This is a short part in English of the YHD research 2015 – "Analysis of the Institutional Care System and the Opportunities of the NGO's to Provide Community-based Services in Order to Achieve Deinstitutionalisation in Slovenia"

Interviews with users who live in institutions

The goal of 27 structured interviews (with 13 women and 14 men aged between 30 and 64, two of which are mothers of persons with severe impairment) is to give a vivid portrayal of people's living conditions inside 10 institutions, to look back at times when those people lived in their homes and to raise awareness of some of the problems in such accommodations. Structured interviews will be presented at qualitative and narrative levels, with quotes and short commentaries. Our goal is not to portray their content as representative, but to give a colorful personal and at times heartbreaking, yet fleeting (incomprehensive) document of everyday life of people with impairments in contemporary social care institutions.

Interviews have numerous limitations: a) the sample was only partially randomized because our interviewees were selected by the staff; b) occasionally the staff was present at the interviews or the interview was interrupted with a question such as: "Is the interview over?"; c) in some cases it seemed that the staff knowingly "selected" users who had difficulties answering our questions (a 90-year-old woman, a man who spoke in such a way that the interviewer was unable to understand him) and consequently had to be dropped from our analysis; d) interviews were done by students at the Faculty of Social Work who are in process of training for such research, so interviews are often not as in-depth as we would like because students stuck to pre-prepared questions and did not attempt to acquire in-depth data where that would seem necessary. We decided not to include exact accommodation data to ensure anonymity of interviewees. Sometimes we included no data at all, so as not to endanger critical users.

The interviews consist of 5 parts:

- Accommodation. Where does the person live, how long has he or she been living in the institution or an NGO, reasons for relocation, where did the individual live before the relocation, did the person have any say in his or her accommodation, current living conditions, what is the person satisfied with, what does he or she miss.

- Needs. What services are available, what would the person need, what has to be paid extra, daily routine, what would the person wish to change.

- Contacts. We wanted to know with whom do the interviewees most often socialise, including contacts with professionals: are they satisfied with them, would they wish to change anything, what is the density of their contacts, how many and what kind of contacts do they have outside of institutions or residential groups, who initiates them and in which activities are they included.

- Control. We limited ourselves to financial control. We wanted to know how much money do our interviewees have at their disposal, how autonomous they are at handling their cash, do they know the costs of their accommodation and which services they need to pay by themselves, and how

satisfied are they with provided services (food, care).

- Future. Where would people want to live, what would they need to live outside their institutions; what kind of support would they need, who would they choose to provide support for them, and what is the individuals' opinion about how they would do in community.

Living in institutions or residential groups and satisfaction of users

Before they were placed in institutional care, people lived in various ways. Some lived alone, others with their spouses and children and others still with their parents and relatives in primary families. Reasons for placement vary widely, from accidents or sickness, loss of close relative who cared for the person, financial trouble, conflicts in family and placement of children into institutions because their parents did not provide satisfactory care for them.

> They decided where I would live through bureaucracy, they did not ask me much. They only asked me if few things about my impairment and then they pressed on me; and because I cannot take care of myself, because I cannot dress myself, and because I am dependent on other people I am rarely asked about what I do or do not want. I know about personal assistance, but they told me I cannot have it in the institution and that the use of personal assistance inside institutions is illegal. (Male, 51, CWC Tončka Hočevar where he has been living for 29 years, he entered the institution at the age of 21, he has been living in his room alone for 3 years).

> When they took me away from my mother no one asked me anything, they just said we were going on a trip. The centre said that we would go on a trip, they did not say I would go to Dornava, they just took me and we were gone. I did not know what was going on, my sister told me. They just told me we were going on a trip but that was not true. They also took away my sisters who were in school. They took them away at their school. I was the second one and I also had a brother who was their favourite. My brother lived with mother. He is no longer alive. (Woman, 43, Dornava institution, where she has been for 10 years, since she was 33).

Yes, the decision was mine. Actually the placement to an institution was recommended to me by a social worker. She asked me if I wanted to go and I said yes. But I decided on my own. (Man, 49, has been living in institution for 15 years, Dom Nine Pokorn Grmovje, lives in a residential unit with 5 roommates).

> I cannot choose with whom I want to live. I live with five others in one room. Beforehand I was with four people and it was ok. (Man, 57, SCI Dutovlje, has been in institutions for 7 years, 6 men in one room).

Services available to individuals, their needs and daily routine

Institutions offer and provide their users with basic services, sustenance, care and physiotherapy. Basic care is very scarce. Users blame this on the lack of staff. In some institutions, people who need help with washing are bathed twice a month when nurses also shampoo their hair. People come to

terms even in such meager conditions, although their needs are not satisfied. They are happy to have their clothes washed when it is dirty or at least every 14 days, and that the staff bring users' clothes back clean the following day when users put them into dirty clothes basket. It seems people are thankful for all such services. Food is a very important element of institutional life, because meals are served regularly, and they interrupt their routine. They seem exciting and are perceived as a chance to socialise. The food seems very good to some but others are dissatisfied with it and look for ways to get food from outside the institution (people on wheelchairs go to nearby pizzeria).

Care, help with various tasks, food, therapies, laundry washing are readily available. (Man, 42, Residential home for the elderly, Bežigrad, has been living in institution for 18 years).

I am very satisfied here, I have no complaints regarding laundry washing. Sometimes I have to change twice a day and I have guarantees that my clothes will be washed if I have an accident. I have to say, this is well done in the institution. Washing is paid on a monthly basis when municipality sends money. (Male, 51, CWC Tončka Hočevar where he has been living for 29 years, he entered the institution at the age of 21).

You have to pay extra for basically any extra accessories you may have. Sewing and cutting hair, additional meals, all charged extra. (Man, 42, Residential home for the elderly, Bežigrad, has been living there for 18 years).

For example if I have a craving for a pineapple and if I want them to peal it for me, I have to pay extra. (Man, 34, Residential home for the elderly, Bežigrad, has been living there for 2 months).

Yes, cutting hair, if you want to go anywhere, and if you want them to make you coffee and bring it into the room. But if you are late for lunch, you have to pay extra, so that they heat it for you. Nothing is free today. I had to pay for the refrigerator as well. (Man, 53, Residential home for the elderly, Bežigrad, has been living there for 33 years).

We would maybe need escort in winter as an extra service. (Man, 34, Residential home for the elderly, Bežigrad, has been living there for 2 months).

I would like to be taken outside but there is no one here for that. I make effort on my own as much as I can. I would love to go for a walk. A friend of mine and her friend come here and take me outside. (Woman, 64, Dom Danice Vogrinec Maribor, has been living in an institution for 15 years, lives in her room alone.)

