the beneficiary. Generally speaking, prices of state-founded and privately-owned homes cannot be compared, because the beneficiaries do not pay economic price in state-founded homes[14], but the one determined by the Ministry.

Price range in visited state-founded homes is from 175EUR in inpatient care units for independent beneficiaries to 460EUR in studios/single bed apartments for dependant beneficiaries. Paying is for previous period and in accordance with pension payments' dynamics. You pay additionally for diapers for the beneficiaries who use it but do not receive it via RHIF or do not get sufficient number of diapers, medicines which are not on RHIF list, as well as the participation in the costs of medicines and/or other diagnostic or therapeutic procedures.

Employees at state-founded homes point out the fact that they have no influence at all on setting the price of accommodation as a problem, and they consider that the prices would be more adequate if they were able to influence them, as well as that it would make work with the beneficiaries much easier, i.e. it would reduce dissatisfaction of the beneficiaries.

*"Price is the same for two-bed, three-bed and four-bed rooms and that is the problem. People prefer to wait for two-bed rooms or they are not satisfied to be in four-bed room and pay as much as the one accommodated in the two-bed room."* (the employee at Home Vozdovac)

*"There is a small price difference for partially-dependent and bed-ridden beneficiaries, and the large difference in staff's engagement... Once determined, the prices only be enlarged can by predetermined percentage regardless of the change in housing conditions."* (the employee at Home Prokuplje).

14 Part of the costs of state-founded homes is covered from the budget of the Republic of Serbia, by the Ministry of Labour, Employment and Social Policy and the Ministry of Health, and in some cases a part of costs is covered by local governments

The recommendation to the Ministry is to accept the opinion and suggestions of the managements of the institutions when setting the price of the services in state-founded homes.
The recommendation to the Ministry is to amend and supplement the Rulebook on Criteria and Standards for Determining the Prices of the Social Protection Services Financed by the Republic, in a way to include in the calculation of the accommodation price paid by the beneficiary or someone on his/her behalf, the calculation for three-bed rooms and four-bed rooms.
Prices should vary in accordance to comfort and contents of the service which is provided.

When it comes to paying for the services, the situation in privately-owned homes is completely different. The basic price is between EUR300 and EUR1,200 per month. Payments are usually done at the beginning of the month for the following month, in accordance with the previously determined pricelist for the basic price, stated in EUR, but paid in RSD. We encountered situations where the institutions do not return money if the beneficiary dies during the month, despite the fact that the relatives have emptied the room and took all of the beneficiary's personal belongings. Along with the basic price, it is paid additionally for all those things which are not covered by the basic service, i.e. apart from the things paid by the beneficiaries of the state-founded homes, beneficiaries pay for: lab analyses in some cases, in some for medical specialists' services, sometimes for the physical treatments, additional services of the social worker and psychologists, transport to medical institutions and back, hairdresser's services, pedicure, manicure, etc. Some homes take monthly deposits for this purpose and it goes from several thousand dinars to EUR100, and in other homes this is paid at the end of the month in accordance with the receipts.

Payments are regulated by the Agreements on Accommodation and/or Decisions on Accommodation if state-founded homes. In minimum number of cases, the payment is done by the beneficiary himself/herself on the basis of the Agreement entered into by and between him/her and the home (practice in some of the privately-owned homes).

In the largest number of cases, Agreements are entered into by and between the relatives, home and CSW, and there are situations where the agreement on accommodation in privately-owned home is signed by the beneficiary as the third party. Consequently, payments to privately-owned homes are done by relatives. In state-founded homes, pensions and other income of the beneficiary, if any, are directly paid in the Home's account or CSW's account. If that money is not sufficient to cover the costs, difference is paid by the relatives or the State, in accordance with the Decision on Accommodation.

Employees consider that it would be much better that in all those cases where the state is not participating in accommodation costs, the payment should not go via CSW, but that the direct agreements are signed with the beneficiaries, i.e. their relatives, and that the payment is done to the Home directly, without intermediate (CSW). This would enable more regular payments and avoiding debts.

## 6. STAFF

*Homes are women's story*

In all of the visited institutions, the largest number of employees are women. This specially refers to those staff working most directly with the beneficiaries (nursing staff, health care workers, servers, cleaning ladies, etc.). Traditionally, women are those who are more often caretakers, whether they nurse children while growing up or ill family members, most often the elderly, so they professionally more often turn to "supporting" professions such as those in homes, which are less paid but very demanding.

When we talk about staff which is directly providing services to the beneficiaries, for the purpose of monitoring of human rights of older people in residential care, three aspects were analysed: is the number of employees working most directly with the beneficiaries adequate, bearing in mind the categories of the beneficiaries; whether the staff is additionally trained to work with older persons, are they trained in human rights of the elderly, gender equality and/or violence against older people, especially work with those with dementia or are in palliative care, and are they sensitized to work with the older people, i.e. what is their relation to the beneficiaries like.

When it comes to number of employees and work organization, situation differs in state-founded and privately-owned homes.

In all state-founded homes, employees are organized in services/task-force units, usually as follows: professional service, health service, maintenance service and service for general and administrative affairs. Type and number of employees are set forth by the standards determined by the Ministry in accordance with the capacities, accommodation category and the number of the beneficiaries. In average 3 beneficiaries are per employee in state-founded homes while in privately-owned homes, according to the interviewees, the average is two beneficiaries per employee. The most unfavourable ratio of the employees to the beneficiaries among the state-founded homes is in Smederevo, where is one employee per 3.22 beneficiaries, and the most favourable is in Sombor where one employee covers 2.37 beneficiaries.

Structure of the staff is not always the most adequate to the needs of the beneficiaries. The number of those who work most directly with the beneficiaries on providing care and professional services is insufficient. According to the current Rulebook, 1 caretaker is envisaged for 10 beneficiaries with I and II degree of support, as well as one professional worker or professional associate for every 70 beneficiaries. Employees in public institutions told us that it is not enough, because the functioning of institution should be organized in three shifts, 365 days a year. Interviewees point out that they do not provide services of the dentist, which are very important to the beneficiaries, as well as the services of the neuro-psychiatrist.

Privately-owned homes usually do not have special services/task-force units, except from Home Lug, which is the largest one and has 42 employees on 143 beneficiaries, according to the interviewee. All other homes have smaller number of employees but significantly smaller number of the beneficiaries as well. Among employees, the largest number make caretakers or nurses, i.e. those who work most directly with the beneficiaries.

Employees did not have training in human rights of the elderly in residential care, gender equality and/or violence against the elderly.

Employees, especially in privately-owned homes did not have any training in or education about aging and old age, but would like to improve their knowledge.

In connection to other training, i.e. continuous education of the employees, situation is not satisfying. Namely, apart from health workers who attend educations required for renewal of their licences and occasional gatherings/education courses for the directors and/or professionals from the state-founded homes, which are organized by the Ministry or the Institute, there are no continuous (even though necessary) education for all employees who work directly with the beneficiaries.

Situation is not any better in privately-owned homes, where, also, only health workers attend education courses in order to renew their licenses.

None of the visited homes has the staff education plan for 2013.

As a positive example, we can point out the Nacionalni dom where the training sessions on nursing and care of Alzheimer patients are organized, as well as for care of patients with Parkinson's disease. Not a single nurse can start to work in the Home unless she successfully passes the training.

Staff employed at social protection institutions face great level of responsibility and increased scope of work. They are at risk of developing the burn-out syndrome.

The positive example is the one of Home Villa Ancora where they take care of employees and organize excursions, transport, and accommodation if they are not from Subotica, etc. Smiling, satisfied staff adds value to the quality of life.

Employees point out their need for education, because they lack specific knowledge, e.g. in geriatrics, gerontology, psychotherapy. Education from the abovementioned areas is not in curriculum of, for example, mainstream medical education of any level in Serbia. (The question of education of all profiles of staff remains – what education do they need to have in order to work with this population?)

Employees pointed out that the most important is education on following topics:

- Work with the beneficiaries with dementia and efficient communication with the elderly (Agape, Meliorvita, Vinijum, Smederevo, Voždovac, Luana, Eskulap centar)
- Work with persons with psychical impairments (Prokuplje, Eskulap centar, GC Sombor)
- Prevention of the burn-out syndrome among the professionals in social protection (Voždovac, Smederevo)
- Work and occupational engagement of the beneficiaries (Prokuplje, Vinijum)
- End-of-life care (Eskulap centar)
- Anti-discriminatory practise and gender equality (Voždovac)
- Training for caretakers (Betanija I)

When it comes to sensitivity and attitude of the staff to the beneficiaries, we have noticed during the visits that the staff are usually professional, polite and dedicated to the direct work with the elderly. The problem is in frequent changes on the staff, which was pointed out by the beneficiaries of the significant number of privately-owned homes. From the beneficiaries' point of view, staff are too busy and, therefore, lack patience.

*"I am satisfied with everything. Staff is polite, and they treat us kindly..."*

*"They take care of you here, cause your own (family) doesn't want to."*

*"...the older ones are better and more polite, the younger ones do not want to work"*

*"I just get used to a worker, they let her go, and so on..."*

*"...It is difficult for me to beg for her to come, they are rough when they bath us, and I'm afraid they'll hurt my leg, they do not have the touch..."*

*"They should treat us differently, to pay some attention, not to act as if we are in a hospital. To talk to us.."*

Staff's actions sometimes do not respect human rights of older people, but the general impression is that they do not do it intentionally but out of ignorance, e.g. when they come into the beneficiaries' rooms without knocking, show what is there of equipment without asking for the permit, talk about them even though he/she is there and listening, etc.

We had the situation where the employees took the beneficiaries' knives which they brought with them from home to peal fruit or cut something. When asked why, they answered that the beneficiaries would not hurt themselves. They explained that they rinse fruit if the beneficiaries cannot eat them whole. They do not understand that they encourage helplessness and passivism of the beneficiaries instead of his/her activity. They do it out of ignorance, but with the best intention, and therefore, we consider education of all employees who directly work with the elderly or come in contact with the beneficiaries to be of great importance.

The recommendation to the managements of homes is to design annual work plans, as they are legally obligated to do. Those plans should include an education plan for the staff, as well as resources required for its implementation. Of course, that education plan should be implemented.

The recommendation to the Republic/Provincial Institute for Social Protection is to further strengthen their engagement and activities on promotion of the quality of work of care providers in social welfare, starting with the ones in CSW, over employees in public institutions to private care providers in accordance with the description of the Institutes' scope of activities.

It is necessary to accept, apart from the programmes for work with the elderly which are accredited at the Republic Institute for Social protection, other relevant education programmes (such as accredited programmes for work with the elderly with psychological impairments, which are accredited at the Health Council, etc.).

## 7. ACTIVITIES OF THE BENEFICIARIES AND THEIR CONTACTS WITH THE FAMILY AND LOCAL COMMUNITY

*Key for the Quality of Life in Institutions*

Apart from accommodation and the staff's attitude to the beneficiaries, contents of their daily activities influence significantly their quality of life and contribute to their active participation in social life as much as possible. The contents of the beneficiaries' activities in the basic segments of the service are similar in all of the institutions, while in those segments of meeting the social and community needs, development of personal preferences and engage of preserved potential, vary a lot. Situation vary a lot from institution to institution, as well as within the institution and depends on various factors – on the philosophy of the employees, their focus of work, on spatial, staff and material resources of the home on one side, and the beneficiaries themselves on the other. Personal preferences, interest and health abilities of the beneficiaries could influence the level of their activities. Encouraging environment contributes, and the division of the beneficiaries to those who came to the home willingly and those who are there against their will and sometimes forced to be there, should not be neglected, either. They are usually not interested in what is happening in the institution, they are apathetic, appear distant, sometimes depressive…

Average day of the beneficiaries of the visited institutions looks more-less the same. All is subjected to the routine and the staff-friendly schedule, a lot like hospital environment. Day starts early, at 6:30 a.m. Key activities are personal hygiene, care, therapy and five meals a day – 3 main meals and 2 snacks. During the morning, beneficiaries are taken out of their rooms, for a walk in the garden when the weather is nice, or to the common room. They sit there, TV is on, they have newspapers available, etc. Where the home has physical therapists, those who need to, have exercises, and where there are work therapists, they have daily terms for work-occupational activities for the interested beneficiaries.[15] Usually, everything is finished by lunch, and then the beneficiaries rest.
The last meal is at 18h after which they could watch TV shows, etc., then go to sleep at 20h. General impression is that the life in homes "dies" in afternoon hours.

Apart from the cultural-entertaining activities, homes provide social games, organization of performances when appropriate, when the kindergarten children, art associations, singers and the others come.

> *"During our visits, several beneficiaries set in the common premises and "watched TV". All attempts to animate them or at least make them react on our questions remained unsuccessful. Even after several hours of our visit to Home, we found them in the same condition, no one went out to the garden…"* (impression of the members of the monitoring team).

This is often situation we encountered during our visits to the institutions. The beneficiaries seem remote, do not communicate, not even with each other. This specially refers to privately-owned homes where the management and staff who talked to us justify this by insufficient interest of the beneficiaries for the activities or their poor health status. They do not connect this kind of behaviour of the beneficiaries with the lack of space and/or offer of the occupational-recreation activities.

> *"Impression is that apart from physical care little care is taken of the spiritual needs of the elderly."* (the member of the monitoring team).

> *"There is no fun, theatres, entertaining evenings, organized socialization and that is what all of the interviewed beneficiaries miss the most."* (the member of the monitoring team)

15 All of the visited state-founded homes have work therapists and Lug, Nacionalni dom and Villa Ancora among the private ones

*"One of remarks is in connection to psychological health and socialization. It is an important issue that no one practices cognitive exercises for persons with dementia (brain stimulating activities), and it is necessary to point out that the health, psychological and social components are equally important for slowing down the progress of disease, and slowing down the progress of disease helps not only the older person but the family, caretaker and the community, because, among other things, the costs of care are reduced. Nurses lift them regularly so that they do not lay down all the time and take them out when the weather is fine, they listen to the music, which is good, but it is not enough."* (the member of the monitoring team).

A large number of the beneficiaries confirmed that there are no continuous contents of the activities, which are organized in homes apart from those in appropriate occasions (two or three times a year).

*"It would be nice if they took us to the theatre, cinema… To organize something."*
*"Nothing is organized… I sit here all day, by the door, waiting someone to come to visit me."*
*"Life in home is all about bed and dinning room."*
*"We watch weddings in the restaurant, over the fence."*
*"They organize (activities) occasionally, usually social games, but I don't participate..."*
*"Priests came, and the children from the kindergarten, who brought us drawings..."*
*"We celebrate holidays and organize parties."*

Employees in privately-owned homes about the activities of the beneficiaries:

*"Many say that they are not here to work, because they worked enough, but to rest and get medical treatment."*
*„...we would be happy to have some volunteers who would work with the beneficiaries a bit more, for nurses do not have time due to their regular assignments."*
*„...Breakfast at 9.30. After that the beneficiaries walk, draw, read, do puzzles. We are insisting on memory and oral exercises, object recognition, etc."*

As an exceptional example of rich and organized social aspect of life of the beneficiaries in privately-owned home we would like to point out Villa Ancora.

*"In the morning, after the exercises, we have work therapist's sessions and organize various activities. We have a minibus, which we use to bring in the beneficiaries from the other Home. We organize excursions, visits to the zoo, wine degustation. Children from the Medical High School come and help with the beneficiaries in the wheelchairs. Birthdays are celebrated once a month."* (the staff, Villa Ancora)

This was confirmed during our interviews with the beneficiaries, by review of video and photo documentation of the Home and insight in the Home's journal which is printed both in Serbian and Hungarian language.

