Ieva Leimane-Veldmeijere, Uldis Veits

# NEEDS ASSESSMENT OF USERS OF MENTAL HEALTH CARE SERVICES

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LATVIAN CENTRE FOR HUMAN RIGHTS

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# PREFACE

*"I am forgotten and alone, I have no friends, no home, and no work.*
*However, just like you, I love life very much,*
*I want to feel the taste of home made food,*
*to work, to be loved and to belong.*
*I can do it!"*
*(Patients' Council of Aknīste psychiatric hospital)*

In Latvia, similarly to many other new EU member states, institutional care at psychiatric hospitals and social care homes at present is the most widespread form of care for users of mental health services. In January Latvia, together with other countries of the European region of World Health Organisation (WHO) signed the Mental Health Declaration and Mental Health Plan of Action for Europe 2005–2010, which demands that the relevant authorities in each member state introduce a mental health policy and legislation harmonised with international standards and develop public care for persons with serious mental disorders to replace care in large institutions. However, to date deinstitutionalisation and development of community based services is progressing slowly.

In deciding future mental health care policy it is unforgivable not to ask the views of users of mental health care services, and unforgivable to plan services without finding out the needs and satisfaction with the quality of present services of users of psychiatric services, because services of mental health care are provided not for the needs of civil servants and mental health care professionals, but for the needs of users. The aforesaid WHO Helsinki Declaration calls for involvement of users of mental health care services in decision making. Furthermore, it is essential to give users of mental health care services the opportunity to affect decision making both at the legislative level and issues of day-to-day living while at an institution.

Noting that during the past two years the Ministry of Health has been drafting a new strategy for improvement of the mental health of the population for a ten year period, the Latvian Centre for Human Rights (LCHR) thought it necessary to ask the views of mental health care services' users themselves concerning the presently available medical and social care services. Therefore, in August 2005 with the financial support of the Soros Foundation-Latvia and the European Commission LCHR in cooperation with the Union of Psychiatric Nurses of the Latvian Association of

Nurses, organised a poll of mental health services' users at a number of psychiatric hospitals and specialised social care homes for the mentally disabled in Latvia. Although results of the poll were published a year later, the information obtained is still current, because in the hallways of Ministries work on drafting a mental health care policy is still ongoing.

I wish to thank all those 408 interviewed users of mental health care services for their part in the study and sharing their personal experience, Ministries of Health and Welfare, for their support during the study, members of the working group developing the questionnaire: psychiatrists Māris Taube, Uldis Veits, Māra Dīriņa, social work specialists Inga Esīte, Sigita Rozentāle, Līga Rācene and Eva Ikauniece, psychiatric nurses Skaidrīte Pudāne, Jekaterina Jeremejeva, users of mental health services Inga Laicāne and Broņislavs Jaņickis and sociologists Indra Strautiņa and Sanita Vanaga. Also thanks go to users of mental health services at Strenči psychiatric hospital and the organisation "Gaismas stars" (A ray of light) for their part in the pilot interviews and the training seminar for interviewers. Thanks to representatives of the Union of Psychiatric Nurses for conducting interviews with users – Jekaterina Jeremejeva, Inese Zārdiņa, Skaidrīte Pudāne, Margarita Grīva, Žanna Kozlova, Irēna Purmale, Ilze Dzervane, Zinaīda Aļeksejeva and Līga Rācene.

A special thanks goes to Uldis Veits and Sanita Vanaga for their invaluable involvement in the study, and Executive director of the Soros Foundation-Latvia Andris Aukmanis for the provided moral support during the study and when looking for necessary additional funding. And last but not least to my mother who, living with her illness, gave me a deeper understanding of the day-to-day reality of users of mental health services.

*Ieva Leimane-Veldmeijere*
*Director of Mental Disability Advocacy Program*
*Latvian Centre for Human Rights*

# I. INTRODUCTION

This study for the first time demonstrates the views of users of mental health care services on the medical and social care services available to them, provides an insight on the human rights situation at psychiatric hospitals and social care homes for people with mental disorders in Latvia as seen by users of mental health care services, and assesses their satisfaction with available mental health care services.

In planning to do a needs assessment of persons with mental disorders, intended in the form of a poll, the Latvian Centre for Human Rights (LCHR) established a working group in the Summer of 2004 which included representative professionals of the Psychiatry Centre (current Mental Health Government Agency), Health Statistics and Medical Technologies State Agency, Welfare Department of Riga City Council, Social Services Board of the Ministry of Welfare, Strenči Psychiatric Hospital, NGO "Paspārne" (Shelter), Latvian Union of Psychiatric Nurses, and representatives of patients from Aknīste and Strenči psychiatric hospitals. The task of the working group was to agree on the form of needs assessment, pinpointing a target group, and agree on questions to be included in the questionnaire. The working group also included an employee of LCHR, 4th year sociology student Indra Strautiņa, who consulted the working group and drafted the questionnaire for needs assessment, and sociologist Sanita Vanaga, who trained interviewers – psychiatric nurses – and processed the obtained data.

The working group agreed that both a qualitative and quantitative study was necessary, however, because of the limited funds, only a quantitative study has been completed at present. The working group also agreed that the data obtained may be very useful to the Ministry of Health, which is presently drafting a new Mental Health Care Strategy for the period of 2006–2016. True, at present the strategy is being drafted without the participation of users of mental health care services, but LCHR hopes that the completed study will present an opportunity to ensure the emergence of views of users of psychiatric services in the process of developing a national mental health care policy.

It was decided not to entrust the carrying out of the poll to one of the public opinion research centres, who would use their own interviewers, but rather to ask psychiatric nurses and social workers of the facilities trained in seminars to do the interviewing at psychiatric hospitals and social care homes for persons with mental disorders. This strategy was chosen because of the specific audience, considering

also that the project partner – Latvian Union of Psychiatric Nurses – already had experience in doing small patients' polls. In order to make interviewing easier and ensure that interviewers had access to the selected facilities, LCHR approached the Ministries of Health and Welfare to ask for their support in interviewing users of mental health care services and to advise management of facilities of the anticipated study. LCHR also advised both Ministries that the interviews would be anonymous and results of the study would not mention specific facilities. Both the Ministry of Health and the Ministry of Welfare supported the idea of the study and informed the management of the relevant facilities selected and asked them to give necessary support to the interviewers – psychiatry nurses of the Latvian Union of Psychiatric Nurses. It should be noted, however, that at one psychiatric hospital in a couple of interviews, notwithstanding the interviewer's request, the privacy of the interview was not ensured and during one interview a nurse even interrupted with a comment, "What kind of questions are these?"

## Objectives of the study

The objective of the study was to carry out a quantitative study of needs assessment of users of mental health care services (on satisfaction with existing medical and social services in mental health care, conditions at facilities and the human rights situation, and the need for community based services).

## Composition of Sample[1]

**Method of interview** – a direct structured interview (conversation with the respondent guided by the interviewer following questions in the questionnaire). During the interview, on certain questions respondents were given the opportunity to give additional comments, which are included in the analysis of the study.

Interviews were done by instructed interviewers. Considering the specifics of the study and the target group, special instructions were given – a one day training seminar was organised.

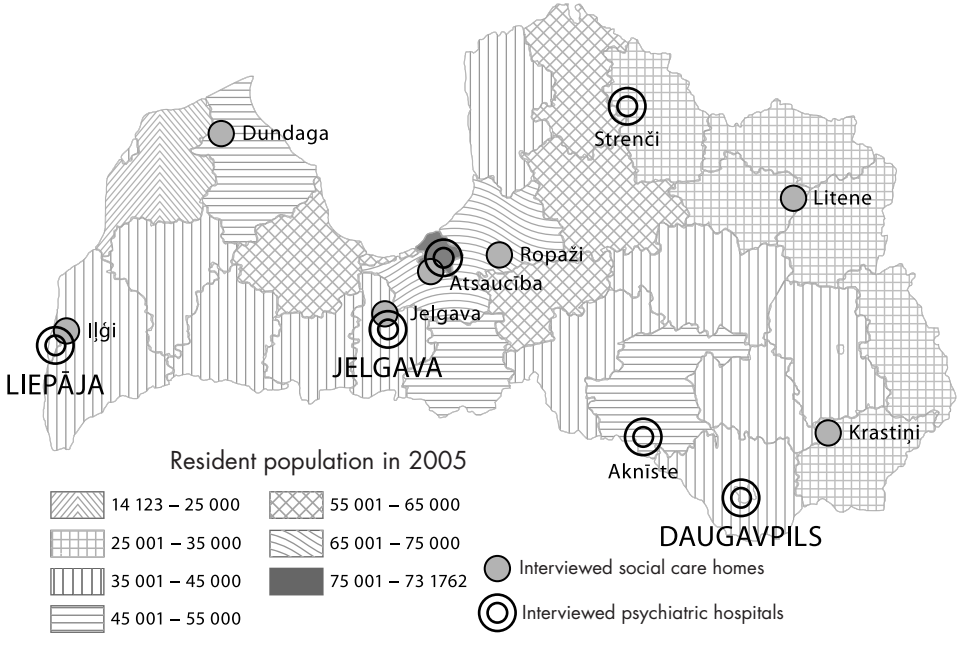
Interviews were carried out during the period from 8 July to 8 August, 2005. Patients of six psychiatric hospitals (266 patients) and residents of seven social care

[1] Description on Composition of Sample was prepared by sociologist Sanita Vanaga.

homes (142 residents) were interviewed. Questions of the questionnaire were grouped by the following themes:

- health care and social rehabilitation,
- patient's rights,
- social conditions,
- education and employment,
- general information on a respondent.