I miss more personal freedom in the institution. For example, a personal assistant to go to the cinema with me or a pub and so on. Then I would be myself again. (Male, 51, CWC Tončka Hočevar where he has been living for 29 years, he entered the institution at the age of 21).

At first it was not so hard in the institution but in recent years things got complicated. It was just two days ago... It was 3 p.m., just after lunch, and nurses said that I should have a bath between 3:30 p.m. and 4 p.m. and then I could go to bed. I told them to just put me to bed right then, so that they would not have to work any more. I was very angry. The staff is bickering amongst themselves which shift is going to do what. (This person has been living in an institution for decades, we left the name of institution out to ensure anonymity.)

In the morning I get up and eat breakfast. I take a shower and shave. I help with preparations for

lunch. Then I eat. Twice a week I clean my room with a wet mop, every Saturday and Wednesday. I put my clothes into a washing machine and dry them in the dryer. At the end I also fold them. I also work outside in the garden, my duties include regular watering. Now, in winter, I shoveled snow. It is pretty ok, I do not feel overworked. All tenants have their duties and I like doing mine just fine. (Man, 49, Dom Nine Pokorn Grmovje, has been living in institution for 15 years).

I like everything, especially security. (Woman, 48, Novo mesto, residential unit, where she has been living for 4 years with a roommate).

Security, so that they help us and that they are available. (Woman, 50, Dom Lukavci, has been living there for 5 years).

Contacts

Contacts with family and relatives are usually the most important. Some people were "dropped off" at the institution and their relatives do not even want to hear about them anymore, let alone visit them. Users, whose relatives live nearby institutions, come for a visit or users go home for short stays, but such examples are rare. None of the interviewees have said that relatives visit him or her often or regularly, although Rules for Residents at SCI Dutovlje explicitly states: "Visits from relatives are welcome every day, especially between 9 a.m. and 6 p.m. (Article 39). Many people wish to have regular contact with their relatives. With some of them, the pain of their relatives not visiting them and not having any contact with them is so insufferable that they wrap their waiting for visits into reproach to hide their bitterness. 63-year-old man who has been living in a residential unit of Dom Nina Pokorn for 12 years, has this to say when asked whether he had wanted any changes: "I would like to see my son." It seems that many relatives are afraid that users would like to leave institutions and come back home. Consequently they prefer to forget them.

International research on preserving contact between users in institutions and their relatives show that relatives would rather come to smaller institutional units where life is more similar to their own life rather than to big institutions. Deinstitutionalisation would hopefully increase the number of contacts between users and their relatives (Zaviršek 1994). We cannot corroborate these findings. Although most interviewees live in residential units and residential groups, contacts between users in institution and their relatives are very rare.

They said they would come when the snow melts but they did not. I mean my daughter. She said they would come in spring. I will keep quiet and I will not pester them. My daughter is insolent, she always finds something to admonish me over. And then it is fine. I call her and drop the connection. She calls me back and then we chat. I still use phone cards. (Woman, 61, SCI Novo mesto, where she has been living for 7 years with a roommate).

No one comes for a visit. My mom and dad visited me until they died. Not every day, but once in a while. (Woman, 52, Dornava institution, has been living there for 15 years, she entered institutional care in 1976 when she was 13).

I have aunts who visit me. In the summer when they have time. (Woman, 48, Novo mesto, residential unit, where she has been living for 4 years with a roommate).

I spend my day mostly with roommates, friends and the staff. (Man, 42, Residential home for the elderly, Bežigrad, has been living there for 18 years).

I socialise with tenants a lot. It is nice and we respect each other. (Man, 56, Dom Lukavci, has been

living here for 1 year, before that in Dom Danica Vogrinec, in a room with 4 beds).

I socialise with tenants and we get along very well. Sometimes relatives come too. (Woman, 50, Dom Lukavci, has been living there for 5 years).

I am happy that Magda, the head of our unit, is available to me. I can go out with her, we shop together, and she is there whenever I need her. She went to a dentist's with me recently and I felt better because she was there. Occasionally I want to visit my friend who lives at an institution in Celje, and Magda goes with me then as well. I cannot imagine living anywhere else because I have all the help I need here. (Woman, 53, Dom Nina Pokorn Grmovje, has been living in institution for 25 years, shares her room with a roommate).

I have regular daily contacts with a professional Helena who is also my friend and my mentor. I feel fine in her office but otherwise I find it difficult. I like it here in the office best. I confide in her. I would ask Helena for help if I needed anything. If I stayed here for longer I would like to have a volunteer, a girl to socialise with. But the problem is transportation, our location is quite remote and public transport connections are too poor for volunteers to come here. (Woman, 54, SCI Dutovlje, has been living there for 26 years, there are 6 more roommates in her room).

Few people spoke of any friends outside their institution. New units of institutional care did not succeed in reaching one of the goals of community-based living to provide people with a normal life.

I have contacts with my friends about three times a week. I like going to football or basketball matches. (Man, 42, Residential home for the elderly, Bežigrad, has been living in an institution for 18 years).

No, outside the institution the situation is pretty bad and I do not know many people. It is a bit hard to find them. (Male, 51, CWC Tončka Hočevar where he has been living for 29 years, he entered the institution at the age of 21).

Control

To keep the interviews as short as possible, the questions regarding control that people have over their own lives were limited to finances. One common point of all discussions about money was that people have very few financial resources that they can freely budget on their own. Those who receive a pension know how much their municipality pays, in addition to their pension, for their institutional accommodation. Many do not know the monthly cost of their living expanses, how much they get from their work at CWC, and how much from their pocket money. Since they receive a small amount of money, most people know well how to allocate it. Their needs are very modest.

I use my money for an occasional coffee or cinema or I go for a walk and use it for desert, and... I do not know, not much money is left at the end of the month (is left with 53 euros of his pension at the end of the month). For example if I wanted to live in the institution like you do at home, when you decide: "I would like to cook this or that..." I would not be able to do that, which makes me sad. These things should be done differently. […] When municipality sends money, 10% of it goes to me but it is a small amount for the whole month. (Male, 51, CWC Tončka Hočevar where he has been living for 29 years, he entered the institution at the age of 21).

I give my money to the nurse and she brings me whatever I need. When you run out of money you have to slum it. (Woman, 50, Dom Lukavci, has been living there for 5 years).

I go to the community center twice a year. I go to church regularly and help the parish priest and earn some extra money. […] I get 50 Euros of pocket money and 20 to 30 Euros for helping the parish priest. I get approximately 80 Euros. Magda keeps the money for me. I can save some money to go on a holiday at the sea resort. (Man, 63, Dom Nina Pokorn Grmovje, has been living at the institution for 12 years, shares his room with one roommate).