When it comes to state-founded homes, more attention is paid to the contents of the activities of the beneficiaries, with some variations among the institutions. Homes have professional services/ staff units where apart from social workers, work therapists and psychologists are engaged. State-founded homes have long tradition and, therefore, better organized social aspect of the beneficiaries' lives. Here is what the employees and beneficiaries have told us:

*"...there is a weekly work plan of the work therapist whose services are used by 40-47 beneficiaries (films, playing darts, pin-pong, bingo, music day, celebration of birthdays, social games, knitting, crochet, needlework, painting, etc.). Independent beneficiaries can go where ever the want during the day..."*

*"We organize many manifestations in our Home, and they can go to the town's manifestations, too.*
*Beneficiaries can work in the garden, laundry room, serving in the dinning room... They receive allowance for their work in the garden and laundry room."*

*"We organize something during the (international) month of the elderly, but it is crisis now, so there are fewer activities,...There are some lectures, but I do not go..."* (the beneficiary)

*"In the premises of the Home there are handcrafts of the beneficiaries, their drawings, songs, etc."* (the monitoring team member noticed in Home Department of CSW Kucevo)

*"I went to every performance. Oh, and when they have cakes, on someone's birthday. Nice. I long for that, such things we had in our village. If feels like home. More of that I'd like..."* (the beneficiary)

Among the state-founded homes, we would like to point out the Home Vozdovac as an exceptional example of rich social aspect of life of the beneficiaries with numerous sections and actions, which were jointly established by both beneficiaries and the staff during many years of this institution's operation.

*"I ran into the Home, thinking I was late. It was 10-15 to 9. A group of beneficiaries practiced Tai-chi with the therapist in the hall. The moving abilities of the beneficiaries were impressive. Pleasant interior, painted in vivid colours. Lively beneficiaries going after their own business, feeling of intensive social life and jou for each new day."* (impressions of the monitoring team member)

*"I participate in the activities in the Home and I'm very satisfied. I'm no longer lonely. We all get together in our common rooms on our floor, drink coffee, tea, play dominoes, etc."* (the beneficiary of Home Vozdovac).

*"...at the moment, I am reading "Make Peace with Yourself"... I also have a hobby, painting and tapestry, and the work therapist helps me."* (the beneficiary of Home Vozdovac)

Interviewees, among the employees as well as among the beneficiaries, pointed out that there are insufficient number of professionals for psychosocial support and work with the elderly. Their role and responsibility is extremely large: to support older people in accepting the new environment, provide support and encourage more frequent contacts with the family members and other persons relevant to the beneficiaries, as well as to motivate and sensitize the beneficiaries to fulfil their free time with work or cultural-entertaining contents in accordance with their preferences, desires and abilities.

It is necessary to question the option of organizing the work of the services in a way to enable them to spend the most of the time in direct work with the beneficiaries. Continuous education and supervision support to the professionals employed at the residential care institutions.

## Contacts with the Family and Local Community

*From isolation to occasional contacts*

Contacts of the elderly with the family and local community are very important, especially when the elderly are moved away from their environment and accommodated in institution. Institution is not very human solution. Actually, we are in a dilemma whether the older person who lives alone and cannot live without support, and has no one near by, should be left like that or accommodated in institution. Many have the children and younger family member far away, some are abroad, and some are on the other side of the world. We consider it less evil to accommodate older person in institution where the social life is well organized, services and conditions are of good quality, than letting him/her die without anyone noticing it for several days. However, it is very important that the decision is planned and mutual, not made in a hurry and single sided by the family members.

Communication of the elderly with the family is largely influenced by their previous relationship, place of residence of the family members – children who live abroad usually come once or twice a year, as well as the relationship the younger and the older.

Situation is similar in all of the visited homes. Some beneficiaries are often visited by their friends, if any, at the beginning on daily basis, and later on weekends, some are taken home for the weekend or to important events. Some are visited at the beginning, and then rarely or almost never. There are those who do not have any visitors.

*"...We have a grandma who did not have a visitor in a year. We have tried to convince her son to come and visit her, and he says he cannot come 'because his mother does not recognize him'... There are those who come only when they have to pay... They are rarely honest that they cannot deal with their parents any more."*

*"We have relatives who are almost aggressive, but it's a small number – 15 or so, and we have those who once they accommodate someone consider him/her the problem of the institution – and forget about him/her."*

Some beneficiaries have mobile phones, so they can contact their families. Managements, usually provide phone communication between the beneficiaries and their families, whether they have phones in their rooms (rarely) or phone box in home so that they can call, and the relatives can call to home's portable phone. Homes Villa Ancora, Meliorvita, Homoljski raj and Nacionalni dom provide Skype and e-mail communication with the children/relatives who are abroad.

In connection to communication with the community, in largest number of privately-owned homes it almost does not exist, and it is slightly better in state-founded homes. The reasons are numerous. Some older people are ill and not able to go out or not interested in going out, especially if the home is not in their place of origin, so they do not see anything in common with their new environment. In some cases, homes are located away from the town/village's centre, so they have nowhere to go to. In some situations, even the staff do not do enough and do not recognize importance of communication with the local community.

Here is what the employees and beneficiaries say:

> *"Representatives of local community rarely visit us. Municipal representatives usually come for holidays."* (the employee)
>
> *"They rarely go to local community, they do not have the store near by, either."* (the employee)

*"Several believers go to church, some go to the Association of the Pensioners and sometimes we get free tickets from the theatre for our beneficiaries."* (the employee)

*"They have a bus stop nearby. Approx. 5-6 of them uses the option to go to town. We take them by van for a shopping in the supermarket."* (the employee)

*"The beneficiaries do not want to go out, not even for a walk."* (the employee)

*"I go out only to the Health Centre to see the doctor."* (the beneficiary)

*"Not much. I did not even walk, mate. Now I can walk a bit."* (the beneficiary)

*"I went once with the owner. I'd like to go, but there is no one to drive me."* (the beneficiary)

Recommendation to the managements of homes is to open themselves to local community. To increase transparency of their work. To make their annual reports on work available to local community and public, and to connect with local organizations and institutions of importance for the beneficiaries (schools, local community office, associations of pensioners, church, institutions of culture, etc.) and to open their doors for them. Students of Medical High Schools should come and have practical classes or the students of other schools should come and talk to the beneficiaries, socialize with them... For Neighbours' Day (the last Friday in May) they should invite neighbours to come and visit the beneficiaries who do not have visitors.

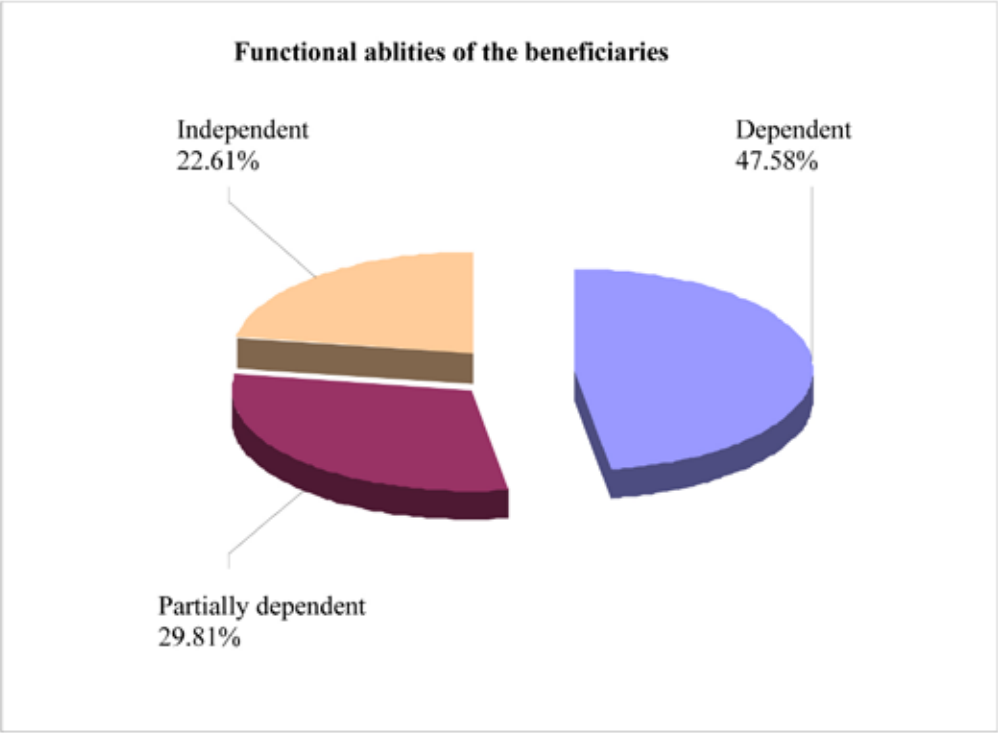
The recommendation to the managements of homes is to increase engagement of social workers on improvement of relationships and contacts of the beneficiaries and their relatives when needed.

## 8. HEALTH CARE IN INSTITUTIONS

### Functional Abilities of the Beneficiaries

We are concerned by the fact that nearly half of the beneficiaries of the visited institutions (48%) are completely dependant on other person's support in daily life (I level of support) and 30% of them who are partially dependant on other person's support (II level of support). Significantly larger number of dependant beneficiaries are in privately-owned homes (54% comparing to 43% in state-founded ones; the largest number of dependants is in Home Nacionalni dom, nearly 90% and in Home Nana, nearly 80%).

Graphic 6. Functional abilities of the beneficiaries



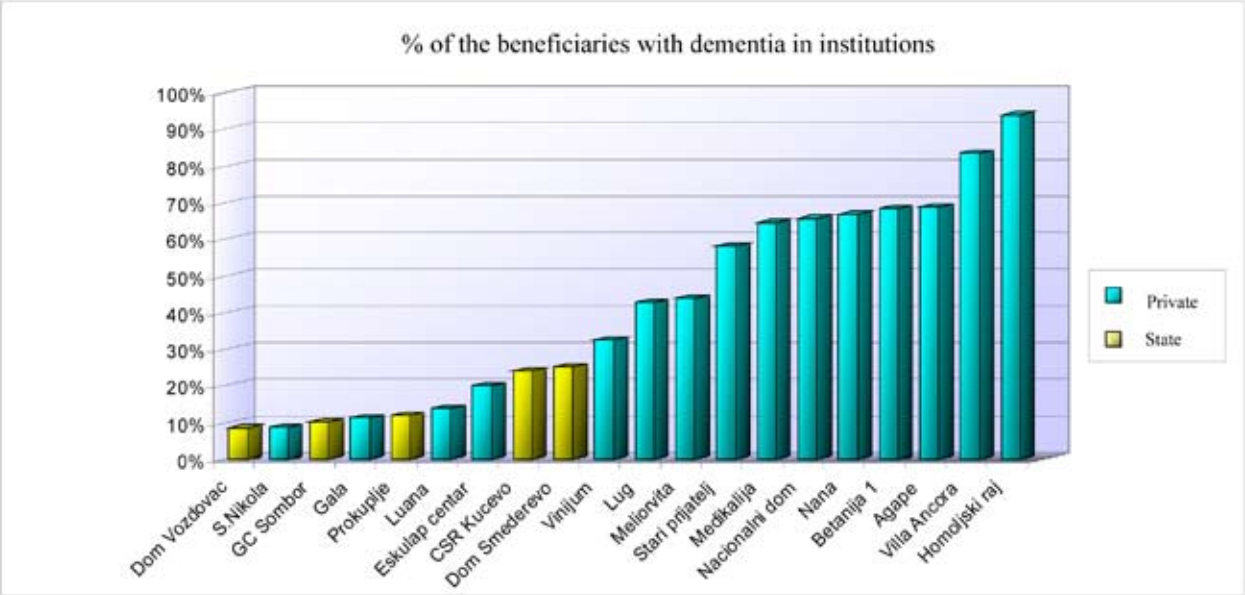

According to data we received from the interviewees, insignificant number of beneficiaries became bed-ridden during the previous six months, i.e. 13 beneficiaries due to hip dislocation or progression of disease. Immobility is more cause than consequence of institutionalization. The beneficiaries come to homes as immobile/bed-ridden, and some become mobile due to support, efforts and care of the staff. Bed-ridden patients are lifted in order to prevent decubitus and other complications of long-term lying (e.g. Agape, Medikalija, Meliorvita), which would be recommendation to all other homes.

Most of the bed-ridden persons came with medical history, with defined *cause of immobility*, usually unoperated hip breaks, *last stages of dementia, and terminal phases of cancer*. Unfortunately, it happens that the beneficiaries are referred from hospital without diagnosis (a beneficiary was accommodated to the Home in Kucevo in very bed health condition, untested, and from social reasons, because the oncologist did not pay attention to an important biochemical factor of malignant diseases such as increased level of alkaline phosphatase).

## Psychological Status of the Beneficiaries in Visited Homes

Often cause of functional dependence of the beneficiary is their altered psychical status with the leading role of dementia. Frequency of the beneficiaries with dementia diagnosed by the neuropsychiatrist, psychiatrist or neurologist, prior or after the accommodation is presented in the graphic 7. Frequency of the persons with dementia varies from 8% in Home Vozdovac to 94% in privately-owned Home Homoljski raj.

Graphic 7 - % of the beneficiaries with dementia in institutions




Number of beneficiaries with dementia is significantly larger in privately-owned homes, where the average is 50% while the average in state-founded homes is 15%.

In Serbia, little is done and known about the ways of psychophysical rehabilitation of the beneficiaries with dementia, so that it is sad to see their common premises which look like the beneficiaries are "being guarded in".

*"World Health Organization defines health as "condition of complete physical, mental and social welfare not only absence of disease". Not only that it is necessary to take care of physical health and medical treatment of the elderly, but it is out duty to motivate social life of the elderly and use of mental potentials. Using mental potentials is very important for persons with dementia, because the cognitive exercises slow down mental deterioration, which is inevitable. Our obligation and their right is to include in regular activities of the persons with dementia apart from administrating medicines, cognitive exercises. It can start with regular informing on day of the week and year."* (monitoring team member, under the impression of absence of the persons with dementia who are only being looked after by the caretakers).

Interviewees pointed out that the Ministry requires that the persons of dementia are deprived of legal capacity. The children of the beneficiaries sometimes refuse the procedure because it creates difficulties. There is a question of assessment of the best interest of persons with dementia, checks of guardianship, fulfilment of obligations from the Agreement of Lifetime Support. In connection with abovementioned, there are attitudes that it is not recommended to violate the privacy of the family relationships and the other ones which insist on importance of recording everything in connection to the beneficiary.

On the other hand, state-founded homes (Sombor, Prokuplje, Smederevo, Kucevo) accommodate large number of younger persons with pshychological problems and those who represent so called "social cases".

Two main problems occurre:

- Younger persons accommodated during the "deinstitutionalization" of institutions for the children and young where certain number of adult beneficiaries was accommodated who due to their specific needs could not have been returned to the families but were transferred to the institutions for the elderly, where is lack of staff, funds and knowledge for work with these types of beneficiaries. It is necessary to form mental health teams, with employment of adequate staff and education of the already employed about work with this population.
- Among social cases are those who gambled away their property or drank it out and now the State takes care of them, and those are usually the middle-age persons of good health, who refuse to work with various excuses, and who are not satisfied with the "services in Home" and make problems to the staff. (Prokuplje, Smederevo)

## Health Insurance of the Beneficiaries

Most of the beneficiaries have health insurance[16]. A certain number of refugees did not solve their health and social insurance due to unsolved administrative problems (they did not take citizenship, but they are the beneficiaries of state-founded homes of Prokuplje and Kucevo). Insignificant number of the beneficiaries have foreign health insurances. During the daily activities of the staff, several phenomena were noticed:

- Medical doctors of the state-founded homes are "chosen doctors", i.e. they have right to prescribe prescriptions covered by RHIF. If there is no home doctor, the prescriptions are issued by the doctor coming from health centre. Doctors in privately-owned homes do not have right to prescribe medicines to be covered by RHIF, so that issue is dealt with in different ways. Some give the recommendation of the medicines to the relatives to show it the chosen doctor at health centre where the beneficiary has his/her health card, and sometimes the doctor prescribes therapy and sometimes it is not possible.
- Some of the privately-owned homes sign the "protocols on cooperation" with health centres and their beneficiaries who have health insurance use services of home visiting service, prescribing medicines, specialists' consultations and laboratory analyses with the priority comparing to general population (Luana, Nacionalni dom, Vinijum). They register beneficiaries' residence at their homes' addresses, enabling the beneficiaries to transfer the health card to health centres in their towns.
- Problem is that you have to participate in the costs of the most of the medicines or you have to pay the full price. The beneficiaries do not understand why they have to pay when they have their health insurance and they were told they have the right to those medicines. Beneficiaries of social allowances, who are accommodated in large number in state-founded homes, also participate in the price of some of the medicines as well as in the price of the dentist's services.
- Right to diapers whose costs are covered by the RHIF (2 parcels of diapers with 30 pieces a month) have only permanently and fully bed-ridden persons (G82), patients with sequelae of cerebral palsy (G81) and patients with the multiple sclerosis (G35). Persons with dementia do not have a right to diapers. Lately, bed-ridden persons with dementia are also deprived of this right.