**The location of social care homes and psychiatric hospitals of interviewed residents**




## Procedure of Sample

A multi-stage stratified random method of sampling was used. This method ensures representation of all regions of Latvia in the sample. Social care homes and psychiatric hospitals included in the sample were chosen according to the principle that all regions be represented – Rīga, Vidzeme, Kurzeme, Latgale and Zemgale. The calculated selection totalled 408 persons. Altogether 266 persons were interviewed in hospitals and 142 persons at social care homes for persons with mental disorders.

## Realization of Sample

As a first step a list of all psychiatric hospitals and social care homes was made up.

10% of patients were interviewed at each selected hospital, see Table 1.

That is, a list of all persons to be included in the sample was made up, and from which by 10th step – every tenth person for interview was selected.

In turn, at social care homes every twentieth person was interviewed, covering a total of 10% to 50% of all residents at social care homes, see Table 2.

**Table 1**

| Location | Number of respondents | % of general total |
|---|---|---|
| 1. Daugavpils psychiatric hospital | 63 | 10 |
| 2. Mental Health Government Agency (Rīga) | 55 | 10 |
| 3. Jelgava psychiatric hospital "Ģintermuiža" | 45 | 10 |
| 4. Strenči psychiatric hospital | 45 | 10 |
| 5. Aknīste psychiatric hospital | 42 | 10 |
| 6. Piejūra (Seashore) hospital (in Liepāja) | 17 | 10 |
| **Total** | **267**[2] | |

**Table 2**

| Location | Number of respondents | % of general total |
|---|---|---|
| 1. SCH "Atsaucība" (Response)(Rīga) | 20 | 10 |
| 2. SCH "Ropaži" (Rīga region) | 20 | 18 |
| 3. SCH "Jelgava" | 20 | 19 |
| 4. SCH "Dundaga" (Rīga region) | 20 | 54 |
| 5. SCH "Iļģi" (Liepāja region) | 20 | 19 |
| 6. SCH "Krastiņi" (Krāslava region) | 20 | 29 |
| 7. SCH "Litene" (Gulbene region) | 20 | 19 |
| **Total** | **140**[3] | |

[2] As a result, 266 patients were interviewed, because one questionnaire was considered unusable.

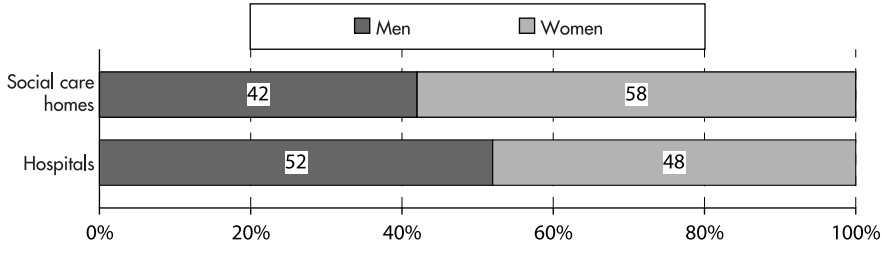
[3] At one of the care homes the number of clients was increased, thus interviewing a total of 142 clients to ensure an equal division of work for all interviewers.

The sample included respondents with the following diagnoses only: schizophrenia, mood and affective disorders, personality and behaviour disorders. The following diagnoses were not included in the sample: mental retardation, organic disorders (including epilepsy) and dementia.

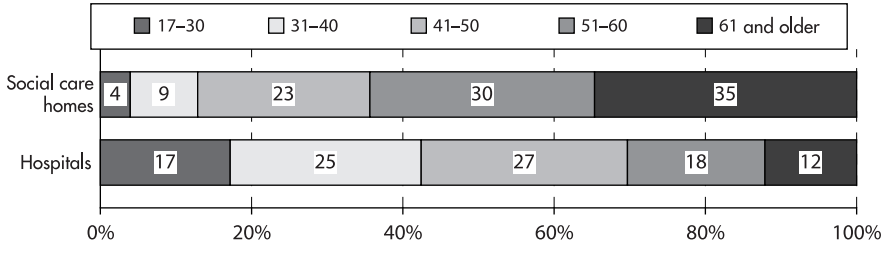
Total of the realized sample is representative in regard to the total population and reflects characteristic features of the total population.

## Demographic indicators of interviewed users of mental health care services

**Composition of users of mental health care services by gender (%) (Question 39) N=408**




**Age structure of users of mental health care services (%) (Question 40) N=408**



# II. DEFINITION OF TERMS USED IN THE STUDY

**Users of mental health care services –** in the context of this study users means the total target group of the study – including patients of psychiatric hospitals and residents of social care homes. "Users of mental health care services" is a more correct term than "patient of psychiatric hospital" or "resident/client of social care home", because the person is a patient or client only in the specific episode of care and in relations with medical/social care personnel.

**Facilities/institutions of mental health care –** this term is used in the study in cases when both psychiatric hospitals and social care homes for persons with mental disorders are meant.

**Psychiatric hospitals** – there are nine psychiatric hospitals in Latvia (including one psychiatric hospital for children and 2 psychiatric hospitals for long term treatment), of those the study was done at six hospitals. Respondents of psychiatric hospitals in this study are named as hospitals' patients or inpatients.

**Social care homes (SCH) for persons with mental disorders –** there are 31 social care homes for adults with mental disorders in Latvia. This study was carried out at seven care homes. Respondents of social care homes in this study are named as clients or residents.

**Community based mental health care –** alternative to institutional care, allowing persons to receive treatment and social rehabilitation services in the community, preferably at their place of residence.

**Mobile treatment team –** provides psychiatric assistance for users at their place of residence with the help of various specialists – doctors/psychiatrists, psychiatric nurses, psychologists and social workers.

**Half-way house –** a dwelling outside an institution provides a place of residence for persons with mental disorders for a limited period of time for the purpose of renewing, strengthening and improving independent life skills prior to being discharged to home or to a group apartment.

**Advocacy**[4] – Advocacy means providing support that would cause changes in the situation of persons in need of support. To advocate often means to speak in place of persons who are unable to speak for themselves. There may be various forms of advocacy:

- self-help groups;
- support groups;
- collective advocacy – people with similar interests speak up as a group;
- peer advocacy – someone else with a similar experience stands up for another person;
- crisis advocacy – short term relationship in crisis situations;
- legal advocacy – performed by someone experienced in the law in order to help a person protect his/her rights.

[4] According to information on forms of advocacy, provided by Hamlet Trust (UK).

# III. THE HUMAN RIGHTS SITUATION IN THE ASSESSMENT OF USERS OF MENTAL HEALTH CARE SERVICES

While assessing the opinion of users of mental health services on the human rights situation, attention was mainly paid to issues of involuntary hospitalization, violations of human rights suffered in the view of users of mental health services, opportunities for submission of complaints, and living conditions at hospitals or care homes.

For several years the Latvian Centre for Human Rights has drawn the attention of politicians to the failure of legislative acts regulating mental health care in Latvia to correspond to international human rights standards, particularly the Council of Europe Convention for the Protection of Human Rights and Fundamental Freedoms, which has been in force in Latvia since 27 June, 1997.

At present involuntary hospitalisation and treatment is regulated by Article 68 of the Medical Treatment Law enacted in 1997, which provides the criteria for involuntary hospitalization[5], also providing that a person hospitalized involuntarily shall be examined within 72 hours by a council of physicians which then makes a decision on the need for further treatment. The law also provides that the patient or his/her next-of-kin shall be informed of the decision of the council. The present regulation of involuntary hospitalization and treatment violates requirements of Article 5 (especially Part 4) of the European Human Rights Convention, which provides that "everyone who is deprived of his liberty by arrest or detention shall be entitled to take proceedings by which the lawfulness of his detention shall be decided speedily by a court and his release ordered if the detention is not lawful."[6]

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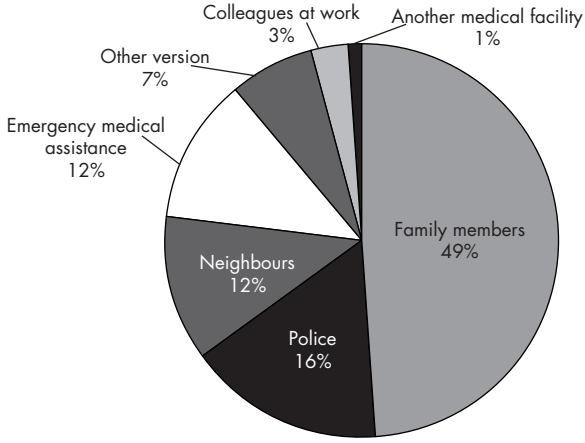
[5] According to Article 68 of the Medical Treatment Law "out-patient or in-patient examination and medical treatment against the will of a patient may be performed only in the following cases: 1) If, due to a mental disorder, the behaviour of the patient is dangerous to his/her health or life, or to health or life of other persons; 2) If due to a mental disorder or its clinical dynamics, the psychiatrist prognoses that such behaviour of the patient is dangerous to his or her health or life or to the health or life of other persons; and 3) If the mental disorder of the patient is such as to prevent him/her making informed decisions, and refusal to undergo medical treatment may lead to a serious deterioration in health and social status, as well to public disorder disturbances", http://www.ttc.lv/index.php?skip=75&itid=likumi&id=10&tid=59&l=LV, (accessed on 10 July, 2006).

[6] Article 5 Part 4 of the European convention for the Protection of Human Rights and Fundamental Freedoms, http://conventions.coe.int/Treaty/en/Treaties/Word/005.doc (accessed on 10 July, 2006).