Future

We were also interested in peoples' wishes regarding their relocation, what kind of support they would need and their assessment of how they would do in the community. Long-term institutionalisation increases uncertainty among people because they no longer have the experience of facing everyday issues without institutional guidance and routine. None of the interviewees mentioned activities directed towards the goal of leaving institutional care. Biomedical definition of interviewees' impairment made such a strong impression on some of the them that they are unable to trust themselves. Although they perceive institutional accommodation as something that is involuntary ("although they try to set us free") they have come to terms with it.

People are afraid of moving into the community because there is no long-term, permanent or continued support available. There is fear that support would cease, that it would be irregular and that the person will be left to fend for him or herself. Many people assessed that their current income would be insufficient to live outside institutions. Consequently people are ambivalent towards relocation from institutional care to independent living. Although residential community is sometimes presented as community-based living, tenants do not see it as such. For them this is still a place "inside" as opposed to the world "outside".

Institutions place people into other institutions instead of searching for ways to get people out of them.

I can go without escort but I do not dare because I am afraid I might get lost. Although I would not, but that is the way it is if you are pretty much always inside and you do not go anywhere. (Woman, 61, SCI Dutovlje, where she has been living with a roommate for 7 years).

My psychoses do not allow me to live outside institutions. I am incapable of that. Although they try to set us free, this is not realistic. I am very happy that they do not force me to go anywhere. (Man, 58, Dom Lukavci, has been living there for 9 years in a room with 2 other men).

I will live here. I do not see myself outside with other people. I do not think I would have enough support, my nerves are very weak and they take a very good care of me here. Money would also be a problem. I could not live outside and I really do not want to. (Woman, 53, Dom Nina Pokorn Grmovje, has been living in institution for 25 years, shares her room with a roommate).

I do not see a positive side of living in an apartment because I would need 24 hours support and it is a problem to get assistance, and I would need three assistants. I know a woman who lived in an apartment and she had an assistant. She did not come regularly or she notified her only a few minutes in advance that she would not be able to come. On one hand I would like to live alone, but on the other I would not. I am motivated to live alone, because if I did I would have more work, something to occupy myself with, because you do not have to do anything here. I will try. (Man, 45,

Residential home for the elderly, Bežigrad, has been living there for 5 years).

I would need more money. I would not be able to live alone because I would not be able to survive on my income. But otherwise I would manage. I would need some help with cooking because I do not know how to do that. I think I would manage with the bills and I know how to take medicines according to prescription. My brother could help me with bureaucracy, which I am not used to. (Man, 63, Dom Nina Pokorn Grmovje, has been living at the institution for 12 years, shares his room with one roommate).

I would like to live in my apartment with personal assistance. I would pick someone from the YHD association. (Man, 42, Residential home for the elderly, Bežigrad, has been living there for 18 years).

It would be a deal for me to live here in winter, but in spring and summer I would live in the house I was born in Skope. The institution would let me, the problem is my sister. According to court's decision I have the right to at least one room at the house in Skope, even the psychiatrist said so. So that I could go home at least for the summer. Sharing a room with five other men is torture. I would have some peace there and I could draw and write. […] I would have lunch in the institution once a day. I would manage great like that. I have finished vocational education and I would like to have an individualised plan made for me, because I have lots of tools and I could work and make some money. Sometimes I ring at somebody's door. I received a decision that I can fell trees in the forest and if I could go home I would cut wood for myself and I would be very happy. (Man, 57, SCI Dutovlje, has been in institutions for 7 years, 6 men in one room).

If I had money, I would buy myself an old farm, which I would slowly renovate. It would be a small house, so that I could maintain it properly. […] I would keep the house tidy by myself but I would need someone to come around once a month to get the papers in order and to see if everything is fine. I would feel safer. I would pick Nataša, head of our residential unit, for support, or maybe Irena, my social worker from Ljubljana. (Man, 39, residential unit at Novo mesto, has been living in a house for 11 years and 20 years at CWC beforehand).

Findings

Interview analysis shows that people do not have a choice and that daily routine is completely dependent on institutional patterns. Branches of institutions do not allow for normal living and inclusion into community, but the real problem is peoples' fears that they would not be able to live independently.

The topic of **relatives is taboo** in Slovenia. For institutions, relatives who are dissatisfied with institutions and their staff and who want to keep control over the care of their children, are taboo ("problematic relatives"). Relatives who see their children — users of social care services — as a source of money for a household struggling with financial deprivation are also taboo ("self-serving relatives"). Taboo are also relatives who have severed contacts with their child or abandoned him or her as a toddler and given them up to institutional care because of his or her impairment ("neglecting parents"). No one speaks of them out loud and even less so about mutually entangled relations between relatives and persons with impairments, professionals and persons with impairments and **the impact that the lack of support network for community-based living has on relatives of persons with impairments.**

In order to successfully complete deinstitutionalisation process, we need to fulfill material needs (sufficient funds for decent living, housing etc.), but also ensure that employees have **appropriate professional skills,** because institutional doctrines are currently directed towards maintaining dependence on institutions, which is an important reason of fear that the staff, relatives and users experience in the process of deinstitutionalisation.

Chapter 4

Characteristics of existing institutional accommodation: state of affairs in institutional social care of disabled people in Slovenia

Overview of accommodations and services within the system of institutional care for disabled people and its characteristics in the light of deinstitutionalization processes

International developments of human rights struggle, individual needs of people and contemporary understanding of barriers as one of the many forms of human existence, and not as an accident or a crime, have had a decisive influence on deinstitutionalisation becoming mainstream trend, which will have an effect on changes in long-term placement of persons with disabilities in Slovenia. Currently, most people with impairments, who do not live with their families, are provided with institutional forms of social care services. Although organisational aspects of institutional care have been reformed, the system has kept institutional nature of accommodation, services and daily activities of tenants and charges, and has not yet come even close to implementation of UN CRPD.

In this chapter we aim to show that institutional care system for persons with various impairments is **expansive**, but at the same time **traditional and undeveloped** in the sense of availability of services tailored to individuals, as well as quite **opaque**. Institutions have been renamed into centers, various institutions receive into their care people with various diagnoses that have traditionally not been a part of institutions' services, branches with different names, per-day costs of medical services differ from one institution to the next, etc. There are aspects of institutional care system that are **out of date with regards to the existing legislation**: persons younger than 65 are placed into residential homes for the elderly, some housing units accommodate more persons than allowed by the Rules on the standards and norms for social services, etc. Professionals in Slovenia, who are institutional care advocates, have espoused until recently that it is in peoples' best interest to live with other people whose impairments they share, an assertion that was opposed by deinstitutionalisation advocates who have been warning for decades **about the negative effects of separating people according to theirs impairments into segregated environments.** Today **economic circumstances have forced** them to disavow this principle, because insisting on dividing people according to their disabilities, an idea rooted in late 18th and early 19th century, would cause a fair number of institutions to virtually lose all their clients.