16 State health insurance, not by the private insurance companies (translator's note)

- Participation in the price of anti-dementia medicines, already expensive, is high (75%), so that the symptomatic therapy of Alzheimer's disease is not being carried out up to the required level.
- Procurement of aids whose costs are covered by RHIF is on individual level.
- Problem with prescribing parenteral therapy such as Fraxiparin (the role of social institutions in health care of the elderly is not being perceived).
- Discriminatory behaviour of the ambulance and transport services: persons are transported from the hospital to their home or state-founded home free of charge, but not to the privately-owned home, i.e. the problem is their transport from the hospital to the privately-owned home.
- State-founded homes have good cooperation with health and social institutions at local level and their beneficiaries have priority comparing to other older persons of general population.

### Health Care Services in State-Owned Homes

All of the visited state-founded homes have relatively good organized health care services, despite the difficulties they face. They try to overcome them by enthusiasm, creativity, experience, professionalism, humanism and good relationships with the local health and social care institutions.

Good example of the practice is the health service of the Home Vozdovac, where the doctors of the Home see the beneficiaries on daily basis, keep personalized health care records and have individual care plans, prescribe medicines. Records include, apart from personalized health care record cards, handover notes and the monitoring list in electronic form, as well as documentation on physical restraining of the beneficiary. Falls and socially unacceptable behaviours are recorded there. In case of physical restraining of the beneficiary, reasons as recorded and relatives or legal representative are informed and asked for approval.

The beneficiaries have right to leave the Home, refuse therapy with signing and informing social worker, psychologist, psychiatrist and relatives or legal representative. Medical specialists make visits twice a month on regular basis: internist, psychiatrist and neuro-physiatrist and they are available for more frequent consulting if needed. Other specialsts are available if needed. There are good relationships of the medical doctors of the Home with those of the Health Centre, MMA, Ambulance. The beneficiaries are always transported with the health care staff as escort. At the moment, approx. 20 beneficiaries are using neuroleptic therapy signed by the psychiatrist, who is making regular controls. Pain is systematically registered by the numeral scale of pain.

Health care staff of state-founded homes are paid by RHIF, which does not accept travel costs/ commuting costs, night shifts, holidays and equipment. There is no nurse at night (Sombor) not full-time employed MD, or there is only 1 nurse per significantly large number of beneficiaries at night (Smederevo). In order to "save" funds some apply the "mermaid phenomenon" – half caretaker – half nurse (4.60 nurses, 11.40 caretakers) which we encountered in the Institution for the Adults and the Elderly of Kucevo).

*According to current regulations, privately-owned homes are not obligated to have health care staff.*

Realizing the importance of health to the beneficiaries, specially bearing in mind the structure of the beneficiaries of those homes, they do take care of health. In homes where is no health service or are few health care staff (Luana, Gala, Homoljski raj), there is awareness on importance of individual monitoring of the health status of the beneficiary, recording data in special "histories, cards, list" and it is enabled and charged in various ways.

Medical doctor, general practitioner, full-time employed or present (Kaculice, Lug, Medikalija, Nana, S.Nikola, Eskulap centar, Villa Ancora), part-time employed (Agape, Betanija, Meliorvita) or comes to consulting visits (Gala, Homoljski raj) sees the beneficiaries at least once a week and additionally, if needed. There is an example of uncritical health status control apart from clinical indications in order to please family members who pay for accommodation for their elderly ("*We carry out laboratory analyses on monthly basis and show them to the relatives, and the beneficiary who broke her hip goes to control to orthopaedist every month and has X-ray then",* proudly states the manager of one of the privately-owned homes).

**Availability of Specialized Medical Services to the Beneficiaries of Privately-Owned Homes**

Medical specialist examine the beneficiaries upon the referral of the general practitioner or as indicated in specialist's report. Out of the specialist services, the potential of health centres, and local hospitals is maximally used, with the note that the large clinical centres such as the Clinical Centre of Nis do not make admissions of the elderly, refer them from the cardiologist to neurologist, turn them back, especially in terminal phases (data from MD of the Home Eskulap centar). When impossible to enable the visit to the specialist or at request and with the family's approval and on MD's suggestion *consultants are provided, whose visits and examinations are mostly paid by the beneficiaries themselves.*

The beneficiaries use the services of the internists, physiatrist, orthopeadian, vascular surgeon, neurologists, and most frequently the psychiatrists, which is the consequence of the beneficiaries' structure (high rate of the beneficiaries with the psychological impairments). Some of the homes have their own regular consultants – psychiatrists (e.g. the homes Nana, Luana, Lug, Nacionalni dom, Stari prijatelj), but relatives can bring one of their own choice or take the beneficiaries to health care institutions where they have priority (Homoljski raj). At Nacionalni dom, as well as at Stari prijatelj, psychiatrist comes once a week, which is included in the price of accommodation. Some of homes have other specialists' consultations for free, e.g. Meliorvita – ophthalmologists.

*Transport* is by taxi *paid by the beneficiary* or is provided by the Home, included in the price (Villa Ancora, Vinijum) or with participation, the beneficiary pays fuel costs only (Homoljski raj) or per mileage (Lug). Some of homes have contracts with civil or military ambulance, so that their services are available 24 hours a day (Meliorvita). An employee usually follows the beneficiary, except from the Home Stari prijatelj, where the relatives are invited to go with the beneficiary.

*Few beneficiaries take medicines by themselves,* to most of them the therapy is "given", i.e. in most homes the staff are responsible for administrating therapy in order to ensure that the patients have taken it.

*Most homes do not keep special records on incidents:* falls, socially inappropriate behaviour, etc., but, as we were told, everything is recorded, usually in the handover notebook or handover book, individual cards, and/or social files of the beneficiaries.

As we were told, falls are not that often, but the *beneficiaries often suffer from short-term upsets,* mainly verbal, especially in homes with high rate of the beneficiaries with dementia. The staff settle them by distraction from the cause of upset, which is the recommendation of the guidebook as well, that non-farmacological measures should be used first when dealing with the upset person with dementia. *Privately-owned homes do not have written protocols for dealing with upset beneficiaries,* but they have developed certain work methods based on their experience.

*Special records on physical sustaining of the beneficiaries are not kept.* Actually, there is no clear perception what the term includes. Beds with the net, semi-lying wheelchair, wide bandage in bed, special belts installed on wheelchair "as in the car, so that they do not fall, not to endanger their dignity" is not considered sustaining in most homes.

*Relatively large number of the beneficiaries is in a need for occasional antipsychotic therapy,* which, as we were told, is determined by the psychiatrist/neuropsychiatrist in accordance with the diagnoses of MKB-10 classification and they guarantee for it with their signature and stamp. Sometimes the Home MDs (e.g. Home Eskulap centar) see that in some cases too large doses of psychotropic therapy are administrated, and that it is not suited to the beneficiaries so they reduce it or gradually introduce it. As we were told, antipsychotic medicaments are not used as the punishment in any of the homes. In state-founded homes doses are often reviewed and cancelled whenever possible. Even though we have realized during the monitoring that there are many beneficiaries with dementia, not all of them use antipsychotic therapy, but symptomatic dementia therapy, and there is abovementioned problem of expensive therapy and high participation in the price of the medicine, so it is not available to all due to material reasons, equally for those in homes and those older persons with dementia living at home.

*Pain is not registered on numeric scale,* except from Home Vozdovac, *but pain relief therapy is applied in all homes,* i.e. they do pay attention that the beneficiaries do not suffer from pain. After explaining the manner of registration of pain intensity, all of the interviewees showed interest in planning its introduction into everyday practice.

*Lack of organized dental care is evident in homes,* as well as it is the case with the entire country. The beneficiaries are usually taken to private dentist's or dentists come to the home for examination and extractions. Those services are paid additionally. Positive example is field action of the Faculty of Stomatology of Nis where they made dentures (Eskulap centar).

In all of the homes, the beneficiaries are stimulated to eat by themselves, in accordance with their abilities. Food is important motivation and social factor in residential care institutions; the beneficiaries are very focused on its quality, and the largest number of complaints is in connection with food.

Recommendations in connection to healthy lifestyles and aging are well known, but those are recommendations, not bans in connection to the habits people used to have decades before, such as smoking, salting, etc. Smoking is forbidden in homes and outside. Is it freedom of choice or health or less complications for the institutions?

When we mention adequate *end-of-life care,* in some of the homes, especially in those with well organized medical service, care in terminal phase is considered. They face problem of refunding of parenteral therapy which is often is such cases. For some, it is post-mortem care and funeral preparation and it is carried out in most homes. Some beneficiaries want to die at their own home. Decisions are respected if possible, they go to their family.

Specially in rural areas, the beneficiaries orally express their wishes in connection to end-of-life care, funeral and customs. Many of the beneficiaries bring their clothes for the funeral. It is very important for them to be buried in compliance with the local customs. In the Home S. Nikola they call the priest and the beneficiaries die "with the candle". *"If it's not respected, it would be a great sin and the relatives must change all the furniture in the house".* In state-founded home of Kucevo there is separate room for the religious service where the candles are lit, because the beneficiaries used to light them in their rooms. A large number of the benefiicaries, mainly from rural areas, comes with the idea where and how to be buried, while many do not want to talk about it at all. In Villa Ancora everybody is referring bilingually and religious marks of all religions are present.

Informing the beneficiaries via notice boards is not always in accordance with their psychophysical and educational abilities (they cannot see well if the font is smal, or they are illiterate). Home Kucevo has exelently marked rooms, with specific images, e.g. flowers in different colours, because it suits illiterate as well as those with mental impairments.

Pet therapy proved, both theoretically and empirically, to be very effective, but there is a problem since the inspection does not allow pets in residential care (Eskulap centar, Smederevo, Villa Ancora).

The beneficiaries we talked to are generaly satisfied with the health services. They say that they are respected by the staff, and that attention is being paid to the problems they mention. They adjust to living together, they respect the efforts of the staff and as one of the beneficiaries says>

*„Life is mixed. The fact that the faith has brought me here has nothing to do with the Home, it just had to be..."*

## Suggestions

Suggestions comply with Article 18 of the UN Principles for the Older People[17] and Basic Ethical Principles in Work with the Elderly with Mental Disorders of the Worlds Health Organization[18].

- It is necessary to stimulate the beneficiaries to take the responsibility for taking the medicines by themselves as long as they can with the supervision and reminding.
- Point out the high participation costs for anti-dementia therapy, which puts them at a disadvantage and strive that the RHIF covers costs and enable necessary treatment to all beneficiaries with dementia.
- People with dementia should not be deprived of diapers at the expence of RHIF.
- Teams of mental health are required in institutions where there are plenty of people with mental disabilities.

Neither years nor any mental illness itself determine the lack of decision-making abilities.

- Consider an item that each person with dementia is deprived of legal capacity
- Consider the introduction of an independent representative of the interests of the person with dementia suggested by the legal framework.

17 " Older people should enjoy respect in terms of age, gender, racial or ethnic origin, disability or other impairment, and be valued independently of their economic contribution."

18 C. Katona, E. Chiu, S. Adelman, S. Baloyannis, V. Camus, H. Firmino, D. Govez, N. Graham, T. Ghebrehiwet, I. Icelli, R. Ihl, A. Kalasic, L. Leszek, S. Kim, C. de M. Lima, C. Peisah, N. Tataru and J. Warner.World psychiatric association section of old age psychiatry consensus statement on ethics and capacity in older people with mental disorders Int J Geriatr Psychiatry 2009; 24: 1319–1324.

Residential care institutions are homes to their beneficiaries, not a place of survival. It is necessary to have an individual, multi-professional approach in meeting their physical and psycho-social needs, i.e. to respect the principle of care.

- For admission to state homes, it is necessary to revise the administrative procedure
- A knowledgeable staff of different profiles to work with the elderly, especially with mental disabilities is needed. [19] Kindness is a necessary but insufficient condition.

*Education is an imperative, a condition without which it cannot be worked with older people. Suggestions for training in the field of:*

• Respect for human rights, prevention of abuse, discrimination and discriminatory behavior, gender equality is essential.
• The care for demented beneficiaries, particularly agitated/upset
• Communication and motivation to engage in activities of social life
• Mental and physical rehabilitation of dementia patients
• Palliative care
• Diagnostics and treatment of pain of the elderly with special reference to the person with dementia
• Suicidology. (In institutions with a large number of people with mental disabilities, suicides are to be expected and it is very important to educate staff for the treatment of suicidal patients as well)
• Burnout syndrome and prevention measures against its occurance and the promotion of mental health in the workplace.

*Knowledge will be the best weapon to fight with for more dignified life of the elderly in residential care.*

19 Milicevic-Kalasic A. Development of the Psychogeriatry in the World and in Our Country. Gerontology, Journal of the Gerontological Society of Serbia 2005; (1):28-34

# 9. VIOLENCE AGAINST WOMEN – THE UNTOLD STORIES

## Gender Aspects of Aging

Older women and men can have many challenges in connection to active life and dignified aging. Each of the challenges should consider different positions and needs of older women and men. Due to those reasons, it is necessary to mainstream the gender approach in an aging society[20]. Many of the women, especially the older ones, are still discriminated against in various areas of everyday life. The governments and states are required to take all measures necessary to eliminate all forms of discrimination against women, to promote progress and empowerment of the women throughout their entire life[21].

Documents of the European Union state that the policies intended to the elderly should be harmonized with the policies for achieving the equality among women and men. It is recommended to the member states and the European Commission to support active involvement of civil society organizations, women's organizations and others, as social partners in promotion and increasing safety, health and full inclusion of the older women and men in all aspects of community's life[22].

Gender aspect of aging confirms the tendency that women live longer than men and that more women live alone.[23] Simultaneously, older women do not represent homogenous group. They differ in experience, knowledge, abilities and skills, and their economic and social position depends on various demographic, political, local, cultural, working, individual and family factors[24]. Both men and women face age based discrimination, but older women experience aging in a different manner. Influence of the of gender inequality they face throughout their life worsens in old age and is often deeply rooted in cultural and social norms. Discrimination, which the older women face, is the result of unequal division of resources, limited access to basic services, neglecting and violence, which happened to them through entire their life. Age based discrimination is tolerated and accepted on individual, institutional, and even policy level, because the awareness on the issue is underdeveloped, as well as mechanisms for implementation of the laws and policies[25].

Many of older women take care of the children, of the husband/partner or older parents, and financial and emotional price of this unpaid care is rarely acknowledged. Their pensions are lower that men's pensions and they are at greater risk of poverty[26]. Rights of older women to self-determination and approval in area of health or social care services. When the public spending of social services are reduced, including long-term care provisions, spending for the older women and other dependant persons are unproportionately reduced[27].