Of the 408 interviewed users of mental health care services 163, or 40%, respondents remembered cases when they had been involuntarily hospitalized at a psychiatric hospital. The following diagram shows the views of interviewed hospital patients and residents of social care homes on involuntary hospitalization. In most cases hospitalization had been initiated by family members (49%), police (16%), neighbours (12%) and emergency medical assistance (12%).

**Opinion of users of mental health care services on initiators of involuntary hospitalization (Question 15) N=202**




In considering actions following involuntary admission, 127 users of mental health care services, or 78% of those involuntarily hospitalized mentioned that the physicians' council had not examined them within 3 days after admission, as it should have been done according to the Medical Treatment Law. Of the 36 users examined by the council only 20 remembered that they had been informed on the decision of the council.

## Violations of human rights and complaint mechanisms

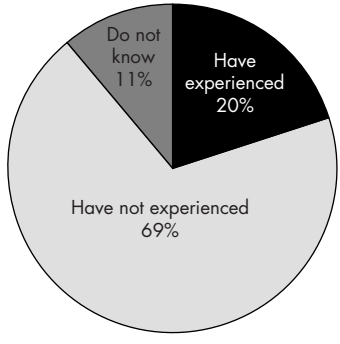
The experts drafting the questionnaire were also interested in the experience of users of mental health care services in facing violations of human rights. In formulating questions of the questionnaire concern was expressed by the working group that users of mental health care services might find it difficult to reply to this question, because they may not know what human rights are; a suggestion was also

made that interviewers first should explain to respondents what human rights are. As a result, the open question was asked, thus also permitting consideration of the awareness and orientation of users of mental health care services in human rights issues. The obtained results of interviews and additional comments provided by users of mental health care services during interviews permitted to conclude that users are aware of what are violations of human rights.

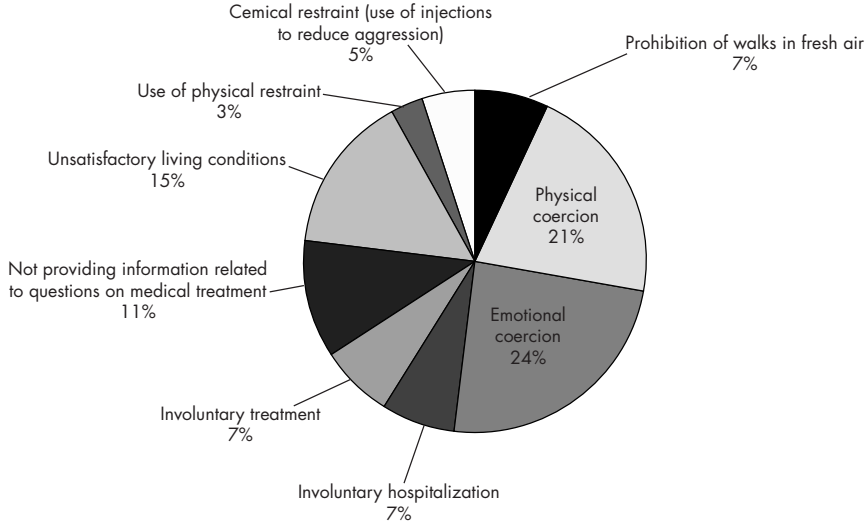
Altogether 15% of respondents of all interviewed users of mental health care services indicated that they had suffered violations of human rights during their stay at a psychiatric hospital or a social care home. The following diagrams analyse only human rights violations suffered by hospital patients, because only 6%, or 9 of 142 interviewed residents of social care homes admitted that they had suffered violations of human rights at their care facilities. 20%, or 53 interviewed hospital patients admitted having suffered violations of human rights, mentioning physical and emotional coercion, use of physical and chemical restraint, control of a person's private belongings without the presence of a patient, prohibition to use private belongings, not providing access to a telephone to contact relatives, not providing information, involuntary hospitalization and treatment, prohibition to have walks in fresh air, unsatisfactory living conditions, not providing information concerning medical treatment related questions. The vast majority of hospital patients, or 66% of those who thought that they had suffered violations of human rights had not sought any kind of help.

Similarly, none of the 9 residents of social care homes who thought they had suffered violations of human rights had sought help. Some respondents explained why they had not sought help – "I was afraid that I might be forced into Ward 1 myself"; "I cannot get out of the (hospital's) unit, I have no chance to get help", "I have not addressed anywhere because it is senseless".

**Breakdown of hospital patients' opinions on facing violations of human rights (Question 26) N=265**



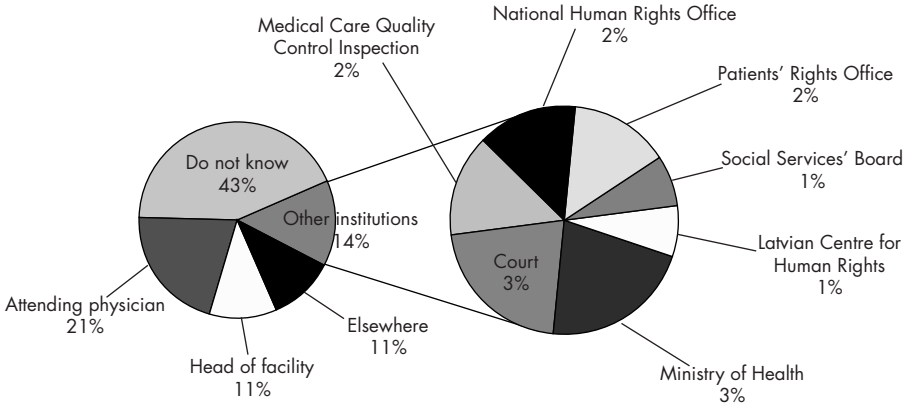
**Breakdown of hospital patients' opinions on suffered forms of human rights violations (Question 26) N=53**



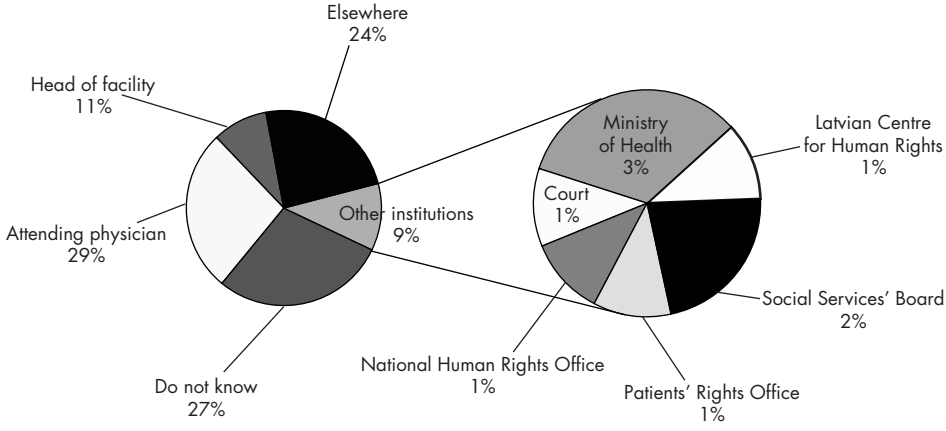

**Comments from users of mental health services on human rights violations they had suffered:**

- They talk to me in Latvian, but I do not understand. When I do not understand, other patients help with interpreting.
- I believe I am entitled to receive information in Russian.
- Patients are scolded, given an injection if they behave noisily.
- I must have my hair cut when I don't want it.
- Every day they (rights) are violated, because I do not want to be here.
- They tell me to make my bed, but I like an unmade bed.
- When admitted, I was given injections against my will.
- There is no sense in talking about it, because patients have no rights.
- They had no right to bring me here to the hospital from the school where I was meeting my son. Nobody explained the situation. I still do not understand what I did.
- I had my turn for a walk, but the hospital attendant did not let me out because the dishes were not washed. She kept me back quite rudely, which offended me.
- Hospital attendant at the supervisory ward does not understand my illness, treats me badly, and shouts (also at other patients).

**Awareness by hospital patients where complaints may be addressed (%) (Question 24) N=266**




**Awareness by social care homes' residents of institutions where complaints may be addressed (%) (Question 24) N=142**




The Latvian Centre for Human Rights during monitoring visits to mental health care facilities in 2004–2006 found that facilities have practically no written and accessible to all patients/residents information on complaints mechanisms at the facility and outside of it. Results of interviews show that 43% of hospital patients and 27% of social care homes' residents do not know where to turn for assistance if quality of medical care, attitude of personnel or conditions at psychiatric facilities does not satisfy them. Both patients at hospitals and residents at social care homes indicated that first of all they would turn to their attending physician. All in all it must be con-

cluded that patients of hospitals and residents of social care homes are not aware of existing institutions which can be used to protect their rights: Medical Care and Work Ability Expertise Quality Control Inspection (Latvian acronym – MADEKKI)), Social Services' Board and the National Human Rights Office (NHRO). It is alarming that only 2%, or 5 of the respondents at psychiatric hospitals know that they may apply to MADEKKI, and 2%, or 3 respondents at social care homes know that they may apply to Social Services' Board, and only 2% of patients at hospitals and 1% residents at social care homes know that they may apply to NHRO. It may be explained partly by the fact that there is practically no information at facilities on complaints' mechanisms, providing an explanation where users of mental health services may turn for assistance in case of human rights violations or inadequate care. A total of 39% of respondents admitted that units of hospitals or care homes do have information on patients' rights, 28% indicated that such information is not available, but 33% of respondents did not know whether information on patients' rights was available.

**Comments from users of mental health services on the possibility to get assistance in cases of inadequate care or incorrect attitude from the staff:**

- The doctor may not be disturbed!
- In case of need I would take the brochure and read it.
- There is no question on complaining – if I say something, I will be locked in a punishment cell.
- It is not favourable to complain, because then you can get injections.