We have sampled institutions which provide services to adults with physical, sensorial and intellectual disabilities, as well as persons with problems in cognitive development) aged from 18 to 65. We were also interested in how many people with disabilities live in institutions to understand the breadth of needs for community-based accommodation in the process of deinstitutionalization. We were interested in services that they have at their disposal, the types of institutional changes that were made, service costs for medical and everyday care, number of staff, and daily activities offered by institutions. Our sample includes (special) social care institutions (SCI), centres and institutions for training, work and care (CTWC and ITWC), combined social care institutions (CSCI) and institutional forms of care and work centres (CWC). In residential homes for the elderly, we determined how many persons younger than 65 were living in institutions and what were the reasons for their stay at these institutions. Legislative foundation for operation of all institutions mentioned so far is Social Security Act and Rules on the standards and norms for social services.

Institutional care system for disabled people includes:

- (special) social care institutions (SCI) that were founded with the goal of providing care of persons younger than 65 who need assistance, protection and care due to physical or intellectual disabilities or both (SCI Hrastovec, SCI Lukavci, SCI Dutovlje, SCI Dom Nine Pokorn Grmovje, SCI Prizma Ponikve). People who live in them are of various age with extremely diverse set of impairments, from social shortcomings, long-term psychiatry users to people with motor and multiple disabilities;
- social care institutions were renamed into social care centres for training, work and care (except for ITWC Dornava, which kept its "institution" moniker) were primarily meant for children, youths and adults with medium, severe or very severe disorders in cognitive development with additional disorders, and are nowadays broadening the set of disabilities that people placed into such institutional care have (CTWC Črna na Koroškem; CTWC Dobrna; ITWC Marijana Borštnarja Dornava; CTWC Dolfke Boštjančič Draga; CTWC Matevž Langus Radovljica);
- care and work centres (CWCs, roughly equivalent to British social enterprises), which are a form of institutional care (full day-care or semi day-care) provides services of monitoring, care and employment under special conditions for adults with medium disorders in cognitive development, medium disorders in cognitive development with additional motor disorders, mild disorders in cognitive development with additional disorders and for adults with severe disorder in cognitive development with mild additional disorders;
- combined social care institutions (CSCI), which accommodate elderly persons along with persons with impairments; among them Centre for the Blind and Partially-Sighted Škofja Loka, formerly a traditional institution for persons with similar disabilities, stands out in particular, and has only recently become an institution for accommodation of elderly persons;
- residential homes for the elderly with a certain number of persons with disabilities, which are younger than 65.

Besides the institutional care services, adult users are also recipients of medical, social, and psychological services, as well as rehabilitation within these institutions.

Assessment of the number of placements of disabled adults currently vary in Slovenia (based on methodology, data sampling, and definition of institutional and community-based living, based on persons' age etc.) Flaker *et al*. (2011), for example, have assessed that the number of all users of long-term care irrespective of their age is 50.380, and also point out that assessments vary from 38.000 to 60.000 persons.

Table 6: *Assessment of number of users of long-term care and its' cost according to various services (Flaker et al. 2011: 249)*

	Number	%	Per	Per year	Total annual	%
Community nurse services	3000	5,95	54	650	1.950.000	0,58
Personal aid (monitor)	600	1,19	75	900	540.000	0,16
Benefits only	17.483	34.70	190	2279	39.836.978	11,81
Domestic help	5780	11,47	237	2844	16.442.637	4,88
Family assistance	841	1,67	525	3300	3.131.100	0,93
Personal assistance	497	0,99	550	6600	3.280.200	0,97
Community	28,201	55,98	193	2311	65.180.915	19,33
Day-care centres	530	1,05	216	2592	1.375.036	0,41
Daily commuters of CWCs	1627	3,23	557	6804	11.070.108	3,28
Residential communities	236	0,47	825	9894	2.335.090	0,69
Gateway structures	2393	4,75	515	6176	14.780.234	4,38
Residential homes for the elderly	15,235	30,24	911	10.932	166.549.020	49,39
Special social institutions	2478	4,92	1446	17.354	43.002.716	12,75
Full-time residents of CWCs	1234	2,45	1803	21.636	26.698.688	7,92
Educational and training institutions	839	1,67	2082	24.984	20.967.986	6,22
Institutions	19,786	39,27	1083	13.00	257.218.410	76,29
Total	50,380	100,00	558	6.693	337.179.560	100,00

Flaker *et al.* also point out: "We predict that such a population requires at a minimum 300 millions Euros, but the sum could be at least twice as much. Long-term care is extremely institutionalised in Slovenia because almost 40% (20.000 individuals) of people in need of long-term care live in social care institutions. Even if we compare only the number of people who live in residential homes for the elderly to those who receive domestic care, we quickly find out that the ratio between them is 3:1. Slovenian system is institutionally oriented to such an extent because more than three quarters of resources allocated to long-term care go to institutional care." (2011: 308)

Our estimate of institutional accommodations is smaller because we focused on persons between the age of 18 and 65 and tried to avoid any sort of duplication of care-receivers. Our research was hindered by the fact that some institutions do not have exact data on the number of people in this age group or errors occurred in the process of data-forwarding (data from various sources usually differed significantly; Ministry of Labour, Family, Social Affairs and Equal Opportunities simply does not possess much of the data). When assessing peoples' needs, it makes sense to cover all people who need community-based support, including children and youths who are currently placed in institutional care and work centres (day care) and are potential users of long-term care when they will be unable to live at home. Currently there are 1272 children and adults in institutional care who will have to be accounted for during preparations of community-based services to put an end to institutionalisation as soon as possible and to prevent relocation of people from one institution to the next.

Table 7: *Children and youths in institutional care*

TYPE OF IMPAIRMENT	NUMBER OF
Medium, severe, very severe cognitive	433
Mild and/or medium cognitive	181
Blind and partially-sighted	19
Deaf and hard-of-hearing	49
Mobile impairment	208
Emotional and behavioral disorders	382
Total	1272

Source: Statistical Office of Slovenia and the Delo daily, 28th July 2015.