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20 Aging policies: *Gender equality, work and old age*; an abstract from UNECE Policy Brief on Ageing No. 2, November 2009, translation by: the Ministry of Labour and Social Policy of the Republic of Serbia

21 Committee on the Elimination of Discrimination against Women, 47th Session (04 Oct 2010 - 22 Oct 2010). *General obligation No. 27 about older women and protection of their human rights*
http://www.gendernet.rs/files/dokumenta/Medjunarodni/Opsta_preporuka_CEDAW_komiteta_br._27.pdf

22 Council Conclusions on Equal opportunities for women and men: active and dignified ageing, 2947th Emplozment, Social policy, Health and Consumer Affairs, Council meeting, Luxembourg, 8 June 2009

23 There are 100 women of 60 on 83 men, on 100 women older than 80 there are 59 men. Apart from that, 80% of men older than 60 is married, comparing to only 48% of older women. Source: UNDESA
http://www.un.org/esa/population/publications/agening/agening2009.htm

24 General Recommendation of the UN Committie No. 27, point 8;

25 Ibid, points 11 and 15;

26 Ibid, point 20; and: The First National Report on Social Inclusion and Poverty Reduction in the Republic of Serbia, the Government of the Republic of Serbia, 2011: 103-104 and 190-198;

27 Ibid, point 21; and: European Women's Lobby, (2012). *The price of austerity – The impact on women's rights and gender equality in Europe, p. 15 and 19*

Gender based stereotypes and practice which originates from the tradition and customs can have negative influence on all aspects of life of older woman, including the attitude and behaviour of the care providers and may lead to psychological, verbal and financial abuse of older women.[28] Poor, older women, older women with disability, those living in rural areas, illiterate or with low education level, those who were unemployed or worked small number of years, refugee and internally displaced women are specially endangered groups[29].

## Older Persons and Abuse

Abuse of older persons is a serious problem, which, as international documents point out, demands urgent attention and action to raise awareness of the problem, prevent it from happening, improve information access, protection and support. All forms of abuse against older persons happen during care and nursing relationship, at home or any of institutions which accommodate the elderly. Most often, they cover various actions of physical, psychological, sexual and economic violence and neglecting (which includes not reacting as well), which causes pain, suffering or can upset the older person. Each person can suffer from more than one form of abuse at the same time. Some forms of violence and neglecting are specific, because they are based on specific characteristics of older persons (reduced moving abilities, dependence on other persons or services, weakness or illness, fears, etc.). Abusers can be family members, friends or neighbours, professionals or volunteers. On institutional level, culture and rules of institution enable or influence on abusive behaviour of the employees. At the system level, the system and its structure and society encourage or allow attitudes, which prolong violence against the older persons.[30]

Due to lack of harmonisation in defining and reporting on incidents, there are insufficient reliable and valid data on scope of violence against the older persons. Helpless older persons are most vulnerable to violence phenomenon and other destructive behaviour, which leads them to danger or hurt them. They are often victims of not only direct forms of violence, but neglecting the basic needs, dignity, band on social contacts and similar degrading actions.[31]

The *Report on Work of Centres for Social Welfare in Serbia for 2012*[32], there are 1,204 victims of domestic violence in population older than 60, which is only 12.9% of the total number of recorded victims. Number of older women who are victims of violence is twice larger than number of older men, who are victims of domestic violence (30.1%). Physical violence is most common, while the economic violence is not recorded (or not presented in the Report). The largest number of registered older persons, are the victims of domestic violence (1,147), and only two older persons were registered as the victims of violence in institutions for residential care. The procedure was commenced in only 245 cases where the victims were older persons. The procedure of sentencing measures of protection against domestic violence was commenced in 40 cases and indictment was raised in 34 cases.

The Research[33] on prosecuted acts of domestic violence on the territory of police administrations of Nis and Novi Sad in 2010, states that approx. 10% of violent acts were against the older family members, which confirms that this violence is less reported and more difficult to identify comparing to violence against younger family members. More than 75% of older persons who were the victims

28 Ibid, point 16;

29 Ibid, point 19

30 Petrusic, N., N. Tordorovic, M. Vracevic, (2012). *Violence Against the Elderly – Case Study on Domestic Violence,* Red Cross of Serbia

31 Regional Strategy for Implementation of MIPAA was passed by the Economic Commission of UN for Europe in 2002 (UNECE). ECE/AC.23/2002/2/Rev.6 of 11th September 2002, http://www.unece.org/pau/_docs/ece/2002/ECE_AC23_2002_2_Rev6_e.pdf.

32 The Republic Institute for Social Protection, *Synthesised Report on Work of Centres for Social Welfare for 2012,* Belgrade, June 2013

33 Petrusic, N., N. Tordorovic, M. Vracevic, (2012). *Violence Against the Elderly – Case Study on Domestic Violence,* Red Cross of Serbia

of domestic violence are of female gender, which confirms gender aspect of domestic violence. Among the offenders, violent acts against older family members in the research sample dominate men (over 90%) and the largest number of offenders is between 35 and 45 years old, which implies that the violence against the elderly is committed by their children or grandchildren. Violence against older women by their spouses is "prolongation" of continuous violence they were subjected to in their younger years. Cause for prosecution of the acts of domestic violence against older persons is physical violence. Psychological violence is rarely reported, because it is not insufficiently recognized, there is high level of tolerance of this form of violence present, and the reaction of the institutions of the system is not expected for there are difficulties in proving the violence.

Records of violence against older persons in social residential care institutions also show increase in number of reports/complaints, which was 112 in 2012, made by 67 victims of violence[34]. Comparing to 11,637 beneficiaries in public social care institutions for the elderly, number of the victims of violence is merely 0.57% of the beneficiaries. Forms of violent acts which were registered are: physical violence (13 persons, 10 men), emotional abuse (3 women), exploitation (5 persons, 3 women), while the largest number is in the category 'other' (46 persons, 28 women). Sexual abuse was not registered, as well as neglecting and maltreatment of the older persons in residential care institutions. Structure of offenders (55 persons, 39 men): among the staff of institutions is merely 3 persons (2 women and 1 man), while the category 'other' includes 52 persons. It is important to point out that the number of the registered cases of violence is from merely 5 out of 40 institutions. Charges were brought against 26 offenders, out of which, only one was against the employee in institution. The Report concludes that the total number of the registered cases of violence is small, that the cases of violence between the beneficiaries is mostly recognized, and that there is a significantly small number of offenders among the staff, as well as notably large number of cases in the category 'other'. In addition, it is stated that further more detailed research of the violence against the beneficiaries of the institutions for the adults and the elderly is required, as well as to sensitize the staff to recognize the violence and prevent its escalation, and to provide better procedures for registering, protection of the victims and sanctioning of the violent behaviour of the employees.

### Older Women and Violence

Many of the older women used to live in the environment filled with violence and abuse for many years, in times when the violence in partnership and family was tolerated phenomenon. Those attitudes began to change recently but older women could still give up trying to get help or consider that it is too late for them. The society recently began to acknowledge rape in marriage, and has no perception of the older woman as a victim. Signs of physical violence could be contributed to the injuries due to falls. Older man can sound reasonable and harmless when reporting on his actions. Older women could be confused or presume that there is no purpose in talking about the abuse. Those are some of the reasons which may influence the professionals not to notice violence against older women. Due to that, it is important for the experts to listen carefully and observe, as well as to always talk to women separately from their partners or family members. All assessments (in social and health services) should contain questions on abuse of the older women by their partners or any other family member[35].

Researches confirm that the cases of older women victims of the violence in partnership are usually long-lasting violent relationships. The victims usually suffer from many various forms of violence, and a long period passes before they ask for help, and their environment is usually aware of the existence of violence. Alcohol abuse often leads to escalation of violence, and physical and mental difficulties

34 The Republic Institute for Social Protection, *Synthesised Report on Work of Centres for Social Welfare for 2012,* Belgrade, June 2013, page 24-26

35 Mullender, A., (1996). *Work with Older Women, in: Rethinking Domestic Violence, The Social Work and Probation R*esponse, Routledge, London and New York, p. 131-133

and illnesses the victims have, as well as the abusers, represent risks for further violence[36]. Some partners become abusive when woman get ill and becomes weak and powerless. Older women can be less willing to call the police to intervene against their violent partners, who can also be weak, ill or disabled themselves. Woman can take revenge against her abuser when he finally weakens and becomes dependant on her. However, physically weak men can continue their dominance over their physically stronger women, by psychological and emotional abusing, practiced throughout the previous years[37].

Older women are especially endangered when it comes to exploitation and abuse, including economic abuse, when their legal capacity is referred to the family member of representative, without their consent[38]. Recovery from injuries is more difficult in old age, earlier strategies of overcoming the violence and stress are not available or efficient due to poorer health status or other changed living conditions of the older women. Numerous are the consequences of the violence against older women including increased risk of poverty and homelessness[39].

Sensitive and believing approach represents ease after many years of hiding the abuse or refusing help. Someone to listen to her may be the only thing older woman wants, even if the abusing partner is dead. And when it comes to older women, there is a lot of space for organizing self-support groups and opportunities to talk about the past and present experiences of abuse. This can affect them to recover their lost confidence and self-respect and trust or to make new choices in life[40].

## Research about the Right to Make Decisions and Experiences with the Violence Among the Women in Residential Care

This part presents research findings in relation to the current status of human rights from the point of view of the older persons who are residential care beneficiaries, with the special focus on extreme forms of their violation, such as residential care institution violence and/or domestic violence. We focused on the position of older women, due to the gender inequality present during their entire life, which got their position worse in their old age.

Project concept and frame for interpretation of data were set by the structure of human rights and their universal applicability. Basically, the point of view defined by this approach sees the system (social welfare system, residential care institutions, both state-founded and private ones, education and training of the staff in those institutions, especially those in managing and organizing positions) as an instance which should learn and improve itself, not to refrer to the beneficiaries of the residential care as the ones who should be adapting (to the present conditions). In other words, it means redefining the roles and different assigning of the responsibilities.

In accordance with the general objectives of the Project, this part of the research was carried out by Autonomous Women's Centre in cooperation with the Institute for Psychology of Belgrade. During the period May – July 2013, we carried out the qualitative research on the territory of Serbia (individual, semi-structured interviews) targeting the older women living in residential care institutions. Interviews were realized by Dragana Vujinovic and Vedrana Lacmanovic of Autonomous Women's Centre, and the Research Report was compiled by Dragica Pavlovic Babic of the Institute of Psychology.

36 Amesberger, H., B. Haller & O. Tóth, (2013). *Mind the Gap. Improving interventions in intimate partner violence against older women – Summary Report*, Institut für Konfliktforschung, Vienna

37 Mullender, A., 1996, p. 131 - 133

38 Ibid, p. 27

39 Ignjatovic,T., D. Pesic, (2012). *Poverty Risks among Women Experiencing Violence*, Autonomous Women's Centre, Belgrade

40 Mullender, A. 1996, p. 131-133

*Methodology*

On the basis of many years of experience we assessed three topics as of special relevance for understanding the problem and options for improving the position of this specific group of older women: (1) independence in decision-making, (2) experiences with domestic violence and (3) experiences with the violence in institution.

Several reasons influenced the decision to use qualitative methodology, i.e. semi-structured interviews. The first group is in connection to the nature of the phenomenon: (a) personal perception provides more developed, sensitive and, finally, livelier image when its said in one's own words, rather then assessed on previously defined attitude scales; (b) possibility to analyze the answers at various levels, integrating data as per meaning or different type or different sources, multiple categorizations; (c) broadly defined concept which was being assessed was not possible to describe in detail over indicators in advance; (d) implications and recommendations for policies in this area are better founded when the integral part is the perception of the interviewees, than when we make indirect conclusions, based on predefined answers.

The second group of reasons is in connection to the interviewees who made the sample for this research. There was an assumption that: (a) there was large variety in connection to education level, verbal fluency, development of vocabulary and abilities for generalize personal impressions, so that it was more appropriate to answer orally rather then in writing and to use open instead of closed questions, (b) there are large differences in connection to ability to focus on the questions, development of the answers and the patience to answer them. Therefore, it was necessary to apply the technique which was flexible in time of asking and which was adaptable to the conditions and abilities of the person the answers were expected from.

Bearing in mind that the questions are relatively generalized, we considered that the best option is to provide answers to key issues in the beginning, and that they can provoke longer and/or more developed answers. Questions describing important characteristic of the environment where the interviewee lived are not mandatory, i.e. if the interviewer assessed that she has no capacities (patience, concentration) to continue conversation, interview could have been shortened for the context questions, but not for the key ones.

Basic analysis of the answers is based on categorisation of the answers. Possible categories were predetermined, on the basis of analyses of the limited number of interviews. Not every answer had to be in any of the predefined categories, because they were defined to cover sensible scope of answers, not all of the answers. In other words, if the answer was irrelevant, it was not categorized.

Apart from the interviews with the beneficiaries of residential care, data were gateherd in two more ways: (a) observations and comments of the researchers in the reports from the interviews and (b) talks with the management of the residential care institution. The questions for the management had, apart from informative, the control function as well. Namely, they were used to compare the two perspectives, but also to complete the data provided by the interviewee and check them with additional data.

*The Sample*

The research sample were the female beneficiaries (total of 79), who were accommodated in any of the residential care institutions for the elderly in Serbia. They differ in social-demographic characteristics (place of origin, age, educational level, occupation, nationality, etc.), as well as in accommodation characteristics (type of institution, duration of accommodation). When choosing the interviewees the important criteria their responing abilities, i.e., mental abilities which enables them to participate in conversation.

The research was carried out in 20 institutions in 13 towns/cities in Serbia, out of which 5 are state-founded and the rest are privately owned.

In 5 state-founded homes, the interviews were carried out with 25 women (32%), and in remaining 15 privately owned institutions we talked to 54 women (68%). The youngest interviewee was 65 and the oldest one was 91. Considering the duration of accommodation in residential care institutions, there are large variations from month or two to ten years (the longest period was 11years). However, the largest number of women was 2-3 years in home.

Most women (67, i.e. 85%) have children and that is, as per analyses, very important circumstance for making decision about accommodation to home.

Only every sixth of the interviewed women decided to independently manage its properties (12 women, i.e. 15%). However, most women, 43 of them (54%) gave up this right and chance to independently decide on property, by referring their right to others. Finally, there are women who claim that they do not own a thing (11 answers, 14%).

## Findings and Discussion

### 1. Right to Make Important Decisions Independently

If it is possible to assess the status of human rights on the basis of a single indicator, that indicator would be the right to make decisions independently. Independence in decision making is taking the responsibility for the decision and its consequences and it is a presumption of autonomy and authenticity, as well as the dignity of a person. As every human right, this one is very fragile, especially when it comes to living conditions that are mutual to all of the interviewees: old age and residential care.

This research assessed the right to independent decision-making on the basis of one situation of the decision-making, situation when very delicate and emotional decision with long-term consequences, which are connected to the change in social environment and way of life is made. Therefore, the question was *How the decision on your accommodation in residential care institution was made?* There is large variety in answers, but on the basis of the criterion WHO made the decision, they could be divided into two categories:

1.1. *The beneficiaries who independently, of their own free will, made such decision* (45 answers, 57% of the interviewees). It is difficult to assess whether it is a lot or not. Considering that those are adult, mentally preserved and functional persons, it is presumed that they will make such decision independently, i.e. freely and on the basis of information. Three types of decision-making can be differed under this category:

(a) *The decision was made completely freely and independently from other persons and influences* (29 women, 37%). It is interesting that the large number of answers in this category talks about the choice of coming to residential care institution as of the decision which brings emancipation and independence to the person (e.g. from the obligations they can no longer fulfil or from the persons who have the right to live separately, as they want to, not in mutual household).