**Comments from users of mental health services on the issue of availability of information on patients' rights in the unit of institution (in the form of brochures or on the notice board):**

- Patients' rights – first time I hear it.
- There is no information on rights.
- Nobody has told about rights – probably something is held back from us.
- Brochures on rights are needed in Latvian and Russian.
- I would like to have a booklet and learn about my rights.
- There is information on the notice board in Latvian only, should be also in Russian, in order to know my rights. I should like to read a brochure on patients' rights.

- I have not seen or read anywhere about rights for mentally ill people, I do not know institutions that would protect my rights. I want to see such a booklet and hear lectures of specialists (lawyers, for example, at the hospital).
- Information is available, but only in Latvian, I cannot read it.
- There was information on patients' rights, but when I started to read it, they took it away.

Considering results of the interviews concerning the awareness of users of mental health services on complaints' mechanisms available in the country, and lack of internal complaints mechanisms[7], it should be recommended to psychiatric hospitals and social care homes in co-operation with relevant ministries to start a discussion in order to establish effective internal complaint mechanisms and ensure appropriate information for users of mental health care services. As an example of good practice in establishing a mechanism for internal complaints the system of Patients' Trust Person in psychiatric hospitals in the Netherlands can be mentioned.

**A Patients' Trust Person at the *Buitenamstel* psychiatric hospital in Amsterdam[8]**

Since 1981 every hospital in the Netherlands has independent persons of trust (called PVP in the Netherlands), working in a number of units of each psychiatric hospital. Patients' trust persons are paid by the National Fund which decides where the patients' trust person will work. The patients' trust person works only for patients. It is not necessary for him/her to be a lawyer. The vast majority of patients' trust persons are educated in social sciences. The National Fund provides initial training and for the first year the patients' trust person works with a senior colleague. The patients' trust person attempts to clarify the complaint, usually by trying to organise a meeting with the particular doctor or nurse involved in the complaint. Most often the complaint is resolved during this meeting. A patients' trust person may also help to write an

[7] The lack of internal complaints mechanisms was ascertained during LCHR monitoring visits.

[8] According to the Netherlands study visit materials of Ieva Leimane-Veldmeijere (carried out on 2–5 November, 2005 in the framework of EU project).

application to the Complaints' commission[9] and he may go with the patient to the meeting at the Complaints' commission. All hospitals pay annual fees to the National Fund which pays the salaries of Patients' trust persons (amount of fees depends on the number of beds per hospital). The Board of the National Fund has three places for patients' organisations and 3 for health care institutions. The Patients' trust person of *Buitenamstel* hospital mentioned that in cases of complaints on sexual violence or theft between personnel and patients he recommends to turn to the Police, because he believes that the Complaints commission is unable to resolve complaints of this type. The patients' trust person does not review complaints submitted by one patient against another.

## Living conditions

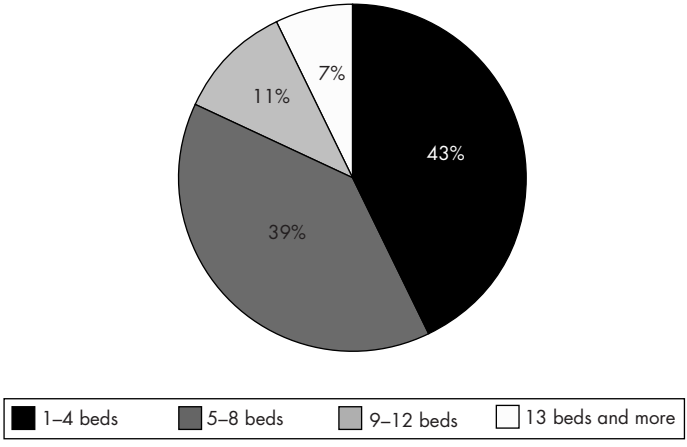
Although the Council of Europe Committee for Prevention of Torture has recommended eliminating overcrowding and has indicated that large wards with 15–20 beds do not ensure a positive therapeutic environment, 7% of respondents interviewed at psychiatric hospitals were located at the time of the interview in a 13 bed ward, and 11% of respondents at hospitals stayed in 9–12 bed wards. Situation of residents at social care homes is better because only 2% of the interviewed respondents lived in rooms containing more than seven beds. Unlike hospitals, at social care homes for persons with mental disorders the State has stipulated a minimum living space (6 sq. m) per resident. On 1 January, 2005, Clause 27 of Cabinet of Ministers' Regulations No. 431 *Requirements of hygiene for social care institutions,* entered into force, providing that at social care homes for adults no more than four persons may be placed in living/bedrooms.[10] Information provided by residents of

[9] Amsterdam has one common Complaints' commission which focuses on all three Amsterdam psychiatric hospitals and all psychiatrists' private practices in Amsterdam. The Commission reviews complaints according to two Laws – the Law on Patients' rights for complaints about health care and the Law on Psychiatric Hospitals (involuntary hospitalization). A complaint must be submitted in writing. If a patient is unable to write it him/herself, he/she may ask for the assistance of the hospital's Patients' trust person. A patient may also decide afterwards whether to file a case in Court along with the complaint. 30% of complaints concern involuntary treatment, medicines, isolation, limited opportunities to go for a walk. The rest of submitted complaints concern staff attitudes towards patients.

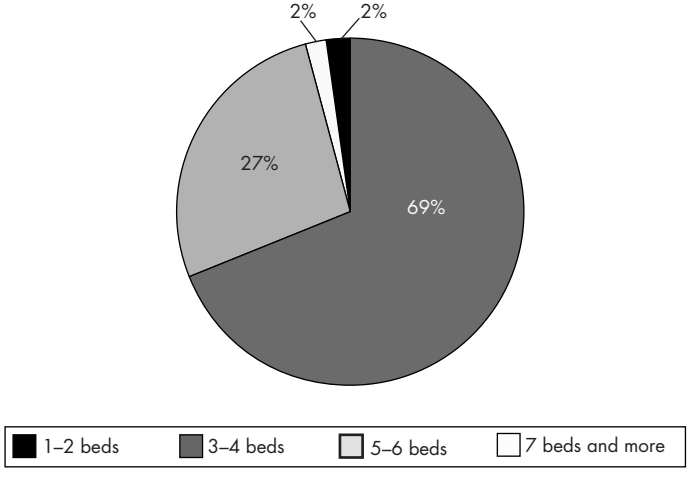
[10] Cabinet of Ministers' Regulations No. 431, *Requirements of hygiene at social care facilities* (adopted on 12 December, 2000), http://www.socpp.gov.lv/lv/img/431.doc (accessed on 10 July, 2006).

social care homes shows that in August 2005 the Regulations of Cabinet of Ministers were not implemented in the case of 29% of interviewed residents.