Most of institutions sampled in this research have increases their capacity by building additional structures beside their main building or they set up their branches within the wider region (residential units, residential groups and residential communities or individual apartments). Some people see it as an institutional form of care others as a collective of tenants and others still as community-based living. Formal particularities of these units are defined in Rules on the standards and norms for social services. Each apartment is supposed to have a capacity of 4-6 beds while residential units are supposed to have 24 beds.

Our short descriptions of units include **number of persons** living in different arrangements of institutional care (main buildings, mansions, laundry room, residential units, residential groups, residential communities and individual apartments), **activities in which users are included**, number of **staff**, types of **extra services**, **commercial activities** that institutions provide for their external users, and **costs** of institutional care. We have provided an especially meticulous overview of various forms of accommodation to determine the number of people who need community-based accommodation and other services.

All institutions for adults are **very similar** to each other according to their organisational arrangements with regard to accommodation and services. Professional services are divided into medical services (medical care and rehabilitation), social and psychological services, and special needs education. Among most frequent activities available to tenants are "care for yourself", healthy living activities, occupational therapy, socialising, occasional shopping in near-by stores, occasional

trips, and annual holidays, attendance at various local events, sports activities, work at CWCs, and church services. We carefully enumerated all the services in some of the institutions in order to give the readership an impression on the diversity of the institutional supply of services.

All institutions are almost fully occupied. There is some significant divergence only in residential homes for the elderly. All SCIs except one and all CTWCs share one characteristic: they run **a commercial activity for external users** (delivering lunches, cooking for kindergardens, domestic help, massage, social activities, renting holiday capacity etc.) in order to adapt to persons who live in the community and are changing the mode of thinking that people can only get access to services from within institutions.

Analysis of documents of individual institutions shows that in spite of wide selection of options of different available placements, **social care institutions have retained institutional mindset**, because these services are not aimed at a goal or a vision of people living independently, outside the limits of institutional care. Let us use an example we can generalise. Article 2 of rules for residents of SCI Dutovlje states: "Institution provides its tenants with basic care, living conditions in furnished, maintained and heated rooms, use of common area, sustenance matching one's age and medical state, help with serving sustenance, medical care with rehabilitation and social care and monitoring." Such an attitude based on existing legislation needs to be thoroughly updated before we can complete the process of deinstitutionalisation.

Due to the difficulties with acquiring data described in the chapter about methodology, we collected data in various ways via a survey, an analysis of annual reports and other documents, through telephone polls, institutional visitations and website analysis. Data on the number of tenants often did not match and in many cases it was difficult to determine which persons are aged between 18 and 65 or which ones live in other branches of institutions. Short descriptions will only provide some general overview of institutions. We eschewed data which is widely known and easily available. All data cited is from 2014. In cases when data in annual reports and web sources or surveys differed, we always used data acquired via survey.

Social care institutions

Findings

In 2014 1522 people lived in SCIs, most of whom, 1094, were aged between 18 and 65. Of all the tenants 1063 lived in main buildings, while 459 lived in various branches. Gender analysis shows that **more men than women** live at SCIs. At SCI Ponikve there are 50% more men than women.

Five SCIs employ 964 staff.

SCIs have reorganised some of their residential units **that retain the spirit of institutional care**: a large number of persons live at the residential unit. The rooms offer no privacy since most adults live with at least one more tenant, in rare cases even more. In other branches, people are sometimes assigned into rooms according to their impairment instead of their wishes, interests, and social connections. People can enter the wider community only collectively or with guidance.

Staff in institutions is **a proxy between users and outside world** (other people and relatives).

Services provided by institutions are very similar and entail: social, medical, psychological aspects, as well as experts in special needs learning.

Daily activities entail: "care for yourself", occupational therapy, socialising, occasional attendance at various local events, sports activities, celebrations and church services.

Individual plans are used for activities inside institutions not outside them.

All SCIs except one provide **commercial activities for external users in the local community**.

All institutions provide essential (individualised) services that are to be paid separately which only highlight the lack of respect and support to individual needs of persons.

In SCIs **per-day costs differ**, although the services are the same.

Centers for training, work and care

Findings

In 2014 1203 persons lived in CTWCs and ITWCs, 961 of whom were aged between 18 and 65, mainly men.

Similarly to SCIs, these institutions also founded new branches which are more or less similar to institutional forms of living. Some residential units have many tenants, more than 13 persons.

Services and daily activities are very similar between the different institutions. There is a lot of emphasis on work at care and work centres. Sometimes users work outside of CWCs for nearby farmers and private citizens, but since the legislation is not well regulated, much about this work is unknown.

The number of staff is roughly the same as with SCIs, 1353 in total, which is more than the number of users in full daycare (16 + 8 hours).

All institutions provide commercial activities for external users.

There are big differences in per-day costs, although all institutions provide the same activities and services. The difference between the lowest and the highest per-day cost is 17,77€.

Care and work centres

Findings

CWCs provide institutional and daily care.

There are 29 CWCs with 86 units in Slovenia (if we also count CTWCs and ITWCs, which also have CWCs, there are 34 of them, with 102 units). 13 CWCs with 30 different units have a concession to provide CWC services.

CWCs are increasing the number of short-term contingency placements which are important for deinstitutionalisation processes.

There were 689 people living in the institutional form of CWCs in 2014 and 3200 persons worked in daycare CWCs.

Daycare in CWCs is in need of conceptual and legal changes. This field requires changes to legislation (Act Concerning Social Care of Mentally and Physically Handicapped Persons, and Vocational Rehabilitation and Employment of Disabled Persons Act, right to work at an ordinary work place, and right to integrated employment).

Many people with disabilities who are formally CWC users work at temporary jobs that they are able to find on their own, which is very important for the process of deinstitutionalisation, however institutions cannot support them officially, because legislation does not allow such a form of labour.

People who work for nearby farmers and private persons earn significantly more money than people at CWCs, and also report on a higher level of satisfaction, because they are "properly" employed.

Combined social care institutions

Findings

2824 persons lived in CSCIs in 2014, 497 of whom were aged from 18 to 65. None of the institutions with the exception of Impoljce have a separate branch of residential units.

The staff amounts to 1450 employees.

CSCI users must pay for additional services, which are a reflection of their need for individuality. Costs of the same services also differ between the various CSCIs.

Residential homes for the elderly

Findings

945 person younger than 65 live in 84 residential homes for the elderly in Slovenia, which is a consequence of lack of other forms of support for people with various impairments and lack of community-based living opportunities.

Residential homes for the elderly (except two) do not have units for persons with disabilities younger than 65 as mandated by the Social Security Act in case when residential homes for the elderly provide accommodation for the people younger than 65. Inspections, however, have found no violations.

Professional staff in residential homes for the elderly often use naming that devalue and disable their users.