*I agreed with the family, it was the most reasonable.*
*Grandson got married, it was too crowded, I did not want to disturb them or they disturb me.*
*I was lonely at home, and it was upsetting me.*

(b) *Decision was made with or because of someone* (9 women, 11%). It is always about two close persons (partners, sisters, close friends) who assess that the residential care has some advantages for them (solving their housing problem, healthcare problem, etc.).

(c) *It was their decision, but under pressure* (7 women, 9 %). The significant number of cases includes persons who feel that they disturb others and seek for options to get out of that situation.

*I had realized I had to go to home, I became a nuisance and they expected me to make decision on my own, and I did, I came to home.*

1.2. *Someone else made the decision on accommodation into the residential care institution* (34 women, 43%). Those decisions also varied by the manner of decision-making, i.e. interference of the others.

(a) *The decision is completely someone else's,* the interviewee was not consulted at all, and in some cases she did not even know she would come to the institution (18 women, 23%). In most cases, the person making such decision is close family member, but there are examples, if the interpretation of the interviewers is correct, those were health care employees.

*Social worker brought me here when my sister died.*
*I was first hospitalized on the psychiatry department, and then here. I did not sign anywhere, I did not want to go to any of the homes.*
*My son tricked me. He did not tell me where I'm going. I did not even know.*

(b) *Decision was apparently their own, but made under large pressure* (16 women, 20%). This category was described similar to the category (c) in group of independent decision-making. However, repeated attempts of classification demonstrated that there is difference in quality of the decision between the two groups, i.e. in argumentation on which the decision was based on. What differs those two groups of women who were under the pressure to go to home? The difference between them is not in the level of satisfaction with residential care or adaptation to the home environment, but in maturity of the decision which was made. In the previous group (independent decisions), person discussed and considered all circumstances and based her decision on them, even unwillingly. In this group, however, women were overwhelmed by the feeling of rejection and/or existential fear (such as that they are unable to take care of themselves) and that emotion is pushing them to the residential care.

Data about the independence of the interviewees and their right to make decisions were analyzed from another point of view as well – from the point of view of the institution itself. The institution, of course, has insignificant, if any, influence on making the decision about coming to the institution. However, the life in home, as everyday life of any adult person consists of a large number of situations which require decision-making. It seams that the conclusion that the policy of institutions is to discourage independence and decision-making of their beneficiaries in many ways is somehow justified. The reasons justifying the strategy are care of the beneficiaries and risk prevention, and the mechanisms are the rules of the home, explicate or implicit. The nature of the rules is general, of course, they are not selective and equally affect all of the beneficiaries, but there is a great issue of their justification, especially if they are applied non-selectively. Namely, the institution manages the money of the interviewees and how it will be spent, there are bans of locking the premises during bathing or closing the room, entering the kitchen is forbidden or cooking is forbidden, work on home's property, too (e.g. picking fruit), etc. The list is practically endless (of course, not all bans are present in all of the institutions, each institutions specifies its own set of bans and rules). And again, even though the reasons behind those bans are clear, their consequences to the dignity and independence of the beneficiaries are also very clear and negative.

Apart from decision-making, the right to privacy is another indicator for making conclusions about human rights of the beneficiaries of residential care. Again, we can conclude that from the institution's point of view the privacy is recognized as an important topic when it comes to the quality of residential care. All of the interviewed representatives of the institutions talked about the efforts they make in their institutions to protect privacy of the beneficiaries and that it is being violated only when the

safety is in question. However, it is evident that the lack of privacy is chronic and general problem, only that in some institutions staff works on it more actively. One of striking examples which illustrate this statement is equipment and size of the rooms. All of the rooms in all institutions have unified – modest and depersonalized furniture, single and unchangeable schedule, lack of space. The number of the beneficiaries per room is certainly determined by the need for accommodation, but most institutions, including the ones which are purpose-built, include multi-bed rooms. No one commented or justified the circumstance. Maybe there is an assumption that the beneficiaries will get closer and be more referred to each other. However, as in "real life', there is not a single evidence which shows that the quality of social aspect of person's life improves by the number of the beneficiaries sharing the same room.

### 2. Experience of the Domestic Violence

Experience of the domestic violence is the topic our interviewees have lot to talk about, even though it does not appear like that. A bit over a half of the women stated that they never experienced domestic violence (45 women, 57%). Significant number of them speak of tender and caring partners. On the other hand, women who talk about domestic violence, testify about various forms of domestic violence, as well as various duration of violent behaviour. Those testimonies are classified in two basic categories:

2.1. *Violence against the woman in her family environment* (22 women 28%). Testimonies about the violence registered under this category are specially dramatic, even though those are no longer present experiences. Women, when speaking of experiences of violence, typically chose particularly harrowing and memorable experiences. The most commonly reported cases were of chronic sexual abuse, either in childhood (4 women) or in marriage (8 women). Sexual violence in marriage was always accompanied by physical abuse. In some cases, it had a tendency to expand, in two ways: the abuser became violent against other family members, or other members of the family became violent against the victim. In some cases, the women reported that they had protection (5 women), and 12 women had left the family and thus stopped the violence.

2.2. *Current violence against woman by her family members* (12 women, 15%). Although less dramatic forms of violence, these statements require more attention, as they take place in institutional environment. Unlike the previous category, the basic form of violence that these women suffer from is neither sexual nor physical violence, not even verbal.

In most cases, it is the financial violence (7 women). Abusers are sometimes aggressive both verbally and/or physically, but the basic motives that drive violent behaviour are expectations to gain assets. Although aware that they are the victims of violence, women generally do not report it to the institution, do not expect protection and solution from the institution, because they probably believe (there are no explicit confirmation of this interpretation), that it is their private issue, which should be resolved by themselves.

Five women reported on their reactions to the violence they suffered from their direct descendants. In all five cases, the abuser is the son, and in two cases his marriage partner, too. In each of these situations, the woman sees that the generator of domestic violence is the partner who provokes violent behaviour of her son.

> *When my husband died, the older children turned against me. I know they are good, but her husband and his wife joined against me, they kept pressuring me to sell my home and buy two smaller ones. Only after I shared everything, the problem was gone. I, unfortunately, have nothing more of personal property, but I'd left money for my funeral and it is safe.*

## 3. Experience of Institutional Violence

3.1. *Violence by the staff.* Almost all of the interviewees, said without hesitation that they do not suffer any form of violence by employees of the residential care institution (66 women, 84%, other 13 women did not provide any answer). There is no reason to doubt this finding, or the honesty of the answers, or not to be happy about it.

However, when interpreting the findings we should bear in mind two general circumstances: (a) the average population in Serbia, and the population our interviewees belong to restrict the definition of violence to explicit physical or verbal violence; (b) the same is true for institutions, many forms of violence is practically invisible, especially those that subtly threaten the dignity of the older person.

While they agree that there is no violence, the interviewees do notice behaviours or attitudes that threaten them. They do not refer to it as violence, but formulate it as general comments or observations, such as:

*There is no violence, but the conditions are violent.*
*There is no violence, but they could be nicer.*
*No, but the service is poor.*
*There is no violence, but the staff is like in a hospital, and the food like in a restaurant.*
*Sometimes, they bother us, we to always have something to do.*

3.2. *Violence by other beneficiaries.* When asked whether there is violence between the beneficiaries of residential care, and whether they were the victims of such violence, not a lot of answers were obtained (19 women, 24%). However, these responses are sufficient to provide us the possibility to reconstruct the image of violence among the beneficiaries, and to see that the violence exists in various forms, including as the basic forms:

(a) *Aggressive behaviour at the level of personal relationships*. The interviewees report on examples of arguments or verbal attacks. Another form are the rude behaviour and harassment. In both cases, the rule is to leave it to the staff of the institution, to regulate it (by warning and reprimand or transfer), in satisfying manner. The tone of presentation of these examples shows that such cases do not disturb the interviewees a lot.

(b) *Non-selective aggressive behaviour* directed at anyone or not directed at all. This behaviour is sometimes an expression of personal style (e.g. making a constant loud noise and expressing dissatisfaction), and sometimes the consequences of disease (e.g. the beneficiaries with dementia). In this case, ignoring is applied. Such behaviour is usually not seen as violence directed towards the person, and the interviewees are fairly tolerant and full of understanding, especially when it comes to ill people.

## 4. Specific Living Conditions

This heading provides a brief overview of some evidence, which make up a significant interpretative framework for the collected data.

Based on the different answers of the interviewees, it can be concluded that the fact whether it is a privately-owned institution or state-founded makes some significant difference: the beneficiaries of privately-owned homes have greater awareness that they can initiate and ask for change and, consequently, are more agile in establishing conditions which suit them. This may be due to the fact that women who are accommodated in privately-owned institutions are of better average educational and financial status. Most institutions are located in the "peaceful environment" away from urban areas. Although this circumstance is generally assessed as an advantage, from various answers and comments of the interviewees it is clear that they what should be peace in fact perceive as isolation followed by a feeling of anxiety.

*Descendants and communication with the descendants*. The majority of women (67 of them or 85%) have offspring, and that is, as shown by analysis, a very important factor in making a decision about going to a home. The women who have no direct descendants make that decision easier. We can conclude from their explanations that they start thinking about going to the home earlier, and see it as an opportunity for someone to take care of them, since there is no one in the family.

The situation is not quite reverse, when it comes to making these decisions by women who have children. In fact, for a certain, larger number of them, the fact that they have children makes the decision more difficult, because it is highly emotionally saturated, specially with the feeling of rejection. There are, however, those women who make decisions with their children, and even against their will, not wanting to make too much pressure and ask of them something they were not able to provide (typical answers in this category are about the children who are too busy, small living space, distance ...).

In addition, the existence of children in many cases colours emotionally the experience of home and determines adaptive capacities of women. For those who do not have offspring, or came to the home in agreement with the children, the adaptation is more successful and shorter, and the home gives them positive feelings. This conclusion is not true in all cases, but it describes well the trend.

*Financial situation/property*. Only 12 women (15%) manages their own assets. Among them, there is a wide range of difference in the value of assets at their disposal - from a number of houses and apartments, large estates to those who have nothing more than a modest pension. However, what makes this group of homogeneous is the position that they do not want give up the responsibility for managing their own property, as thus, indirectly, they still have a feeling that they manage their own lives and, consequently, that they can make decisions which are in their best interests. The right to manage their own property, at least to some extent, have been preserved by women who maintained a pension, and distributed other property (6 women, 8%). However, most women gave up the right and opportunity to make independent decisions - 43 of them (54%), by signing the property over to children and/or grandchildren (21 women) or will do so soon (4 women), transferred the right to home (1 woman) or municipality (2 women) or to a third person who in return subsidize the cost of residential care (1 woman). This category includes the women who did not perform the procedure of transfer of ownership, but they do not manage their property, someone else does, usually the direct descendant or relative (14 women). Finally, there are women who say they do not have “anything in their name” (11 answers, 14%). However, for some of these answers we can not unambiguously conclude whether it is the women who have already transferred the property to someone or who have never owned any assets. However, resignation is a striking characteristic for this group of women.

*Duration of accommodation in residential institution*. In terms of length of stay in a residential care institution, there are major differences. However, this rule does not apply to the fact that the length of stay increases the level of adaptation to the home. This is true only to a certain extent. In fact, there are cases where dissatisfaction is growing with the of time (initially she was satisfied, and then more and more disappointed), or where initial enthusiasm turns into resignation and helplessness. In addition, there are large differences in the level of adaptation among women who are in the home for a short period of time (less than a year). Among them are also those who are very unhappy and want to get out at any price, and those who believe they began to live when they came to the home. In any case, it is clear that the length of stay in a residential care institution cannot be considered an indicator of adaptability of the people to the institutional environment.

*Responding*. The comments by the interviewers, as well as the variety of the answers, clearly demonstrate that these women have shown a high degree of cooperation, willingness to participate and honest disclosure of personal content. Interviews were conducted in an atmosphere that was

friendly and exuded confidence. This relationship was expected, and our interviewees behaved quite in line with the prejudice that older people in residential care are looking forward to any opportunity to talk to someone because they are eager for any kind of human contact. This is a serious signal which speaks of the (more or less hidden) social deprivation. In other words, behind this receptiveness is their need to have someone to talk to about important things in their lives, to show respect and consideration to what they have to say, and that "casual conversation" is not enough. However, the fact that they were willing to talk does not mean that all the answers were focused and direct. On the contrary, there is a significant number of irrelevant or collateral responses, as well as the unnecessary elaborations.

## 5. Control Variables: From the Perspective of Residential Care Institutions

In order to make the image of life in residential care institution more complete, interviews were also conducted with representatives of management of institutions (usually one person). The meaning of communication of these findings is in option of their comparability, when the same subject is viewed from different perspectives, which provide a more comprehensive analysis.

*5.1. The right to privacy.* All participants correspond explicitly (11 out of 20), or implicitly, by listing examples (a total of 8 out of 20), that the privacy is an issue which is being considered and that the institution is making efforts to provide users with a high degree of privacy. Most of them state they manage to be successful and explain situations which deviate from this principle. However, when these situations are analyzed, it is evident that there are situations when the limitations are (perhaps) justified, for example, assisting with bathing and changing clothes, reporting to the doormen, increasing the number of beds in the room... However, there is a larger number of examples where it is not clear why the limitation was introduced, and in particular it is not clear why it is applied uniformly to all beneficiaries. Examples of such restrictions are: always opened door to the room so that the beneficiaries can be monitored, non-participation in the work of the home's farm (fruit picking); cabinets/wardrobes are not locked, no sound on the TV; there are no organized activities; restricted movement; unadjusted furniture and equipment in the room, small space; personal belongings in the room can not be seen, no gathering in the common area, except for meals; the beneficiaries are not allowed to have their money in their possession, no shops nearby, no phone, other than in the manager's office; they can not to leave the building of the home, except in special circumstances and with escort, etc.

The answers of the interviewees show that they do not experience these limitations as a measure which is in their best interests. On the contrary. Sometimes these restrictions are unbearable for them. For example:

> *I do not like it. Anything. They are all silent on me. Do not give me the shampoo, soap, do not let me buy clothes, shoes. Do not let me go to the gate. When I was able to serve his mother and father, his sister, I can serve myself. They won't give me my ID card. I'm penniless, with no way out, worse than in Zabela (*prison*). I want to go. I want my freedom. I'm not a war criminal so that they keep me here.*

However, there are the reverse examples, where they work actively, even against common standard, on the inclusion of women in various activities, their social integration, on fostering feelings of belonging to the institution. Here is a description provided by the interviewer:

> *First contact radiates with width and warmth, few dogs are basking in the big yard with lots of flowers and greenery. At each step, there are the table and chairs, daily delivered print. A large number of the beneficiaries are looking forward to us, they say they have a lot of guests*

*and are very happy to attend lectures, concerts and other social activities. The manager was changed and she continued to maintain a positive attitude of the prior, and according to the happy comments of the beneficiaries I talked to, she is successful. Confirmation is that the beneficiaries call their rooms - "house/home" (they invited me to come as a guest).There are spaces for socializing with large TVs on each floor. Premises are light and there are pictures on the walls. Garden around the home is decorated, the grass mowed. They were very willing to talk. The rooms are designed as suites, each has a TV and fridge, and the beneficiaries socialize, and drink coffee together. All problems are being solved in the meetings and they are willing to hear their suggestions and criticisms.What disturbs the work are the younger beneficiaries who are ill and there are many of them, but the beneficiaries are all together and I have not noticed they are being separated from each other. It was interesting when the host of occupational therapy said she organized the cooking competition, as it was recognized that many beneficiaries need to cook, so, as this was forbidden, they organized a competition when the beneficiaries could use the the kitchen.*

5.2. *Neglect and abuse of the beneficiaries in the institution*. As expected, all answers to this question were negative. Everybody denies the existence of such behaviour. Several of them said that some beneficiaries do not understand the diagnosis of other beneficiaries and they complain about their aggressive behaviour. They do not deny that there are aggressive beneficiaries, or that they do not have many solutions for the aggression that is part of the symptoms of certain diseases.