**Breakdown of premises for patients at psychiatric hospitals (%) by the number of beds per room (Question 28) N=266**

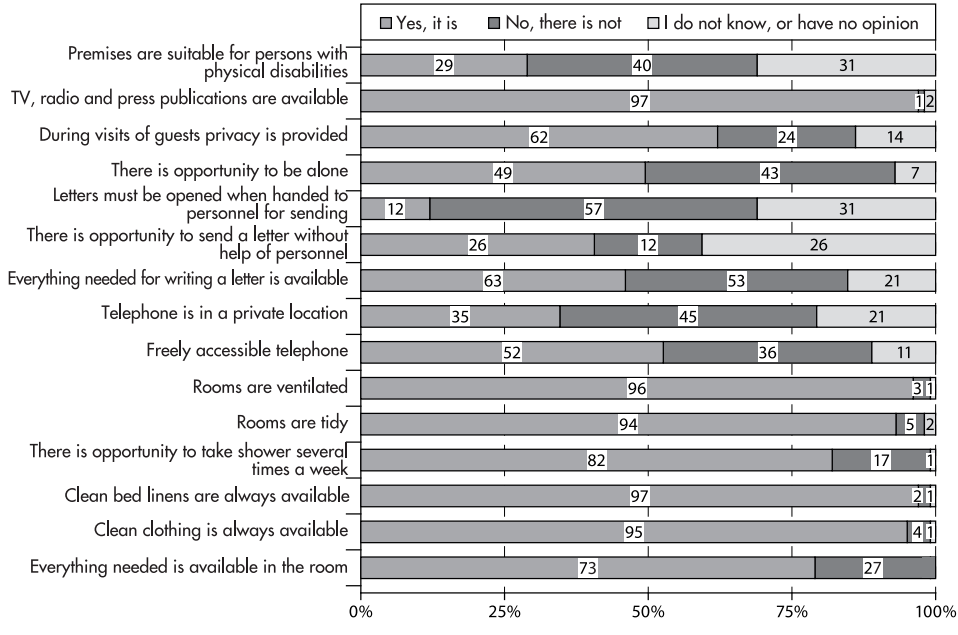



**Breakdown of premises for residents at social care homes (%) by the number of beds per room (Question 28) N=142**

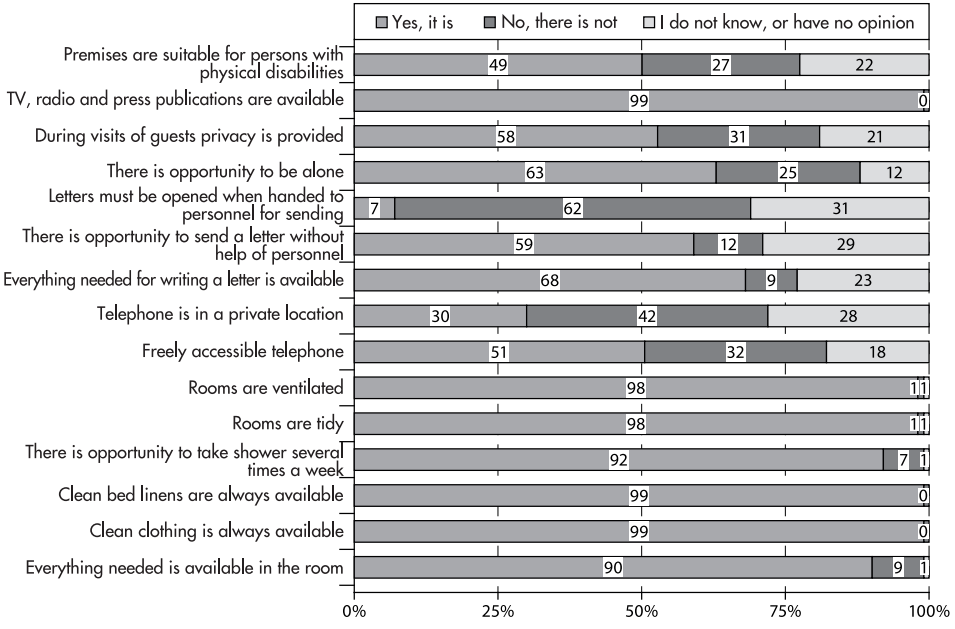


Concerning living conditions, results of the interviews show that most of hospital patients and residents of social care homes are satisfied with existing living conditions in the units. The interviewers – psychiatric nurses – were surprised at the high percentage at certain facilities and explained it by the fact that some of the users of mental health care had not had the opportunity to experience better living conditions and so they are satisfied with the existing situation. 36% of hospital patients and 43% of residents at social care homes indicated that they do not have an easily accessible telephone, but 45% of hospital patients and 42% of residents at social care homes indicated that the location of the telephone does not ensure privacy of conversations. 12% or 32 patients and 7% or 10 residents at social care homes admitted that letters must be opened, when handed over to personnel for sending, which is considered as a violation of human rights.

**Patients' assessment of living conditions in hospitals (%)**
**(Question 29) N=266**



**Residents' assessment of living conditions in social care homes (%)**
**(Question 29) N=142**




**Patients' comments on living conditions in a unit of the hospital:**

- It is difficult for a person in a wheelchair – there are no arrangements.
- I would like to change bed linen and underwear more often, but it does not happen.
- Radio and press publications are not available.
- Hospital rooms are not sufficiently ventilated – 3 comments from one facility.
- Staff does not take to a telephone when it is settled to call with relatives.
- The ward is very large. There are two suspended lamps – it is not enough – the ward is in darkness.
- Staff does not let to keep a bottle of water in the locker, but I am often thirsty.
- There is a light on in the ward at night and that disturbs my sleep very much.
- A bath is available once every ten days.
- There are no towels available.

- The problem of telephone is very acute. I am not always taken to the payphone in the hospital when I need to call. Calls from the telephone in the unit are permitted in special (rare) cases.
- Telephone is available only during free regime, the telephone is in the territory of the hospital, and there is none in the unit.

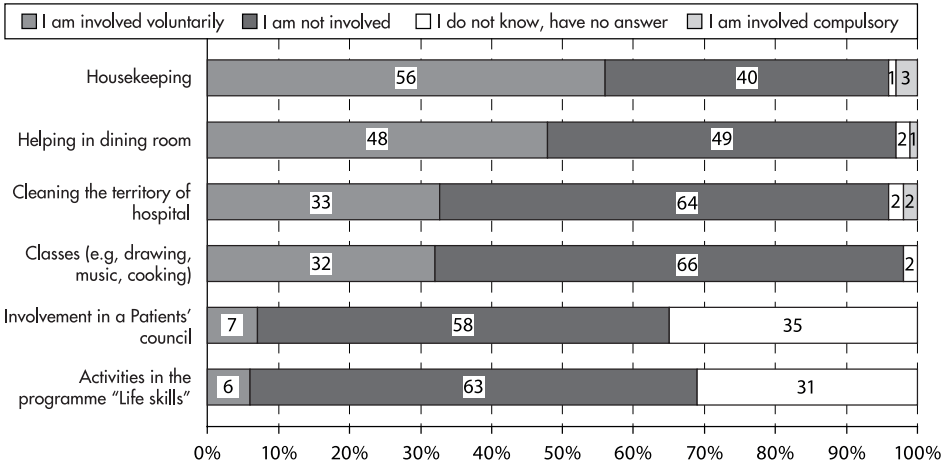
**Residents' comments on the living conditions in a unit of social care home:**

- There is no room where to spend time with relatives and talk. If we want to talk, we must go out to the street.
- The room is good, but rain comes in on the bed. We were given a plastic sheet to put on the bed.
- The care home attendant does nothing, only dusts the lamps.
- Cold wind comes in through the windows. We plug the windows with rags.
- There is nowhere to hang out washed clothing to dry, management took it away – they said that it is not aesthetic.
- We can use a telephone once a month for 5 minutes.
- Rooms are aired, but there is an unbearable smell of urine throughout the care home. At times I have nausea from the smell.
- It is cold in winter, heating is bad.
- I am not satisfied with the very strict regime – I can take care of myself, therefore I could sleep longer. Even on Saturdays and Sundays it is not permitted to sleep longer. I use medicines and I am very sleepy in the morning.

## Opportunity for activities in hospitals and social care homes and outside of them

Users of mental health care services were asked to assess the present opportunities for activities at facilities. The vast majority of respondents both in hospitals and care homes are involved in housekeeping work, helping in the dining room, cleaning the territory of the facility and various classes (for example, music, drawing and cooking). Only 7% of interviewed patients and 6% of residents of social care homes are involved in activities of patients' councils or social care councils. 6% of hospital patients and only 1% of residents of social care homes are involved in the programme "Life skills".

**Opinion of hospital patients on activities they are involved in while undergoing treatment at a hospital (Question 7) N=266**

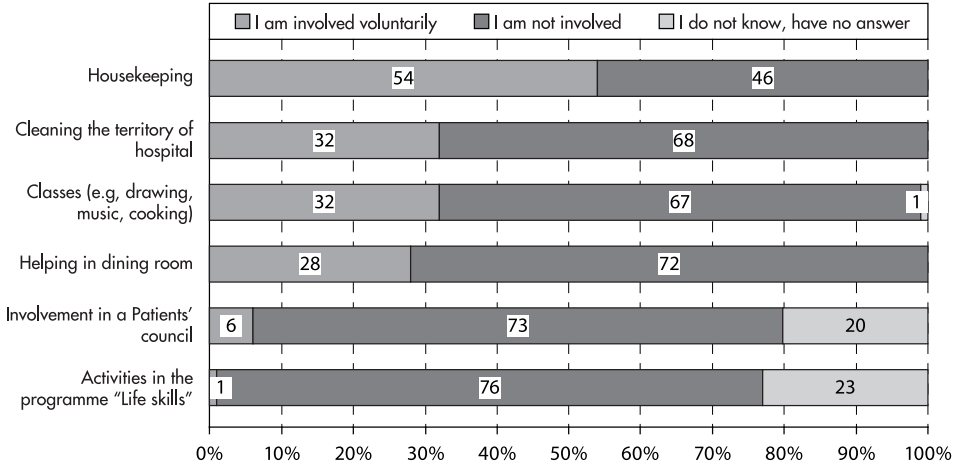



**Comments of users of mental health care on opportunities for activities at hospitals:**

- How long can you wallow in bed!
- I wish there were a sports hall, but that is not possible.
- Hospitals are intended for treatment not to do silly things.
- It is very boring in a hospital. I would like to do something, but the unit does not offer anything.
- No activities are offered.
- I wish there were various recreational evenings at the hospital – games. It does not happen. I would like to do metal work, but there is no such possibility.
- I would like to sing, if there were musical activities, but we are not permitted to go to the room where the piano is.
- I do not like and do not want to do anything and to take part in anything.

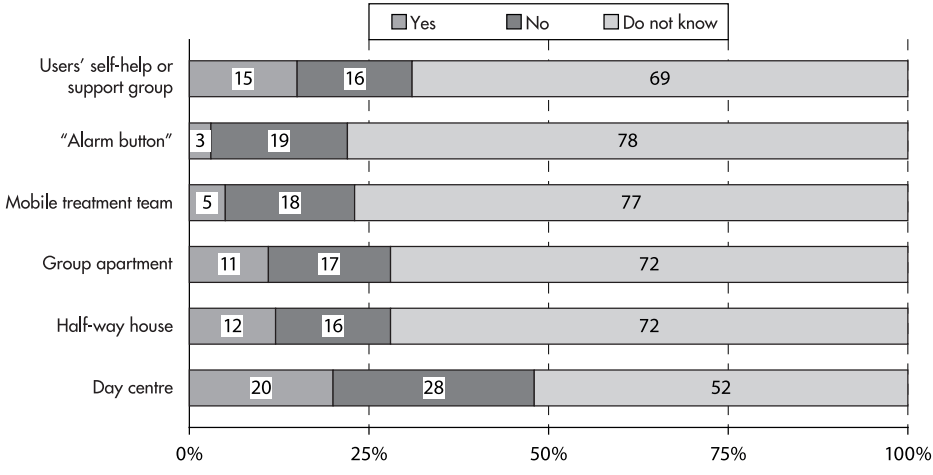
The researchers, drafting the questionnaire, were interested in the views of users of mental health care services on community based services. At present community based services are available mainly in Riga (day centres, out-patient medical care centre on Veldre street) and Jelgava which is relatively close to Riga (day centre and mobile treatment team). 20% or 53 hospital patients indicated that there is a

**Opinion of residents of social care homes on activities they are involved in (Question 7) N=142**




day centre available at the place of their residence, 15% or 40 hospital patients indicated that there is a users' self-help or support group available at their place of residence. 11% and 12% of hospital patients respectively indicated that there is a group apartment and half-way house available at their place of residence. However, the vast majority of hospital patients did not know whether the above mentioned community based services are available at their place of residence.