Professional staff often don’t see individuals as individual service receivers, but as dependent or related groups.

Service costs

Table 12: *Care cost (institutional care for adults, 24-hour care)*

PER-DAY CARE COST IN €										
		CARE 1:	CARE 2:	CARE 3:	CARE 4:	CARE 5:	CARE 6:	AVERAGE COST	CARE IN BRANCHES:	CARE IN RES. COMM.:
SCI										
1.	SCI Hrastovec	/	/	31,22	/	36,67*	/	33,95		
2.	Dom Lukavci	27,21	22,76	29,45	/	33,3	/	28,19		
3.	SCI Dutovlje	26,95	29,42	27,10	33,68	37,29*	/	30,89		
4.	Dom Nine Pokorn Grmovje	22,69	24,65	28,13	29,26	31,77*	/	27,30		
5.	Prizma Ponikve	26,40	32,41	/	/	36,8	28,22	30,98	36,41	
Total SCI AVERAGE COST OF CARE								30,26		
CTWC/ITWC										
6.	CTWC Črna na Koroškem	/	31,03	35,81	37, 97	43, 17	/	37,00	Avg. 28,16 (16 h)	49,13
7.	CTWC Dobrna	/	/	/	/	51,74	/	51,74		
8.	ITWC Dornava	/	/	/	/	45,03	/	45,03		44,00 (16 h)
9.	CTWC Draga	/	/	/	/	56,47	53,07	54,77	Avg. 49,37	Avg. 56,22
10.	CTWC Matevž Langus	/	/	36,47	38,36	43,95	/	39,59		46,68
Total CTWC/ITWC AVERAGE COST OF CARE PER DAY								45,63		

PER-DAY CARE COST IN €										
		CARE 1:	CARE 2:	CARE 3:	CARE 4:	CARE 5:	CARE 6:	AVERAGE COST	CARE IN BRANCHES:	CARE IN RES. COMM.:
CSCI										
11.	Dom Impoljca - unit	24,03*	26,24	29,53*	30,54*	34,67*	/	29,00		
12.	Dom Danice Vogrinec Maribor, average	26,50*	28,52 *	28,53*	29,01*	31,18*	25,64*	28,23		
13.	Residential home for the elderly Idrija - unit Marof	25,69*	28,77 *	32,57*	/	38,95*	25,04*	30,20		
14.	RHE Ljubljana - Bežigrad	/	/	/	/	/	42,20	42,20		
15.	RHE Ilirska Bustrica	27,50	27,50	33,06	33,06	33,06	27,50	30,28		
16.	RHE Metlika	24,22	24,22	29,48	29,48	29,48	/	27,38		
17.	RHE Podbrdo- unit Petrovo	27,95*	35,46	31,00*	/	40,80*	/	33,80		
18.	CSS Škofja Loka	/	/	/	/	/	21,79	21,79		
Total CSCI AVERAGE CARE COST PER DAY								30,36		

* price for double bed room

Medical care costs are covered by Health Insurance Institute of Slovenia. Average costs of medical care also differ among institutions. Health Insurance Institute's data [34] show that sums that individual institutions receive from the Health Insurance Institute vary and depend on their capacity. Data available at Health Insurance Institutes website are cumulative and cannot be applied to the population sampled in our research. They cover the period between January 1 2012 and February 31 2012. Zavod Hrastovec received the highest amount that year, 336.327,00€, followed by Lukavci 114.752,00€ and Zavod Ponikve 49.128€. Approximate average sum for other institutions is 70.000,00€.

CTWCs with a five-year contract with Health Insurance Institute (they provide cares I, II and III and calculate the average sum they are eligible receive) provide the most expensive services (there are no standards yet for CTWCs, but they are being prepared by the Ministry).

Table 13: *Average prices of medical care at CTWCs:*

CTWCs and ITWCs	Average price of medical care paid by Health Insurance for
CTWC Črna na	18.02
CTWC Dobrna	15, 63
ITWC Dornava	25.87€
CTWC Matevž	18.75€
CTWC Draga Ig	27.96€

Chapter 5

Number of potential users of community-based services

We need to account for the fact that many people who would need community-based services are not entitled to any cash benefits or services listed above (e.g. many persons with cognitive health issues) and we can legitimately claim that **the total number of potential users (with intellectual, motor and sensorial disabilities and individuals with mental health insures aged between 18 and 65) of community-based services is 15.000 persons.**

Chapter 6

State of affairs in the field of non-governmental organisations, providing community-based social care programmes for persons with disabilities in Slovenia

Findings

1. Most NGOs providing social care services for people with impairments are **traditional disabled peoples' organisations**, which are **the most equally distributed all over Slovenia, but only a few of them** are able the support deinstitutionalisation processes with their own means. Out of 96 humanitarian NGOs **only 9 organisations** actively support deinstitutionalisation processes.

2. List of DPOs shows that they are mostly focused on **biomedicinal classification of their users** who are classified by their diagnoses and not their individual needs which is why their **conceptual stance towards deinstitutionalisation processes** is questionable as well. Other NGOs have sometimes also shown **medicinal orientation** and **use of institutional care models**.

3. NGOs are often financed on a per-programme basis from **multiple sources**: Ministry of Labour, Family, Social Affairs and Equal Opportunities, Ministry of Health and other ministries, Foundation for Financing Disability and Humanitarian Organisations, Employment Office of Slovenia, contributions from municipalities and our users, and other donations. NGOs that work in the field of disability receive **insufficient funds** from the Ministry of Labour, Family, Social Affairs and Equal Opportunities **to finance their programmes.** From 2011 on financing of special social programmes has been reduced continually (IRSSV, 2015:172). Programmes are financed 80% at most (this is an exception, usually it is much less), which has a direct effect on unstable financial situation of NGOs, fluctuation of the staff, as well as service quality for users. Several cases show that **NGOs are seriously understaffed**. Since most public tenders are annual (except those from the Ministry of Labour, Family, Social Affairs and Equal Opportunities and The Employment Office in 2014), this is a cause of severe programme instability, precariousness among the staff and users and red tape in daily operation of NGOs. Staff wages are usually not on a par with public sector employees with comparable jobs (personal assistant is paid less than a social carer). Consequentially much of the work in NGOs is done by **volunteers**.

4. Capacity of most of the programmes **is limited,** and the rate of co-financing cannot be increased although users' needs far surpass them.

5. NGOs are aware that as one of the social care service providers, they need to put **a lot of effort**

and work into staff training, evaluation of their work and increase their service quality in the future.