## Conclusions

1. Direct/close environment, especially, close family, are the powerful factor that determines the adaptive capacity and general attitude, primarily the emotional relationship to the home accommodation. It is therefore very important that the decision on accommodation in the home is discussed and shared with the loved ones. It is especially risky if a woman thinks she is placed in a residential care institution against their will. In that way, the "front is being opened" in the initial phase, i.e. the cooperation is not established. Decision on accommodation in the institution made by others generates a feeling of dissatisfaction and rejection.

2. Neither the social welfare system nor the culture we live in support independence of the older people's decision-making (optional: the impact of the gender dimension should be examined). In this regard, the population of older people in residential care is endangered on the basis of both criteria (age and institutional accommodation), and the degree of vulnerability is difficult to estimate, because they themselves share the view that they "should not be allowed to interfere in everything," as they told us in one of the homes.

3. We identified factors which, in terms of residential accommodation, largely contributing to the experience of autonomy and control over their lives: (a) the disposal of and managing the assets, (b) an assessment of one's own position in the family (is he/she 'in the way', do the family members perceive him/her as an nisance), (c) the distribution of care (this factor is a controversial position - some women "like" to care, because this is how they involve in family matters and feel useful, while others see the advantage of placement in the institution in the fact that they no longer have a great number of responsibilities and worries, and they now have considerable free time which they can arrange as they want).

4. Topic of autonomy in decision-making and the right of the elderly to make decisions is not identified as an important, either in the eyes of the beneficiary, or from the perspective of the institution. This issue requires development of institutional sensitivity. However, the issue of privacy is an important issue. Although the privacy is the topic of many discussions, it is clear that it is chronically endangered in (almost) all residential care institutions, and different forms of violation of the privacy have been demonstrated.

5. The mechanism which endangers the privacy of the beneficiaries and their autonomy in decision-making is a residential care rulebook. This paper stipulates the rules which apply to all. It is this universality of the rules that represents the first step in the invasion of privacy.

6. We can see from the answers of the interviewees, as well as the comments of the interviewers, that the institution takes social integration little info account. Typically, the attitude of staff to beneficiaries is polite, but conventional, superficial and impersonal. In addition, some institutions do not provide the conditions for social contacts between the beneficiaries and/or people from the "outside world".

7. Violence in institutions for elderly people is present in various forms - by institution, and by other beneficiaries, as well as by the family. Violence is present more often than the beneficiaries and institutions are able to recognize. It seems that the beneficiaries protect themselves more successfully from violence in the institution, than from domestic violence, they recognize it easier, name and describe it more accurately.

8. When it comes to family, it is not just about the history of violence to which a woman was exposed to, but also to violent behaviour toward her that continues in the institution. Eventually, the violence typically gets harsher and harsher face. Basic forms of domestic violence in the context of the past experiences were sexual and physical violence, while the current violence represents financial exploitation and psychological abuse. Many women decide to give up the property just to break up the chain of violence. The beneficiaries rarely or never talk about this issue to the staff of the institution.

## Recommendations

1. Quality standards of residential care accommodation should guarantee the respect of human rights, as well as the needs of the beneficiaries - social, emotional and intellectual needs. The current regulations are narrowly focused on the physical conditions of accommodation, safety and health care, but the dignified old age means taking into account all the needs.

2. Home's rules should be harmonized with the general standards from the perspective of human rights, and not to be provisional and formulated in accordance with (someone's) intuitive understanding of such important concepts, such as human rights. There must be a system of appeal and the possibility that the elderly receive assistance (independent representatives) when they complain about the service in residential institutions.

3. When formulating the home's rules, provisions should be considered from different perspectives and those perspectives should be harmonized. In addition, home's rules should be used flexibly in accordance with the specific circumstances and depending on the essential characteristics of the beneficiaries.

4. Encouragement of the responsibility and independence in decision-making, instead of submissiveness and helplessness, is an important matter of respect for the rights and dignity of older persons. The most important aspect of this is disposal of one's own property, because the property provides a sense of control over one's own life and choices. In addition to the property, various other factors contribute to the independence of the beneficiaries (medical treatment procedures or bathing procedures, thing that are not allowed, etc.).

5. However, the question is which measures are possible to achieve by encouraging responsibility and independence of older persons at the system level. At the level of regulations, it would be appropriate to "translate" basic principles of social protection and users' rights guaranteed by the law to the level of standards and rules, with consideration of different perspectives, including the

perspective of the elderly. At the level of the institution, one of the measures would be cultivating attitude and creating internal rules, which respect human rights and dignity of older persons. Good governance, empowering employees, encouraging an open and supportive work environment, transparency of the complaint process, reduce the risk of violations of the rights of older persons in the institution. Another measure would be to educate staff on how to respect those rights, and how to encourage responsibility and independence of the beneficiaries of residential care institutions.

6. Staff should have basic knowledge of domestic violence, a basic knowledge of gender issues and an understanding of the stereotypes and prejudices related to gender roles. The institution should consider the possibility to give older women a chance to talk about their experiences of violence, i.e. to have someone to listen to them carefully, because than their stories can make sense, and therefore increase their feeling of self-esteem and faith in possibility of making the new choices.

7. Special attention should be paid to the protection against the current violence by the family members, the financial and psychological abuse, which some women are exposed to in the institution. The beneficiaries should have the information on whom to contact and what the measures and services are available to them. Staff of the institution should be sensitized to these issues and should enjoy the trust of beneficiaries, in order to provide the necessary support and protection.

8. Institutions should develop sensitivity to the issue of institutional violence, which includes not only physical and verbal violence, but also other, more subtle forms of psychological violence, neglect and negligence, which do not originate only from other beneficiaries, but also the staff. Low awareness of the problem may contribute to the abuse by the staff. There must be a system that supports staff to report incidents of abuse of the elderly, whhich encourages open communication between staff and the beneficiaries. All older persons, especially abused ones should have access to the independent representatives.

9. It is important to promote human rights education specifically related to the characteristics of older people, and older women. This is especially important for those who make immediate environment and are directly responsible for the welfare of the elderly. Raising the awareness of the general public, the media, and children and young people in the education system is also important for an aging society.

10. Active engagement of the civil society and the Ombudsman in monitoring and improving the quality of care in institutions for the elderly is needed.

## 10. GUARANTEEING THE BENEFICIARIES' RIGHTS

*Guarantees of the rights of the beneficiaries of residential care are insufficient*

When we talk about protection and respect for human rights of the elderly, who need to go to or are already users of residential care, we must bear in mind that this is a very complex situation, because it is a high-risk social group of the population, which is due to its health status and powerlessness in a subordinated position in relation to the relatives/guardians, providers of social care services, whether public or private ones, in relation to the state. Potentially, the human rights of the elderly, who are in residential care, may be endangered by the relatives themselves or other people who accommodate older person in home if they act against his/her will, the guardian who accommodates the older person to home, although it does not always have to be in the best interest of the older person, then, the service providers if they do not respect the human rights of the beneficiaries for any reason, and, finally, the state itself, if it does not incorporate obligations it has assumed under international treaties into the national legislation or has failed to provide mechanisms for their application as well as the control mechanisms. The situation is complicated further by the fact that the older person is not always capable to fight to protect his/her rights, either because of the weakness and the subordinated position in which he/she is or out of ignorance, out of fear.

The State of Serbia included in the legislation at the national level, the rights of the beneficiaries to which it has the obligation under the international treaties. However, it did not provide adequate mechanisms for the consistent implementation of the human rights of the elderly in residential care.

In this case, the Law on Social Protection has defined six rights of the beneficiaries who use social care services, ranging from the right to information, through the right to participate in decision-making, the right to free choice of services, the right to confidentiality, the right to privacy to the right to complaint. These rights are extremely general, for example, "the beneficiary has the right to privacy in the provision of social care services." However, the Rulebook governing the detailed requirements and standards for the provision of services does not include those standards on the rights of the beneficiaries. Instead of detailing the legally defined rights, the Rulebook does not even mention them. They are mentioned in the Rulebook on Licensing Social Welfare Organizations, Section 5 - Evidence of compliance with standards for the issuance of a license, where among 17 conditions, four of them are those that are related to the beneficiaries' rights. However, neither these Rulebooks nor the Law define the timeframe for licensing the existing social welfare organizations. One gets the impression that this Rulebook refers more to newly formed organizations and other service providers, rather than to those who are already operating.

Inconsistent respect for the rights of older beneficiaries of residential care can be partly attributed to the lack of familiarity of the staff and beneficiaries with the rights on the one hand and under-developed standards on the other. Each standard of protection of the rights of the beneficiaries, as well as the service quality standards should include indicators of quality, purpose of the standard and recommendations for the acting of staff. This is the only way to provide knowledge, awareness of the importance of respecting the rights and their application.

The recommendation to the Ministry is to issue a special by-law on the standards of rights of the beneficiaries of residential care, which would present in detail all the standards, i.e., would provide for each of them defined quality indicators, the purpose of the standard and key recommendations about treatment, in accordance with the best European practices (e.g. Standards from Ireland or Croatia). In addition, the recommendation is to establish the standards of quality of services in residential care.

The public, representatives of the beneficiaries or representatives of CSOs do not carry out the monitoring of the institutions for residential care, and consequently of the rights of the beneficiaries of the privately-owned homes. In state institutions, the situation is somewhat better, as the governing bodies include, besides the representatives of employees and founders, the representatives of the beneficiaries and CSOs. Out of the visited state-founded homes, this is not the case in the Home Vozdovac, which is a business unit of GC Belgrade, where the Board of Management of the Home includes the representatives of the Home Bezanijska kosa. The same situation is with the participation in the work of the menu commission.

The Law on Social Protection stipulates that only social welfare institutions established by the state, provincial or local government, should have the board of directors with the representatives of the beneficiaries and organizations whose objectives are focused on protecting the rights of persons in nursing homes (Article 132 - Board of the Management and Supervisory Board of the Foster Care and Adoption Centre and Home for Accommodation of the Beneficiaries). There is no legal basis, which would enable the beneficiaries of the privately-owned homes to influence the content and quality of the services they are provided to.

Joint decision-making is crucial to the quality of life in homes. Involvement in decision-making strengthens a sense of community and a sense of control over one's life.

The recommendation to the Ministry is to provide the mechanism via legislation which will enable the beneficiaries from privately-owned homes to formally influence the content and quality of the services they receive, via their representatives in places where the decision-making is.
The state-founded institutions (GC) with several operation units/homes, should allow the beneficiaries to have representatives from each unit in the management of institution - a larger degree of decentralization. In addition, they should allow the representatives of every home in the GC to participate in creating menus.

General and the professional public are not very interested or involved in monitoring the rights of the beneficiaries. They confirmed to us in almost all of the visited homes, especially privately-owned that, except from the representatives of the state bodies and the Ombudsman, none of the public or experts showed any interest in the subject. All attempts to establish relationships with the local community and the public brought no result. We were told that we were the first who came and that they saw our visit as a chance to improve knowledge on this topic.

Many of the beneficiaries do not really participate in making the decision where to spend the rest of their life when they need long-term care, even though they formally agree with the choice. Even when they are in an institution, they cannot influence, and select a daily schedule of life in institution, such as wake-up time, mealtimes, or going to bed/lights out time. They do not have much influence on the content of the services they receive. They do not know much about their rights.

*"I guess what my rights are..."*

*"I don't know and I don't care. I'm not interested. Home is a necessary evil for me."*

*"I am aware of my rights, they are respected, I can give the suggestion, complain, etc."*

*"I do not know what my rights are but can say if I am unsatisfied."*

*"We did not ask because we do not want to stay here."*

In many, especially the privately-owned homes the employees are not exactly sure what we mean when we talk about the rights of the beneficiaries. Generally, they perceive that the beneficiaries have all rights and say "they have a right to express their desires, to eat what they want, go where they want to go, to make phone calls, etc.".

For example, in some homes, they do not realize that the right of the beneficiaries is to be dressed in their own clothes and that it means a lot to him/her – they often dress the beneficiaries with dementia "in whatever is a clean" whether it is their clothes or not.

Often the best intentions encourage passivity of the beneficiaries - by doing something for the beneficiaries instead of stimulating them to do it themselves with the staff there only to monitor and ensure that something is done (e.g. Staff always give medicines instead to the beneficiaries, instead of to enable those who can do it themselves to take the medicines themselves, only with supervision).

Maybe all of this can be correlated with the above-mentioned lack of clearly established mechanisms and standards of human rights of the elderly who are accommodated in institutions.

### Right to information

*"Given the fact that 90% are with dementia, condition after the stroke, they are not able to get information, but the family is informed, everything is listed in the contract"*

*"They know when the meals are, what's for lunch ..." (employee of a privately-owned home)*

*"They have a notice board, everything is available."* (the employee of the state-founded home) - in state-founded homes, 37% of the beneficiaries are with no education and 43% are dependent beneficiaries, out of which most are in the inpatient care units, and many of them do not go to the notice board.

One gets the impression that the managements, especially of privately-owned homes, are more oriented towards informing and attracting potential beneficiaries rather than informing those who are already their beneficiaries. In connection to informing, they are more focused on the relatives than the beneficiaries.

We spoke to the representatives of homes' managements of what about and how to inform the beneficiaries. All the interviewees in state-founded homes said that important information are posted on the notice board (menu, price list, house rules, the amount and time of distribution of the pocket money, etc.). As other mechanisms they mentioned the participation of the beneficiaries in creating menus. They have Councils of the Beneficiaries and other committees, hold monthly meetings with members of the home community. They aso said that the staff is available 24 hours a day, so the beneficiaries can always contact them.

They said that there are many beneficiaries who are not interested.

The situation is very diverse in privately-owned homes. We were told that they talk about everything that is important and inform the beneficiary at the admission if he/she is mentally preserved and if not, inform the relatives. They usually sign contracts with the relatives, and, as they say, "everything is in the contract." In some homes, they told us that the contract, apart from to the contractor, is signed by the beneficiary as well and that he/she is provided with a copy. With regard to the format - font size in the contract is so small in some cases that even younger person who does not wear glasses could barely read them, let alone the older people with impaired vision.

The staff of Nacionalni dom stressed that the Statement of Agreement, signed by the beneficiary

upon the admission, includes information about their rights. This is the only visited home where we saw an excerpt from the Law on Social Protection about the beneficiary's rights on the notice board.

Entire section V of The Home's Rules of the Home Eskulap regulates the relationships of the staff and beneficiaries and behaviour.

In one of the homes, we were told: "It is important that they do not know what the price of home is, and that is why we do not give them a copy of the contract - many would be upset if they knew how much it costs."

In another home, when asked about the beneficiaries being informed about their rights, the answer was: "Unfortunately, we think (they are) not, because a half of them still thinks they are at home."

The recommendation to the managements of homes is to pay particular attention to informing the beneficiaries and/or their guardians. In addition to oral information, those, which are submitted in writing, should be in an accessible format, in accordance with the reading capacities and abilities of the beneficiaries. It is necessary in addition to posting information on notice boards, to ensure that they are available to the bed-ridden beneficiaries who do not go to the notice board. Written information should be written in large letters, to make it easier to be read by the beneficiaries who have vision impairments. In multi-ethnic communities, information should be in two or more languages.

### The Right to Participate in Decision-making

*"I did not get a chance to influence."*

In order to ensure the effective exercise of the right of older persons to social protection, our state has undertaken to guarantee to the older persons living in institutions where they receive appropriate care, that, with full respect of their privacy, they can participate in making decisions which concern living conditions in these institutions (Article 23, Part II, European Social Charter - Revised).