**Awareness of hospital patients on community based services available to persons with mental disabilities at their place of residence (%) (Question 13) N=266**

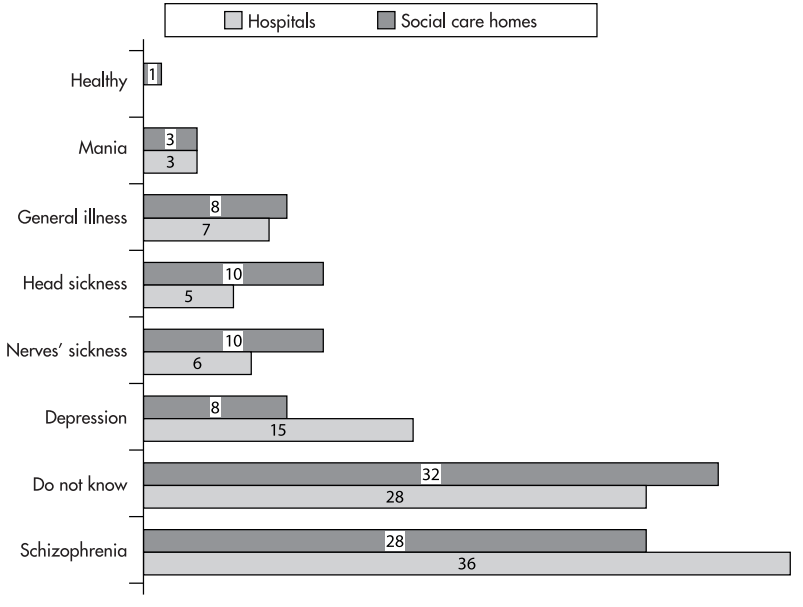


# IV. ACCESS TO MEDICAL CARE IN THE ASSESSMENT OF USERS OF MENTAL HEALTH CARE SERVICES

## Respondents' information on their diagnosis

In order to determine as objectively as possible the needs of users of mental health care services, it was necessary to obtain the opinion of users on their diagnosed illness. One of the 142 interviewed respondents of social care homes (1%) believed that he is well. No interviewed hospital patient had such an opinion. 36% of hospital patients and 28% of residents of social care homes knew of their schizophrenia diagnosis. This indicator can be considered as good because it is close to the average percentage indicator of persons diagnosed with schizophrenia at psychiatric hospitals (43%) and social care homes (23%). 18% of hospital patients and 11% of residents of social care homes have related their diagnosis to mood (affective) disorders which correspond to average indicators at facilities. 46% of hospital patients and 60% of residents of social care homes could not properly name their diagnosis, of whom 28% of hospital patients and 32% of residents of social care homes did not know their diagnosis at all. 18% of hospital patients and 28% of residents of social

**Opinion of respondents on their illness (%) (Question 41) N=408**



care homes had so indefinite knowledge on their diagnosis – named as general sickness, nerve sickness, or head sickness – that it can be compared to not knowing.

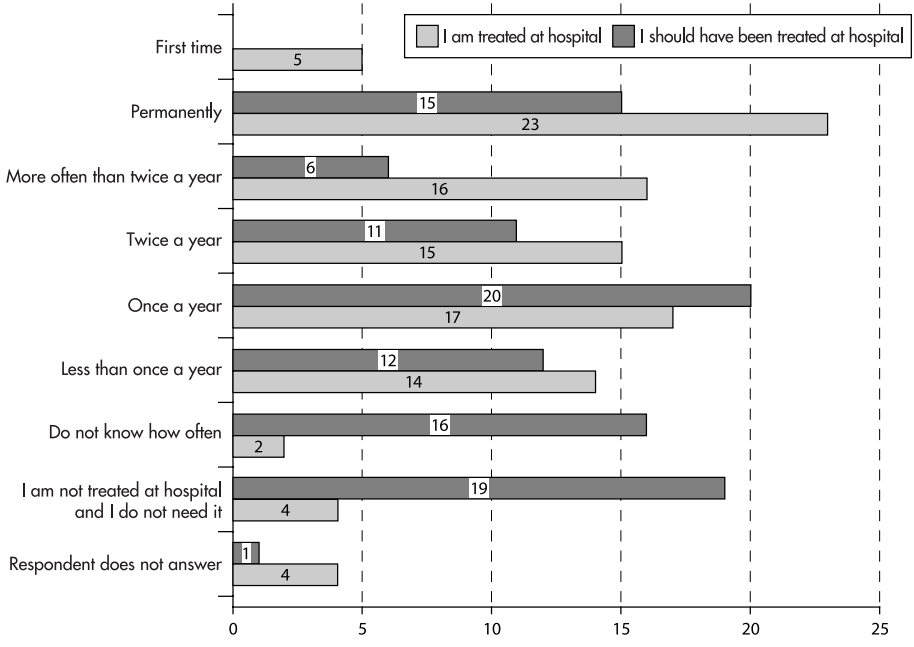
Altogether the level of users' knowledge of their diagnosis can be considered low, because about half of respondents did not have sufficient knowledge of their mental illness. Objectives of the poll did not include in-depth study of causes of lack of information. However, lack of information on the part of users of mental health care services may affect their treatment process and users' involvement in the treatment process.

## Frequency of in-patient treatment

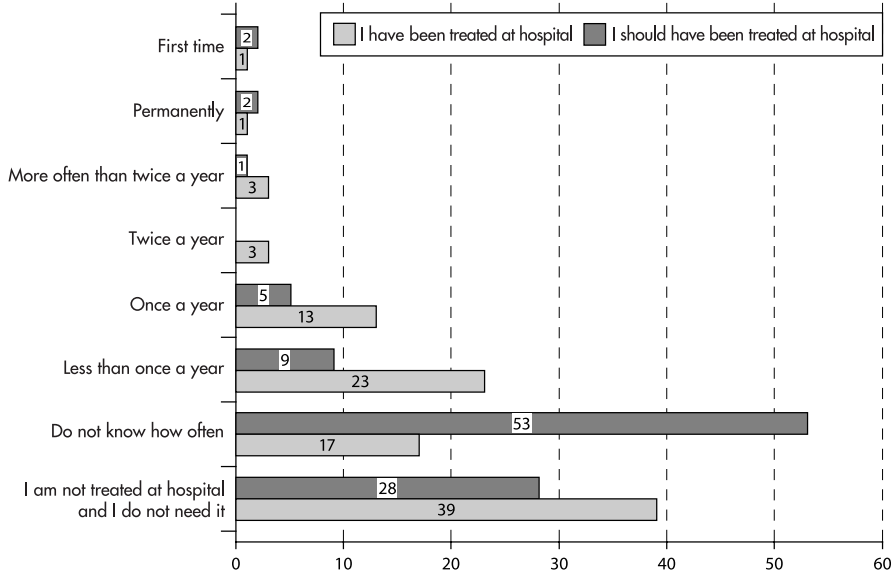
Assessing answers given by users of mental health care services concerning frequency of received in-patient treatment at psychiatric hospitals, it can be seen that answers of 11% of hospital patients and 18% of residents of social care homes give little information because they were treated at the hospital for the first time or had refused to answer the question. The vast majority of answers of hospital patients show that 23% of patients are being treated permanently and most often answers of residents of social care homes (39%) show that they had not been treated at a hospital over the last 3 years. The number of hospital patients who had been treated at a hospital one, two or more times per year is between 16% and 17%. Answers of residents of social care homes show that 23% had been treated in a hospital less than once a year and 13% of residents have been hospitalized one a year. Although only 3% of residents of social care homes had been treated at a hospital one or more times a year, and altogether residents of social care homes had been treated at a hospital five times less than hospital patients, yet, only 39% of residents of social care homes had not been treated at a psychiatric hospital over the last three years. Such a frequency of in-patient treatment can be considered as rather high. The comparatively frequent in-patient treatment could be grounds for concern whether health conditions of all residents of social care homes is sufficiently stable and suitable for life in a social care facility.