6. **Services** which are key for deinstitutionalisation and community-based living and are already provided by NGOs are most commonly the following: personal care and and daycare centers for persons with mental health issues, residential groups etc. Some of the support services are: counseling, informing, support in specific areas, advocacy of people with disabilities, psycho-social help and transportation. There are **large differences** among programmes with the same name (conceptual, regarding their extent, content), which is why some programmes cannot be compared to others in spite the same name. **The gamut of different services and their extent is much too small** and needs to be broadened. Residential groups, which are supposed to be a temporary living solution, have become a permanent way of living for most people due to **lack** of housing and other services for people with disabilities. Some services, which are crucial for deinstitutionalisation are not available yet, have not been subject of public tenders, and have not been tested yet (such as community-based crisis teams and crisis centres).

7. Community-based support needs **a wide network of NGOs which would provide essential and quality community-based services** in the process of deinstitutionalisation: supported living, personal assistance, provision of transportation network for people with disabilities, support in the education process, employment process, on-the-job support, life-long learning support, support for developing independent living skills, support for founding a family, psycho-social support, support for living outside residential communities and satisfaction of other basic social needs, coordination of jobs and community-based support.

8. Compared to institutional care services, NGOs provide **comparable services for less money** (e.g. residential groups). Inadequate legislation preclude them from regular acquisition of funds for daycare (some municipalities reject the payment for users' living costs) and covering of medical care costs, because they cannot have costs covered from health insurance. Needs of the people cannot be separated in various sectors and disciplines, and it is high time **that we stop the fragmentation of services by sectors**. Individuals should have services that they need available in the simplest possible way.

Chapter 7

Recommendations on NGO development for provision of deinstitutionalisation process and basic conditions for community-based living

Importance of NGOs

Research has shown that NGOs in the field of social care to persons with impairments**are able to provide numerous services in the process of deinstitutionalisation**, however, they expect to be taken **as professional partner organisations and not as volunteer associations** (focus group 2015). According to their experience Ministry of Labour, Family, Social Affairs and Equal Opportunities and local governments would rather pay for accommodation of people in institutional care instead of paying for various forms of living outside institutions ("*Right now this is a serious obstacle because most municipalities reject paying for placement at residential groups*"). This is a consequence of lack of legal basis, although the programmes provided by the NGOs **cost less than programmes in institutions**. The role of municipalities of the process of deinstitutionalisation is therefore very important. We also showed that people do not have **any options** in institutional care. Daily routine is completely dependent on institutional patterns. Branches of institutions do not provide normal life and inclusion into the community. NGOs can enable relocation into the community but a significant number of scattered apartments has to be made available to NGOs to provide support for individuals

with impairments.

NGOs point out that deinstitutionalisation should not mean the development of services, which will be available to users whether they need them or not. What we need is to develop **sensible services**. Services shouldn't be split into medical and social services; as many services as possible should come from a single source. It is also important that users do not receive merely services that are currently available instead of the services that they truly need and want ("*I agree that everything ends and starts with money and I hope that funds will become available for users and that users themselves will be able to decide where the money should go, and what they need, so users themselves could decide what they want and how they want it, so we could fight for common goals."*). Some NGO employees have pointed out that we need to change the mentality that NGO employees should do the work which resembles charity ("*Everybody thinks that NGO employees are volunteers, which is not true, and that needs to change."*).

NGOs which have decided to support deinstitutionalisation processes **must focus on individual's needs and not his or her impairment**. There is an important principle in social care that is not yet self-evident in Slovenian mentality: **users must have a choice in their accommodation, services and provider of the said services.** In order to successfully complete deinstitutionalisation process, we need to fulfill material needs (sufficient funds for decent living, housing etc.), but also ensure that employees have **appropriate professional skills,** because institutional doctrines are currently directed towards maintaining dependence on institutions, which is an important basis of fear that the staff, relatives and users experience in the process of deinstitutionalisation.

Recommendations that we have formed based on the collected results are the following:

RECOMMENDATION NO. 1:

Deinstitituionalisation processes must be accompanied with NGO development, so that they will be able to provide required community-based services, which are based on individual users' need and not on their impairment. Community-based services provided by NGOs must become available **both in urban as well as rural areas** (so that people can return where they want to live, where they came from and so they don't have to stay at the location of institution).

RECOMMENDATION NO. 2:

Promotion of networking, integration and cooperation between NGOs to ensure integrated and quality individual support. It is important to go beyond the divisions based on existing classifications (social versus medical; disabled persons versus humanitarian organisations; local versus state-level).

RECOMMENDATION NO. 3:

NGOs must develop **their own standards of quality**. Criteria of service quality must under all circumstances be designed in cooperation with the **users of these services**. It has been demonstrated that there are significant conceptual differences between NGOs, differences in scale, and there are programmes with the same name, however, providers develop their programmes vastly different from one another. Consequently some of the content of the programmes must to be unified.

RECOMMENDATION NO. 4:

We need to provide regular, continued and sufficient financing of NGOs which should become part of regular financing enshrined in law. Changes need to be made in the field of financing of new jobs, because currently operation of NGOs is based on temporary jobs, i.e. via public works programme. Consequently NGOs are faced with high employee fluctuation and uncertainty, which has a detrimental effect on the quality of work. We need to provide a legal basis for co-financing of services by municipalities.

RECOMMENDATION NO. 5:

We need to incrementally **bridge the legal gap between non-governmental organisations** and institutional care providers. Social Security Act must include NGOs as social care services providers. We need to avoid unnecessary red tape and consequentially higher prices of services. **Legal basis must be provided as soon as possible for financing of services that are already tried and tested**, meaning that programmes must be

restructured into social care services which are provided, among others, by NGOs. The government must invite public tenders for yet untested but critical services via experimental pilot projects. For complex services, e.g. personal assistance, we need special law (Personal Assistance Act). For services such as escort, day care centres, residential groups, and transportation we can modify **the portfolio of services** set out in the Social Security Act. Already tested and tried community-based services are:

- residential groups,
- personal assistance,
- psycho-social help,
- domestic help,
- individual support,
- escort,
- transportation,
- advocacy,
- day-care centres,
- aid related to employment.

Until these legal changes are signed into law, the services must still be provided via public tenders as they currently are, but their capacity must be increased by at least 50%.

RECOMMENDATION NO. 6:

Development of direct financing, which users receive directly. Finances must track the user even for payment of NGO services. Users have the right to decide where they will claim the services they need.

RECOMMENDATION NO. 7:

To enable deinstitutionalisation processes, which will include NGOs, we need to immediately call **for intersectoral collaboration** among the different offices of Ministries, local governments, and public housing funds for **acquisition of housing** scattered in the community.