The Law on Social Protection defines that only social welfare institutions established by the state, provincial or local government, should have the board of directors with the representatives of the beneficiaries and organizations whose objectives are focused on protecting the rights of persons in nursing homes (Article 132 - Board of the Management and Supervisory Board of the Foster Care and Adoption Centre and Home for Accommodation of the Beneficiaries). There is no legal basis, which would enable the beneficiaries of the privately-owned homes to influence the content and quality of the services they are provided with.

The beneficiaries need to be actively encouraged to influence their own lives and to be in every way allowed to choose and decide on all aspects of their lives, including those concerning whether to live in an institution. Once accommodated in it, they should participate in the organization of services in the institution, and to give consent to the treatment and care they receive.

Taking the beneficiary's consent at admission, in practice, is often merely bureaucratic and formalized procedure. There is a standard, pre-prepared form - Minutes from the Hearing of the Party stating that under full legal responsibility, the beneficiary makes following statement... (it is not written that it is without coercion). In some cases, the beneficiary writes the statement as he is dictated and in

other, the statement is already written and he/she just signs. The key in the statement is that the beneficiaries is not able to take care of himself/herself due to his/her health status or his/her family is unable to do so and he/she agrees to be accommodated in the home (the implication is that someone comes to the home only because he/she is actually not able to take care of himself/herself).

A greater participation in decision-making is enabled to the beneficiaries of state-founded homes. In every home, there is the Council of the Beneficiaries and various commissions where elected representatives of the beneficiaries discuss key issues affecting the residents and their activities in the home. The second mechanism is a delegation of the representatives of the beneficiaries in the commission for the menu in whose creating participate the employees, too, as well as delegating the representatives to the Board of Directors of the institution.

Beneficiaries from state-founded homes we talked to, are mostly familiar to the fact they have a representative in the menu commission and at the Board of Directors, and some told us they get information from them about what was discussed, and some told us that do not care much whether they do have the representatives or not and what is being discussed.

Employees of privately-owned homes told us the beneficiaries are not included in the governing bodies of the institution and that there is no organizing or self-organizing of the beneficiaries into the Committees. Occasionally, in some homes they participate in the commission for the menu or give suggestions what to cook.

Interviewees among the beneficiaries of privately-owned homes do not even know if there are any governing bodies. Their perception is that everything is solved/dealt with by the owners. They personally do not participate in any decision-making. Their answers were:

*"Nah. If something bothers me I object. To influence what...? "*

*"No, the doctor cames often and she decides about my day."*

*„I'm not interested."*

When it comes to health care, in all of the visited homes, we were told that the user can refuse to take medicine or to go to a specific medical procedure, having previously signed a statement which is kept in the medical record or his/her file.

To provide instructions to the managements of homes on taking – obtaining the accommodation agreement statement, in a manner to comply with the legal procedure but to ensure that the dignity of the beneficiary is not violated. In this statement, the opportunity should be allowed to the beneficiary to say that he/she wants to go home one day, that he/she no longer agrees to be accommodated in the home. They should not insist on the part of the statement, which states that the relatives are unable to take care of him/her, if that is not the attitude of the beneficiary himself/herself. The name of the document should be The Statement not The Hearing and it should not necessarily include the explanation of the reasons for accommodation.

## The Right to Free Choice of Provider

It is difficult for a beneficiary to exercise the right to free choice of provider, before he/she comes to the institution, if there is no organized services for care and nursing of the older people in the community, when they are sick, and need support and even palliative care, which can not be provided or ensured by the family, and if he/she has one.
When he/she decides to go to an institution, again there are not many opportunities to choose, he goes where he was referred to, to home which has vacancies, or to the one he/she has the money to pay for.

The beneficiary of the services of the home should be involved in assessing his/her needs, strengths, risks, abilities and interests, which should be done immediately after admission. In addition, the beneficiary should be involved in making the individual service plan (the Rulebook, Article 13 - Assessment and 16 - Planning).

Individual service plan must also contain aims to be achieved by the provision of services, expected outcomes, specific activities, etc.

From conversations with social workers in state-founded homes, it is clear that there are doubts about the application of these articles of the new Rulebook, while in most privately-owned homes, the staff are not even informed that the new one came into force.

Attempts to talk to the beneficiaries on the subject did not give any results, because they were mainly talking about how they arrived at the home at the urging of others, or under pressure, and sometimes they were even forced to go to home. Some said they came of their own free will, because they actually realized that they did not have a choice. In connection to the selection of a service provider, they told us it was mainly decided by their relatives, who brought them to the home.

The recommendations to the managements of homes to seek actively and continuously feedback from the beneficiaries about the services they provided. It is necessary to conduct a survey among customers about their satisfaction with the services provided, and proposals which segments of the services should be changed, improved and adapted to their needs, at least once a year.

## The Right to Confidentiality

*"We all watch as the big brother"*

The employees we talked to in all of the visited homes confirmed that they do take into account the confidentiality of all beneficiary's data and that they are kept in the file and/or medical records, which are not available to the third parties.

In some homes, we have noticed that there is video surveillance, without a notice about it on the notice board or any other visible place. We discussed this with the management of homes. There are different explanations about its purpose. According to them, it is used to monitor the work of the staff.

In one of the homes, the owner said *"... the nurse stole RSD3,000 to a beneficiary and then I set up 16 cameras to monitor the work of the staff in order to protect the beneficiaries."*

In another privately-owned home beneficiary told us: *"There are cameras everywhere: in the hallways and rooms ... the nurse is not allowed to sit down when she comes into the room."*

This raises the question of the boundaries between using video surveillance in order to ensure the security and safety and possible compromising confidentiality and privacy of the beneficiaries.

The State should urgently regulate legally the use video surveillance in residential care institutions for the elderly. To our knowledge, there is an initiative of the Commissioner for Data Protection to regulate legally this issue.

The recommendation to the managements and owners of homes is to put out the notice on the use of video surveillance. The beneficiaries and/or their guardians should be informed about the use of video surveillance and in which areas. It should not be used in the toilets or in the reception room for visitors, as well as in the beneficiaries' rooms. Administration needs to have an established procedure for the use of video surveillance.

**Right to Privacy**

*"It's not allowed to lock the room or personal belongings."*

Older people who are forced to live in institution, and do not have enough money or relatives are not able to pay them accommodation in a single-bed room, are not in a position to choose or decide with whom they will live, which is essentially an invasion of privacy, by the mere fact that they live with an unknown person/persons in the same room.

There are some bad practices in some of the privately-owned homes in connection to use of the common toilets for men and women, which is potentially one of the forms of invasion of privacy.

The privacy of the beneficiaries of the visited homes is not secured everywhere and fully. This threatens the dignity of the beneficiaries, which is inconsistent with the revised European Social Charter (Article 23) and the Charter of Fundamental Rights of the EU (Article 1- Dignity and Article 7 - Right to respect for private and family life, etc.).

Here is what the employees say about ensuring the privacy of users:

*"First of all, everyone has the right to close the door. No one can enter uninvited. They can talk to the visitors in private; there are many places where they can retreat and talk in private.* "(Home Villa Ancora)

*"There is privacy, conversations are confidential and carried on in the office of the social worker."*

*"Conscience beneficiaries have right to privacy – they bathe themselves, etc. Others, unfortunately, do not know what privacy is. "*

*"When the families come, none of us would be intrusive, they can talk in private."*

*"All events remain in the four walls of the house."*

*"There is no screen for the personal hygiene of dependent beneficiaries."*

During the visits to the beneficiaries' rooms, we noticed that employees often enter without knocking, and sometimes open the beneficiaries' closets to show us that they do have personal items, without previously asking for permission, or explain us the status of the beneficiary as if he/she is not there ("*She is demented, anyway, she does not know...*").

And the beneficiaries we interviewed confirmed that there is not enough privacy in the home.

*"It bothers me that I am not alone in my room, I have a catheter, and I'm not comfortable to be watched by my roommate."*

*"... The only thing I mind is that we have one bathroom for everyone on the floor."*

*"I'm in the single-bed room. In these years, I could not get used to the company. "*

The recommendation to the managements of homes is to implement the standards in order to fully ensure respect for the beneficiaries' privacy (screens during the provision of care and personal hygiene for the beneficiaries with limited mobility, separate bathrooms and toilets for men and women, enough space for personal items of each beneficiary, etc.). Each institution should establish policies and practices in ensuring privacy of the beneficiaries and introduce them to each beneficiary of the home.

### Right to Complaint

*"I know I can complain, but I had no complaints."*

During the interviews, both with the employees and with the beneficiaries of all of the visited homes, we got the impression that the beneficiaries have the option to complain, but that there are no officially authorized and specified (written) mechanisms for filing complaints. They told us that the beneficiaries usually complain orally, to social or health worker, and the director or the owner of the home. Complaints can be filed at any time. In most homes, there are books of complaints and/or books of impressions. These books are more often filled with the impressions, rather than complaints, and in some homes, there is nothing written in them.

The beneficiaries usually complain about the food, the mutual relationships, defects in the home, home prices, the amount of co-payments for medicines, that their children do not come to visit them, etc.

In state-founded homes, there are complaints' boxes, which are locked, and opened periodically (weekly or monthly). Box is opened by the director or social worker, or there are commissions (Home Care Department of CSW Kucevo) and/or the complaints are read on the sessions of the Council of the Beneficiaries (Vozdovac). If the complaints are signed, they answer directly to the complainant. The anonymous complaints are also discussed on the Council. The employees to whom we talked to said that there are not many written complaints annually (about 30 in the Home Vozdovac, and 4-5 in the Home Prokuplje, and they have had one complaint to the Ministry for the last 10 years, while the staff of Kucevo found the complaint in the box only once – about the menu).

*"Once a month we have a regular meeting with the beneficiaries – the manager, social worker, owner and doctor, if available. Here we try to get some "constructive criticism". Once a year we carry out an anonymous survey where we are being assessed by our beneficiaries. "(the employee, Lug)*

*"We have not had a complaint in writing because that would mean that we have skipped a lot of people who can solve the problem." (the employees, Nacionalni dom)*

*"The beneficiaries are instructed to talk, to say what they want and to complain. They can do it by phone, dial 0 and call social worker or the head nurse. "(the employee, Meliorvita)*

*"In connection to the right to complaint we have a book of complaints, box and once a year we conduct a survey among the beneficiaries." (the employee, GC Sombor)*

Here is what the beneficiaries say about filing complaints to the employees and their further actions:

*"I complained at a conference but they did nothing, paper is patient."*

*"I was not thinking about rights. I do not know if I said I was not happy with the bed. "*

*"I complained that the light is turned of in the room at 9 in the evening, so I can not read, but nothing happened."*

The recommendation to the managements of homes is to formally establish mechanisms for filing complaints of the beneficiaries and/or guardians, relatives or visitors, and to establish procedures of acting upon the complaints.

**Beneficiaries Control over Their Accounts and Finances**

*"What do they need the money for when they do not go anywhere?"*

In most cases, the beneficiaries of homes do not manage their own finances. Financial management for the beneficiaries is mainly performed by the family and/or guardian, and sometimes even by the state (CSW) or the institution in which the beneficiary is accommodated.

*"They do not have control over finances. Children take care about it. "(the employee of a privately-owned home)*

*"... They have the right to gain insight in the amount of their pension and how much the home and additional medical services cost." (the employee of the state-founded home)*

The beneficiaries of privately-owned homes usually have no pocket money, because the management of the homes do not recommend it.

*"I have no money; I do not have a penny to die for."*

The regulations stipulate that the beneficiaries of state-founded homes have thepocket money and dispose it personally if they are able to do so, but there is no mechanism for providing the beneficiaries from privately-owned homes with the allowance. Practices and procedures are very different. Employees in some homes told us that they do not recommend relatives to leave money to the beneficiary, but to leave the deposit to the home, and the staff will buy everything he/she needs:

*"They'll lose money or it will be stolen, and we can not be responsible for it ..."*

In other homes, they allow family members to leave some money if he/she insists on it:

*"They have right to keep* (in possession) *up to RSD1,000."*

These old people, regardless of their mental status (whether demented or not) are entitled to financial security, and to them the allowance/pocket money represents it.

Denial of financial security to the beneficiaries whether by staff or relatives is a violation of their human rights.

It is recommended that the Ministry establishes a mechanism, which would guarantee the right to the allowance to the beneficiaries of the privately-owned homes, too.

The recommendation to the management of privately-owned homes is to encourage the relatives to leave some pocket money to the beneficiaries, which would be deposed y those who are able to do so.

**Freedom of Movement (Locking up the Homes)**

*"It feels like prison, but that's how it must be"*

In more than half of the visited privately owned homes, we have noticed the practice of 24-hour locking up the yard, i.e. the entrance of the building. The employees told us that it is done to ensure the safety of the beneficiaries with dementia who are mobile, so that they cannot get lost.

It is understandable that the necessary security measures are required for these beneficiaries, but the question is to what extent and whether this practice violates the freedom of movement for beneficiaries who are not deprived of legal capacity, because all of the visited homes have both categories on accommodation. In some homes, we were told that the beneficiaries could go out, even though it is locked, if they said they were going out. However, locking procedures are not officially regulated as well as the procedure of going out and coming back to the home for the legally capable/independent beneficiaries.

Here is what some of the beneficiaries of the privately-owned homes say:

*"I would like to go out to the market, because I feel difficult, as if I am in prison, because the gate is always locked."*

*"After talking to the owner, I've understood that the beneficiaries do not go anywhere, so I do not even ask to go out ..."*

*"There is no violence, but movement is limited. In two years, I have gone out for a walk only three times, I just sit on the balcony..."*

Isolation and restriction of movement of the beneficiaries are particularly considered to be emotional abuse (Article 7 of the Rulebook on Forbidden Actions of the Employees in Social Protection).

The recommendation to the managements of homes is to regulate procedures of locking the facility and introduce them to each beneficiary, in order to avoid a situation where the beneficiaries do not even try to go outside the home just because the gate is locked.

## Deprivation of Legal Capacity

Employees in institutions informed us that 114 users (7%) are deprived of legal capacity and are under guardianship. Out of that number, 77 are completely deprived of legal capacity, i.e. 68% of those who are under guardianship, i.e. every 20th beneficiary of residential care institutions is completely deprived of his/her legal capacity. Most of those beneficiaries, who are under guardianship, had their guardians appointed before the arrival to the home. For users who are in state-founded homes, in most cases, guardians are appointed ex officio – those are the employees of CSW. Relatives were appointed as guardians only in the minimum number of cases. There are indications that neither in the first nor in the second case guardians visit and take enough care about these beneficiaries.

*"Their guardians are appointed ex officio. Those are the employees of CSW (sometimes even the accountant). In our experience, when one of those people dies, and a social worker calls the guardian at CSW to arrange funeral, he/she is surprised and does not even know that he/she was appointed as one's guardian. Otherwise, when the guardians are employed at CSW, they generally do not come and are not interested in the status of the beneficiary. It is not any better when the relatives are appointed as the guardians, they rarely visit them. All this in connection to guardianship is done "pro forma", to meet the legal procedure, rather than acting in the beneficiary's best interest. "(The employee of the state-founded home)*

*"One of the typical situations when applying the measures of guardianship care refers to the fact that a significant number of people under guardianship is accommodated in social care institutions. This often means that the guardian is a person who lives on the location (municipality or city) far from the residence of the beneficiary, which makes impossible for the guardian to perform his/her duties sufficiently."*[41]

For those users who are under guardianship and live in privately-owned homes, guardians are the relatives and family members and they, according to employees regularly visit the beneficiaries and fulfil their obligations to them as required.

We were not able to talk to these beneficiaries because we did not provide guardian's consent for the interview.