Comparing information provided by respondents on frequency of inpatient treatment and the need for it, it can be seen that hospital patients are in favour of in-patient treatment once a year or less. Of all interviewed hospital patients only 19% of respondents believe that in-patient treatment had not been necessary and 4% of those had not had in-patient treatment. It is possible that this opinion of patients in some cases is justified and with access to developed community care and alternatives, community

**Opinion of hospital patients on frequency of treatment at a psychiatric hospital and the need for it over the last 3 years (%) (Question 4) N=266**



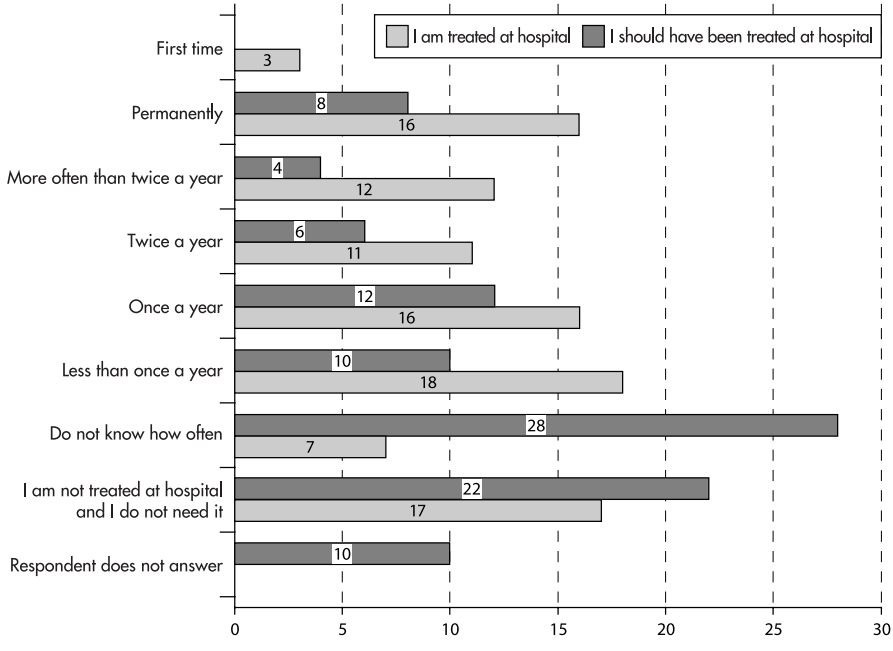

**Opinion of respondents of social care homes on frequency of treatment at a psychiatric hospital and the need for it over the last 3 years (%) (Question 4) N=142**



based forms of support, the number of patients treated at a hospital could be reduced. Worth considering is the opinion of residents of social care homes (2%), stating that they should have permanent in-patient treatment rather than residence in a social care home.

In analysing answers given by all the respondents on the need for in-patient treatment, the highest percentage of answers is 28%, which shows the lack of knowledge on the part of users how often they should be treated at a hospital, and shows lack of information or interest in improvement of their health condition. The second highest indicator was reached by the answer expressing the opinion of 22% of respondents that in-patient treatment is not necessary, which shows reluctance on the part of users and not wishing to cooperate with health care facilities. Both these opinions should be considered equally negatively.

**Opinion of interviewed users of mental health care services on frequency of treatment at a psychiatric hospital and the need for it over the last 3 years (%) (Question 4) N=408**

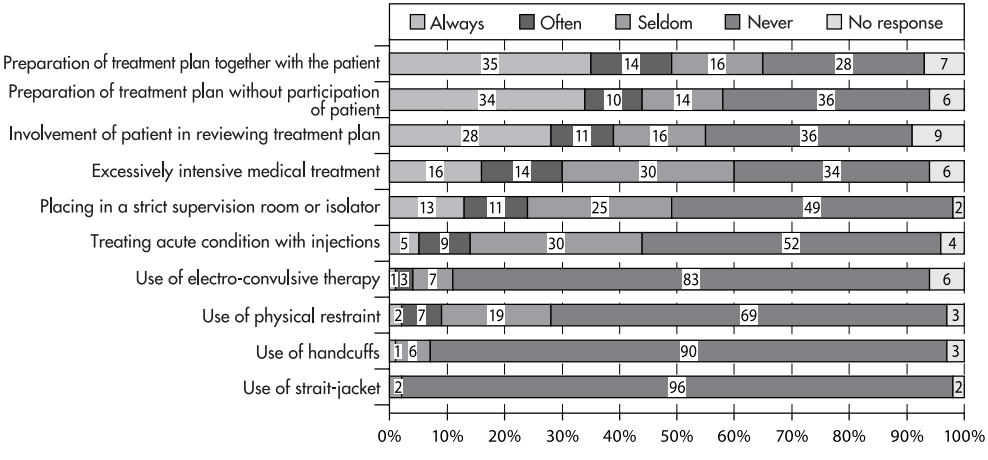


## Treatment process at a hospital and a social care home

In order to determine the opinion of users on the treatment process, they were asked a number of questions concerning cooperation between medical personnel and users. A summary of answers given by users of mental health care services shows that medical personnel in 49% of cases involve users in development of their treatment plan. 44% of users admitted that the treatment plan was composed without their participation. As a whole this indicator can be considered positively, provided that composing the treatment plan without involving the user had justified reasons. For instance, sometimes at the beginning of the treatment there might be a problem to involve the patient in making up his/her treatment plan, but when the condition of the patient's health gradually improves, possibilities of involving the patient in deciding his/her treatment plan should increase. However, results of answers show quite the opposite, since only 39% of users were involved in reviewing their treatment plan. Answers of users indicate a failure to take advantage of opportunities for cooperation between medical personnel and users, and that should be developed in the future.

Answers given by users on freedom restricting methods used in their treatment and frequency of their use indicate that placing users in a strict supervision room (or isolator) had been used always or frequently in the case of 25% of users, but 49% of users had never been placed in such a room, and 25% – seldom. Altogether, physical restraint has been used in the case of 28% of users: always – 2%, often – 7%, seldom – 19%. Use of handcuffs was admitted by 7% of users: always – 1%, seldom – 6%. Strait-jackets have never been used on 96% of users.

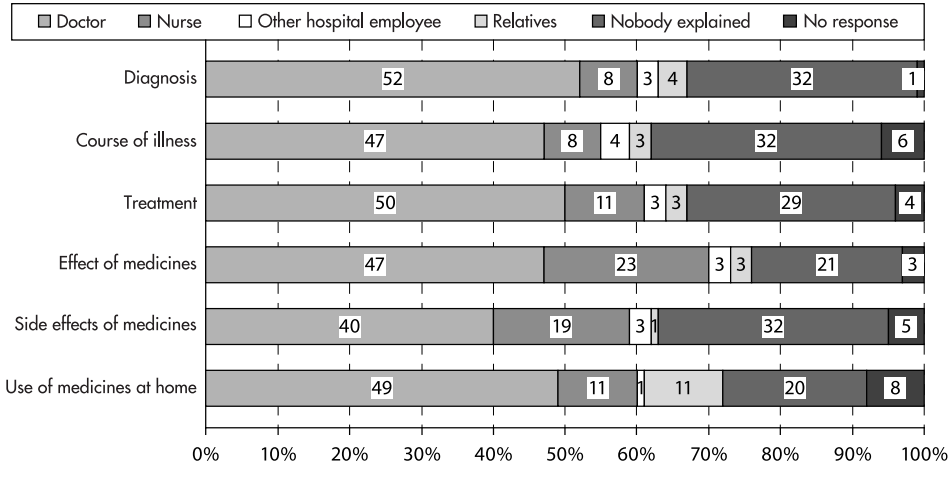
**Opinion of users of mental health care services on treatment process at psychiatric hospitals and social care homes (%) (Question 19) N=408**



Answers from users to questions concerning intensive medical treatment at psychiatric hospitals and social care homes indicate that in the opinion of 30% of users they have always or often received excessive intensive medical treatment, but twice as many users (64%) have not received excessive intensive treatment. In the case of 52% of users injections had never been used in treating acute conditions. In the case of 30% of users injections have been used infrequently, but 14% of users had received these always or frequently. 11% of users had received electroconvulsive therapy (ECT): always – 1%, often – 3%, and seldom – 7%. Three respondents at one medical facility commented that ECT had been used on them 16, 6 and 5 times respectively. ECT had never been used on 83% of users.

The basis of successful treatment is a productive exchange of information between medical personnel and patient. On an average, a little more than half of users (47%) the necessary information on the illness, its progress, treatment and medication have been received from the doctors, and 13% of users have received this information from other staff members of psychiatric institutions. Nurses have provided information to users (19%–23%) more on the effect of medicines, possible side effects and actions in relation to those. About a third of users believe that no one has given them information on questions of their illness, which is a warning signal to improve information exchange between medical personnel and users. An average of 3–4% of users have obtained information on their illness from relatives. Medical personnel should pay special attention to providing direct information to

**Sources of information of users of mental health care services on their illness and treatment (Question 20) N=408**



users and informing relatives. Answers from users to questions concerning their treatment strategy after discharge from the hospital indicate that a third of users lack sufficient information concerning their further treatment and the use of medication at home, therefore for a large group of users there is a risk of failure to ensure continuity of therapy when moving from in-patient to out-patient treatment.

**Comments from users of mental health care services on explanation of diagnosis and other questions related to treatment by hospital personnel:**

- I am surprised by these questions, because I thought we may not ask anybody anything.
- (Doctors) speak of diagnosis in such a complicated language, I can understand nothing.
- Nobody speaks seriously to "loonies" of their illness. Everyone avoids specific talk. They talk to you mysteriously, not understandably, like to a young child.
- I know how to use medicines, but it would be good to have the doctor's advice.
- The doctor prescribes medicines but does not explain anything.
- The doctor explained the course of the illness and reasons for its aggravation, but not at the hospital.
- What can they know what goes on in my head!
- At first nobody explained (diagnosis of illness), later the doctor told me.
- At the self-help group we talked about taking medicines and their side effects.
- The doctor halfway listened to my problems, explained nothing and left.
- I am in the unit for the second day, but the doctor has not spoken to me, I receive no medicines.