Basic conditions for community-based living

In order to streamline the deinstitutionalisation processes we need to find solutions in three areas simultaneously:

- accommodation, community-based residential units,
- provision of basic living resources,
- provision of special services that individuals need to live in the community.

While providing community-based services we also need to provide enough community-based housing for those who cannot acquire enough funds through paid labour.

Accomodation, living in the community

- Increase in temporary residential capacity, (e.g. residential groups programmes and individual assisted residential units). Ministry of Labour, Family, Social Affairs and Equal Opportunities, other ministries, local governments and housing funds must all work in unison.

- Development of permanent assisted community-based residential capacity for people who wish and need continued permanent support every day.

- In order to claim **the right to their own housing** unless the person already has it in possession, the state needs to provide enough scattered individual housing to incentivize deinstitutionalisation processes. Support services need to be retained if people want or need them.

- Looking into the possibility of placement at another family — surrogate family trained in providing

accommodation with all the required support.

Basic resources for community-based living

If an individual does not have income or his or her income does not meet the minimum sum needed to live in the community, law needs to be changed to provide the needed funds (i.e. increased benefits). Law also needs to be changed in such a way that people have an option to acquire a part of the funds with labour they are able to and wish to perform. Most people does not even enter the labour market because they are afraid that they would lose all the benefits they receive (e.g. disability benefit or disability pension), although these are insufficient to support community-based living. We need to develop new forms of labour and work on flexibility of statuses, raising awareness of employers and offer people support even after they have been employed, because employment is one of the key factors of successful social inclusion.

In order to complete deinstitutionalisation as soon as possible, beside the adoption of measures related to community-based services, accommodation and provision of basic living funds, we also propose to:

- stop new placements at institutional care providers,

- immediate relocation into the community (with support),

- stop investments into development and renovation of existing institutions.

RANGE OF REQUIRED SERVICES FOR DEINSTITUTIONALISATION PROCESS

	REQUIRED SERVICE	RIGHT	DESCRIPTION, breakdown of the service
1.	COMMUNITY-BASED ACCOMMODATION (and relocation from institutions)	Right to independent living in community and Right to relocation from institutional care	a) Residential groups with long-term support temporary residential groups with at most 3-year support for adults and youths for emergency accommodation for temporary family relief b) Supported relocation from institutions c) Individual residential units (with or without support) d) Surrogate family — trained surrogate families for adults and youths
2.	PERSONAL ASSISTANCE	Right to independent living in	help with everyday tasks (care, escort, domestic help etc.) for people who need continued wide array of support
3.	PSYCHO-SOCIAL HELP	Right to counseling personal growth, being informed	a) Counseling: • personal, over telephone, web counseling - for users, relatives and people close to users b) Guided self-help groups with support for: • users • relatives and people close to users c) User self-help groups d) Self-help groups for relatives and people close to users e) Life-long learning programmes; preservation of skills and knowledge and acquisition of new skills and knowledge f) Peer counseling
4	DOMESTIC HELP	Right to independent living in	Domestic help (menial tasks, care for users) for a small scale of needs with everyday activities.
5	INDIVIDUAL SUPPORT	Right to independent living in community	Support for performing everyday activities within or outside user's home (e.g. taking care of personal matters) with the help of support staff. - personally (within or outside home) - via telephone or email Individual medical care remote support — (via telephone or email). Support for family relations
6	ESCORT	Right to mobility	Escort for daily activities outside home.
7	TRANSPORTATION	Right to mobility	Accessible transportation due to reduced mobility, inaccessible public transport or inability to use public transportat. Need for transport due to lack of public transport
8	ADVOCACY, SELF-ADVOCACY AND LEGAL AID	Right to protection of rights	Advocacy, self-advocacy and legal aid in the field of mental health and in case of physical, sensorial and intellectual impairments (professional, in lay terms, collectively). Protection of specific rights of service users in the field of mental health, social security, medical services, rehabilitation, employment
9	DAY-CARE CENTRES	Right to social inclusion	Day-care centres for socialising and creative free time, creativity, social inclusion, learning of social skills, inclusion into a wide social environment, acquisition of new knowledge, etc.

	REQUIRED SERVICE	RIGHT	DESCRIPTION, breakdown of the service
10	HELP AT WORK POST AND EMPLOYMENT	Right to employment and social inclusion Right to employment rehabilitation Right to acquisition	Individual support at work, help with finding employment, acquisition of new knowledge and skills with the purpose of gaining employment, mentoring for integrated employment.
11	CRISIS TEAMS	Right to getting through a mental	Regional programmes in community-based multidisciplinary crisis teams for mental health.
12	CRISIS CENTRES	Right to getting through a mental crisis outside the	Network of regional programmes and safe houses for getting through medical crises with the support of community-based multidisciplinary team.
13	REGIONAL CENTRES FOR COMMUNITY-BASED PSYCHIATRIC TREATMENT	Right to integrated psychiatric treatment at primary level	Network of interdisciplinary teams united in regional centres for community-based psychiatric treatment.

1. Services from points **1 to 9 (except 1b, 1c, 1d and 3g)** are currently provided via NGO programmes. For a number of years they have been provided as independent programmes or their integral parts. Most have also been verified by Social Chamber of Slovenia and have been a part of the social security programme network for a number of years or they have a concession for specific activities. These services must be tied to an individual and must become a legal right. We need to change the law in a way so that rights become accessible to all users who need them instead of being limited by "the number of vacant capacity in specific programmes" and in specific area. For some of them, e.g. personal assistance, bill has already been drafted. Some of the services are provided by institutional care providers. We assume that providers of these services will not be only NGOs but also public institutions and private sector.

Until the required legal changes are prepared and signed into law, we need to increase the available capacity in 2016 (along with the funds for these programmes) for social security programmes described above, which are already provided by NGOs. This is the only way to preserve the momentum of the deinstitutionalisation process. Public tenders for training of necessary staff for community-based work need to be invited. Quality of community-based services is a key question that all providers of community-based services must face.

2. For programmes **from 10 to 13** and for services **1b, 1c, 1d and 3g** we need to invite public tenders for pilot project and experimental programmes to verify, evaluate and develop new necessary community-based services. Tenders need to allow for several NGOs to apply together with their community-based pilot projects. Relocations from institutional care into community-based living must urgently commence as soon as possible. Pilot relocation projects need to start as soon as possible: tender by the end of 2015, relocation of 150 persons in 2016.

3. **To claim the services** under points **11, 12 and 13**, we recommend collaboration with regional centres for community-based psychiatric treatment and urgent collaboration and an agreement between Ministry of Labour, Family, Social Affairs and Equal Opportunities and Ministry of Health, which already finance pilot programme of regional centres for community-based psychiatric treatment at the primary level (point 13).