A major problem and challenge for the managements and staff of all visited homes is the issue of deprivation of the legal capacity of the beneficiaries who are unable to give their consent for accommodation to the home, especially ones suffering from dementia. There is a lot of uncertainty whether these beneficiaries should be completely deprived of their legal capacity or partially deprived only for the purposes of accommodation in the home. The official interpretation is that it takes only partial deprivation and that it is carried out at the guardianship authority of CSW, is applied only for accommodation purpose and the beneficiary retains legal capacity to make other decisions.

The persons we talked to told us that the relatives of the persons with dementia often do not want to (deprive their elderly of legal capacity), because they say the situation itself is very stressful and problematic, and that they could not further humiliate their loved ones and make their "bad health status" official in a way to deprive them of their legal capacity.

The recommendation is to provide a mechanism to avoid the abuse of the elderly, in connection with the deprivation of legal capacity.

The recommendation is to increase support to guardians in terms of training in performing their duties and responsibilities.

41 Novakovic, U. and Jovanovic, V. Deprivation of Legal Capacity, Rehabilitation and Employment of the Persons with Disabilities, page 40, SIPRU, April 2013

## Health Insurance and Pension-Disability Insurance Rights

*Using the ambulance transport*

We have noticed some discriminatory behaviour in granting the ambulance for transport of the bed-ridden beneficiaries on discharge from the hospital in situations when he/she is to be transported to a privately-owned home.

Namely, the Rules of the Pension-Disability Fund stipulate that the patient when returning from the hospital is entitled to transport by ambulance to the place of residence if the doctor determines that it is necessary. The beneficiaries can exercise this right if they return to the apartment where they live or if they go to the state-founded home. However, if they go to the privately-owned home located in the place of residence (e.g. Belgrade), the beneficiary or his/her relatives must pay the transport costs.

*Right to Diapers*

*"Older people with mental disabilities should enjoy the benefit of care and protection of the family and society, and to have available medical care and treatment to help them maintain or regain their optimal level of functioning and well-being and to prevent or delay further deterioration."* (Ethics Principles of the World Psychiatric Organization)

The incontinent beneficiaries with dementia are not entitled to diapers, even if they are bed-ridden. It is a big problem for the relatives who do not have enough money to pay for the diapers, as well as it is the problem for the caregiver to nurse such person without the use of diapers.

Right to diapers at the expense of RHIF (2 packages of 30 pieces of diapers per month) have only permanently and totally bed-ridden persons (G82), patients with sequelae of cerebral palsy (G81) and patients with multiple sclerosis (G35). Demented persons are not entitled to diapers. Lately, the bed-ridden persons with dementia are also deprived of this right.

Recommendation to RHIF is to supplement the list of indications for diapers at the expense of the Fund so that the incontinent persons with dementia can exercise that right.

*Co-payments for drugs*

*"Older persons should have access to health care that will help them to maintain or regain the optimum level of physical, mental or emotional well-being and to prevent or delay the onset of disease." (UN Principles for Older People)*

The beneficiaries and/or their guardians, must pay participation costs or pay full price for most of the drugs. This even applies to beneficiaries of social allowances, who make large percentage of the beneficiaries in state-founded homes. Even they have to pay for the dentist's services. Those who do not have money remain deprived of proper treatment and care.

Participation in costs of anti-dementia drugs, which are expensive, is high (75%), so that the symptomatic treatment of Alzheimer's disease in homes is not applied to the desired extent. The medicines are used by those who can afford them (pay for them).

*Problems in exercising beneficiaries' rights to the cash allowances*

Discriminatory behaviour is when members Pension-Disability Commission refuse to go to the field visits to assess the abilities/capacity of the beneficiaries who are bed-ridden and unable to withstand transport in order to respond to the assessment invitation, only because it is in a location, which is not close to the head office of the Commission. In addition, it is unacceptable when bed-ridden beneficiary must pay the full cost of transport by ambulance (RSD 7,000) personally and not only participation in the ambulance transportation costs in order to be transported to an assessment at the Commission's office, upon its call. Those transportation costs should be covered the Pension-Disability Fund.

Employee of a privately-owned home in Negotin emphasized the challenge they face in situations when bed-ridden beneficiary, who is unable to withstand transport by the ambulance, should be taken to Bor for capacity assessment, at the invitation of Pension-Disability Commission. This occurs in situations when the assessment is carried out for the purpose of exercising the right to allowance for other person's help and care. Commission members told them that it is not envisaged that they go out in the field. This means that the beneficiaries, who are not able to withstand transport, cannot exercise the right to the allowance.

## Rights of the Beneficiaries in Unregistered Homes

*No Guarantees of Rights*

Unregistered privately-owned homes freely advertise and provide services, lock their beneficiaries in, with no guarantees of respect for human rights of the elderly. This does not mean only the respect for human rights of the elderly when they are already in homes, but in the first place the violation of their human rights by those who, against their will, bring the older persons to homes and leave them there. Those are usually cases of economic abuse, signing various agreements on lifelong care or the older persons are accommodated in such homes simply because they are slightly cheaper.

In 2012, according to available information, the Ministry issued a decision on banning the operation of two illegal homes.[42] In 2013, according to available information, the operation of one such home in Belgrade was prohibited (September 2013) and after the articles in The Kurir[43] that the elderly are being locked in.

Following these indications, we tried to check the situation in the field. Even though the internet search on "private homes for the elderly in Belgrade" has opened many websites, we chose the first one - http://www.navidiku.rs/firme/staracki-domovi-za-stara-lica-beograd (reviewed on 29th July 2013). Total of 67 homes for the elderly advertised on this site. For each individual home, we checked whether it was registered as social protection institution at Ministry, and found out that 21 homes were not registered. The advertisements for these homes included, in addition to address, fixed and/or mobile phone numbers, websites for 7 of them.

We have reviewed the site BRA[44] whether the homes are registered as companies or some other organizational form and found out that 7 of them are registered or were registered as companies. At one of these homes, there is the information in the Registry that the initial capital was RSD100, and at the second one - RSD1,000. There is note that one of these 7 homes was deleted from the

42 Statement of Nena Darmanovic, inspektor of the Ministry in newspaper article "Homes for the Elderly Lose their Licenses" – The Novosti, 15th January 2013, http://www.novosti.rs/vesti/beograd.74.html:415052-Staracki-domovi-ostaju-bez-dozvola

43 The Kurir, Horror in the Home for the Elderly: I want my freedom and pension back, 1st September 2013 http://www.kurir-info.rs/slikar-kao-u-logoru-hocu-da-mi-vrate-slobodu-i-penziju-clanak-962969

44 Search of the BRA website was done on 12th August 2013

Register and that the one is in liquidation process.

We chose to call two of 21 unregistered homes in Belgrade and to take an interest in accommodation of older person with physical impairments. They told us in a telephone conversation that they do have vacancies, they can accommodate him/her right away, and that we can come in person to make sure what the housing conditions look like, which we did.

Locations of both homes are in private houses, which are not specially built for the home. Courtyard and the front door of both houses were locked and only after the check through the intercom that our visit was announced and that we are interested in accommodation of older person, they let us in.

In both homes, we found one person who cares about the beneficiaries (in one case 8 and in other 20 and some beneficiaries). The price of the first home's services is RSD 35,000 and the second's between EUR350 and EUR400.

Conditions that we saw do not meet the standards, and we were not allowed to enter the room where the beneficiaries are, to see them, due to their afternoon rest. Therefore, we did not have a chance to talk to some of them about their satisfaction with the accommodation. Rooms in both buildings which were shown to us as the place where the person will be accommodated were in the basement (one was in basement, unpainted and not for this purpose - it had an old wheelchair and old mattresses). The explanation was that they would quickly prepare those rooms if we decide to accommode our older person.

In both homes, the persons we talked to, told us that they would receive an old person, even if he/she does not agree with the accommodation: "it is important he/she accepts to enter into the car and that you bring her here, and he/she will get used to home, there is no way out."

There are serious indications of violations of human rights of the elderly, both in terms of housing conditions, quality of service they receive, and the fact that some of them are deprived of the right to make decisions, and the right to freedom of movement.

It is necessary to establish at all costs and without delay a mechanism to ensure respect for the human rights of older persons accommodated in these institutions.

## 11. SUMMARY

Older people, who are in residential care in social care institutions, as well as everyone else, have basic human rights, which must be protected by law. At the national level, those rights are recognized in the Law on Social Protection and all other relevant laws and policies. In order to ensure that the rights of older people are fully respected, efficient mechanisms for their implementation must be ensured.

The complexity of the aging process requires the coordination of health, social and other sectors (palliative care, transportation, housing, care, etc.), both at the national and local level. Despite all the efforts of the Ministry of Labour that the Law on Social Protection, which was adopted more than two years ago, enables the opening of social-health care institutions, for users who require constant medical care and/or supervision, no practical solutions were given. Not all of the responsibility for the state's care of the ill older people, and those who need all-day care should be assigned only to the Ministry of Labour, Employment and Social Policy, but the cross-sector cooperation must be improved to much greater extent, i.e. the Ministry of Health, RHIF, Pension-Disability Fund and others should be engaged.

At the level of regulation, it would be appropriate to "translate" the basic principles of social protection and the beneficiaries' rights guaranteed by the law to level of the standards and rules, with consideration of different perspectives, including the perspective of the elderly.

When it comes to by-laws, some have not yet been made, and some have recently entered into force (May 2013). During the monitoring visits, it turned out that some privately-owned homes were not familiar with the new by-laws. An additional problem is that some by-laws seem confusing and incomplete (such as the Rulebook on Detailed Conditions and Standards for the Provision of Social Services).

Amity in cooperation with the Ministry chose 20 social welfare institutions for monitoring of human rights of the elderly, 5 of which are state-founded and 15 are privately-owned homes. Visits were made to two unregistered homes in Belgrade, with the intention/excuse of accommodation of the older person to home.

The expert team of the Amity, the partner organization AWC and the representatives of local/national CSOs, realized visits in June-July 2013.

In the area of our interest, in addition to interviews with the management, medical and other professional workers were the beneficiaries to whom we also talked to and, by visiting, we gain personal insight in their living conditions and quality of services they receive.

Among the beneficiaries of institutions, 2/3 are women, the average age of the beneficiaries is over 80 years, except that state-owned homes accommodate the beneficiaries who are considerably younger than 65 years. Almost 50% of users are entirely dependent on the help and care of other person and about 70% of the beneficiaries came to the home from single households.

Observed conditions in visited homes included the architectural and technical requirements, hygiene and equipment of the building/facility. Housing conditions are very different and they range from very good to acceptable. Technical conditions are better in those privately-owned homes, which are purpose-built. The overcrowding problem is evident in state-founded homes and in certain rooms of privately-owned homes. Accessibility for the persons with disabilities is not sufficiently provided in all of the homes. Equipment in state-founded homes is old, and is being renewed in accordance with the financial capacities, while in most privately-owned homes it is new, and complies with the minimum of standards. What bothers us is lack of beneficiaries' personal touch in the rooms of privately-owned homes. In terms of hygiene, it is generally satisfactory.

When it comes to activities and contents of the daily life of the homes' beneficiaries, there is a noticeable routine in daily functioning. It is evident that the institution cares little about social integration. In state-founded homes, there are services, which deal with this issue, and the situation is much more favourable. In privately-owned homes, generally there are no activities intended to the beneficiaries – the employees mainly focuse on care and nursing.

Contacts of the beneficiaries with their families are of the utmost importance and they are influenced by their previous relationships, the place of residence of the relatives and the beneficiaries skills and abilities to communicate with their relatives (in some homes only one phone is available and in a way that enables the beneficiaries to receive calls but not to make calls). Sometimes the relationships are good, and in some cases, they do not exist. Contacts of the beneficiaries with the local community are sporadic.

The relationship that develops between old people and institutions is often a long-term relationship of dependency. During our visit, the staff who most directly provide services to the beneficiaries were polite but the conventional attitude towards the beneficiaries is evident. The staff are not sufficiently trained in specific aspects of care of the older people; work with dementia patients or in the human rights of the elderly.

Violence is present in institutions in various forms - by institution, and by other users, as well as by the family. There is more violence than the beneficiaries and institutions are able to recognize. It seems that the beneficiaries protect themselves more successfully from violence in the institution, than from domestic violence, recognize it easier, name and describe it more accurately.

All of the visited state-founded homes have relatively well-organized health services, while according to the current regulations, privately-owned homes are not required to have health workers.

Almost half of the beneficiaries of the visited institutions is completely dependent on the assistance of another person in activities of daily living. Immobility is a consequence rather than a cause of institutionalization, and often the result of unoperated hip fracture or the advanced stages of dementia or terminal stage of cancer. A common cause of functional dependence of the beneficiaries is their altered mental status, with the dementia as a leading cause. Privately-owned homes have much more beneficiaries with dementia – avg. 50%, against 15% at the state-founded homes. In Serbia, a little work is done and a little is known about the procedures of psychophysical rehabilitation of the beneficiaries with dementia.

The beneficiaries often go through short-term upsets, mainly verbal, especially in homes with a high rate of the beneficiaries with dementia. In privately-owned homes, there is no written protocol for dealing with the anxious beneficiaries, but they have empirically developed certain methods. No special records are kept of physical restraint of the beneficiaries.

Guarantees of the rights of the beneficiaries at the registered social care institutions are insufficient, and do not exist in unregistered homes.

Inconsistent respect for the rights of older persons who are the beneficiaries of residential care can be partly attributed to the insufficient familiarity of the staff and the beneficiaries with the rights, and under-developed standards.

In a number of cases, there are indications that the relatives violate human rights of the older people by the fact that they accommodate the elderly in a home against their will, that they have taken over management of the property, or by neglecting them, i.e. not visiting them in the institution, in some cases.

The protection system continuously deprives the elderly of the right to make their own decisions. Despite the fact that the state-owned homes provide the mechanisms for the beneficiaries' participation in decision-making, many are not informed or encouraged to participate. In privately-owned homes, these mechanisms do not exist.

Beneficiaries' privacy is chronically threatened in (almost) all of the residential care institutions. The use of video surveillance in institutions is not adequately regulated and there are indications that video surveillance violates human rights to privacy and confidentiality.

Current mechanisms for informing the beneficiaries are insufficient and often inadequate. The privately-owned homes are more focused on informing relatives and potential beneficiaries.

The beneficiaries of all institutions have the opportunity and ability to complain about any aspect of service, and they do, mostly orally. There are established procedures for complains in state-owned homes, while this is not the case in privately-owned homes.

In most cases, the beneficiaries of homes do not manage their own finances. Financial management for the beneficiaries is mainly performed by family and/or guardian, and in some cases even by the State (CSW) or by the institution where the beneficiary is accommodated.

In more than half of the visited privately-owned homes, we noticed the practice of 24-hour locking up of the yard, i.e. the entrance to the building without having officially established procedures for locking up of the facilities. This is done to ensure the safety of mobile beneficiaries with dementia, while those mentally preserved, mobile beneficiaries gain the false impression that leaving the home's facility is impossible.

Over 7% of the beneficiaries are deprived of legal capacity. We are concerned by the fact that every 20$^{th}$ beneficiary is completely deprived of legal capacity. There are indications that guardians insufficiently care about these people, especially in state-founded homes.

It is necessary to improve the legal framework in a way to regulate the right of the beneficiaries of privately-owned homes to participate in making decisions, which affect them as well as the right to an allowance. The use of video surveillance in institutions should be regulated by law.

It is necessary to improve current and pass the missing by-laws, particularly the Rulebook on Standards of Rights of the Beneficiaries of Residential Care Institutions, as well as the Service Quality Standards for those institutions.

Continuous education, professional and supervisory support to the staff are necessary.

It is necessary to sensitize the beneficiaries and relatives/guardians, the activists of CSOs working with/for the elderly, as well as the general public to the elderly human rights.

It is essential that the State strengthens the mechanisms of control of institutions' operations, and to establish a mechanism for independent monitoring of the human rights of the elderly by experts or CSOs dealing with human rights of the target group, in order to improve significantly protection of their rights.

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