## Out-patient care

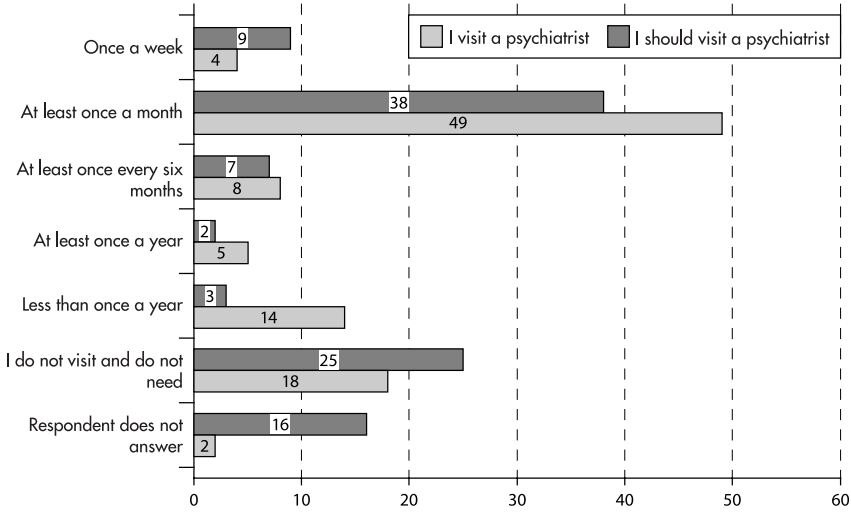
### Opinion of respondents on frequency of psychiatrist's visits

18% of patients discharged from psychiatric hospitals and 18% of residents of social care homes do not visit a psychiatrist as out-patients. 25% of patients of psychiatric hospitals and 35% of residents of social care homes consider visits to a psychiatrist unnecessary. Thus one can conclude that residents of social care

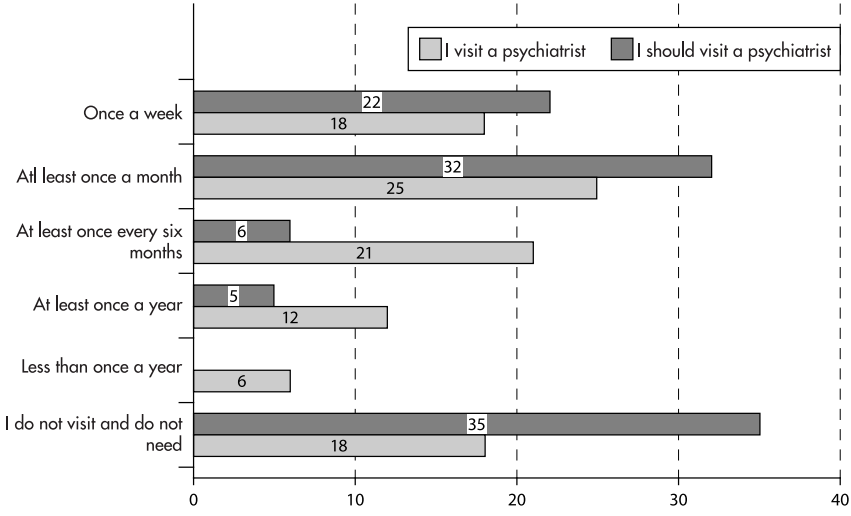
homes, compared to hospital patients, consider themselves healthier. Almost half of hospital patients visit a psychiatrist as outpatients after discharge from the hospital at least once a week, but the remaining 30% are divided equally – 5–8% in each given period for a visit – once a week, once every six months and once a year. Breakdown of residents of social care homes by frequency of visits to a psychiatrist is also relatively even in all given periods for visits. Such an even spread of psychiatrist's consultations could be explained by the fact that personnel of social care homes, guided by the health condition of residents, organise psychiatrist's consultations for residents regularly and according to certain planning. Frequency of visits to a psychiatrist by hospital patients and residents of social care homes corresponds to users' opinions for the need for psychiatrist's consultation. Some residents of social care homes would like to have more frequent psychiatrist's consultations – mostly once a month or once a week, which indicates that intensity of psychiatrist's consultations at social care homes should be increased.

For various reasons hospital patients and residents of social care homes have problems visiting an out-patient psychiatrist. Compared to residents of social care homes, users living in the community have greater access problems. For example, transport to the psychiatrist's office, distance to psychiatrist's office and lack of funds for purchase of medicines are mentioned as problems only in the answers of hospital patients. Limits of visiting hours of psychiatrists (29 answers) and an unacceptable

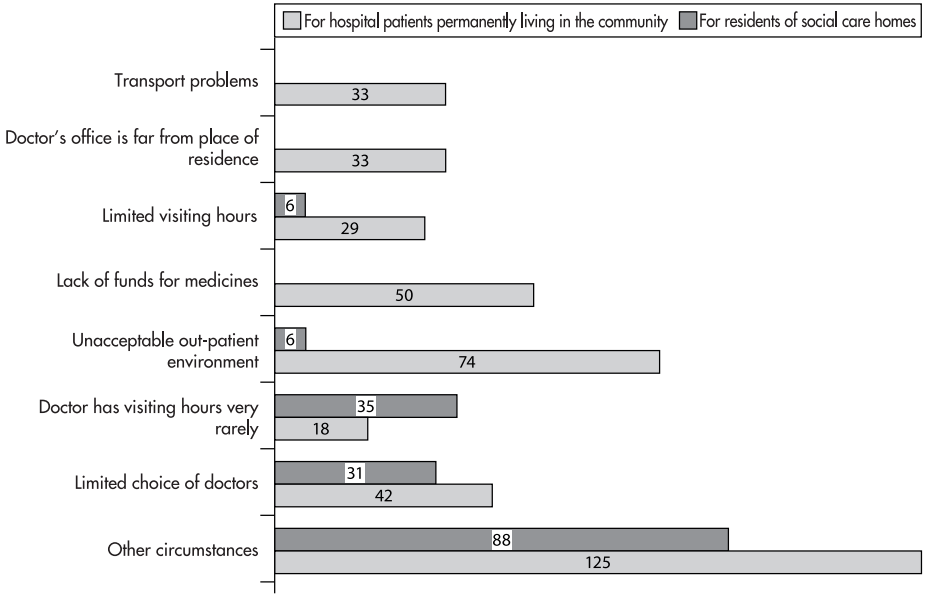
**Opinion of hospital patients on frequency of visits to out-patient psychiatrist and the need for it over the last 3 years (%). (Question 2) N=266**



**Opinion of residents of social care homes on frequency of visits to an out-patient psychiatrist and the need for it over the last 3 years (%). (Question 2) N=142**




**Number of answers of hospital patients and residents of social care homes on obstacles to receiving out-patient psychiatric assistance (Question 3) N=408**

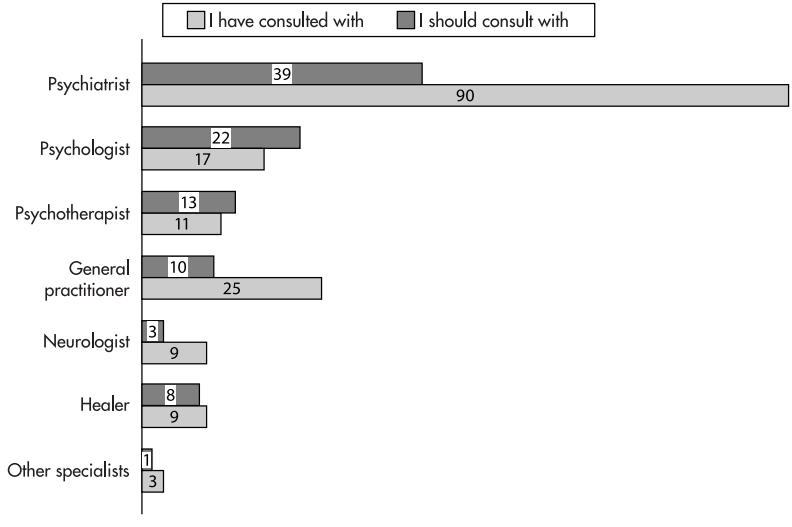


environment of out-patient care (74 answers) are emphasised significantly more in the answers of hospital patients. There were only 6 answers of residents of social care homes on these subjects. Limited choice of doctors is noted in answers of both hospital patients and residents of social care homes, in even numbers (32 and 42 answers). Both groups of respondents mention "other circumstances" as the most often given obstacles to receiving psychiatric assistance (88 and 125 answers). There might be a detailed poll of users of mental health care services planned in the future to determine what these circumstances are.

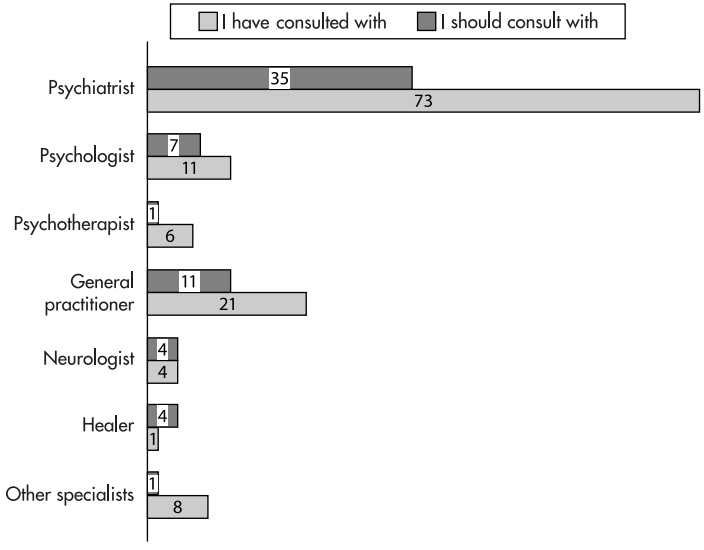
## Received and needed specialists' consultations

To ensure comprehensive examination and treatment of patients, it is necessary to have consultations with other specialists. In order to determine views of users of mental health care services on received and still needed consultations with other specialists, answers of hospital patients and residents of social care homes were compiled. 90% of all hospital patients and 86% of residents of social care homes have received out-patient psychiatrist's consultations. However, only 38–39% of all respondents considered psychiatrist's consultations as necessary. Needs of hospital patients for psychologist's and psychotherapist's consultations exceed the number of patients consulted by these specialists, but wishes of residents of social

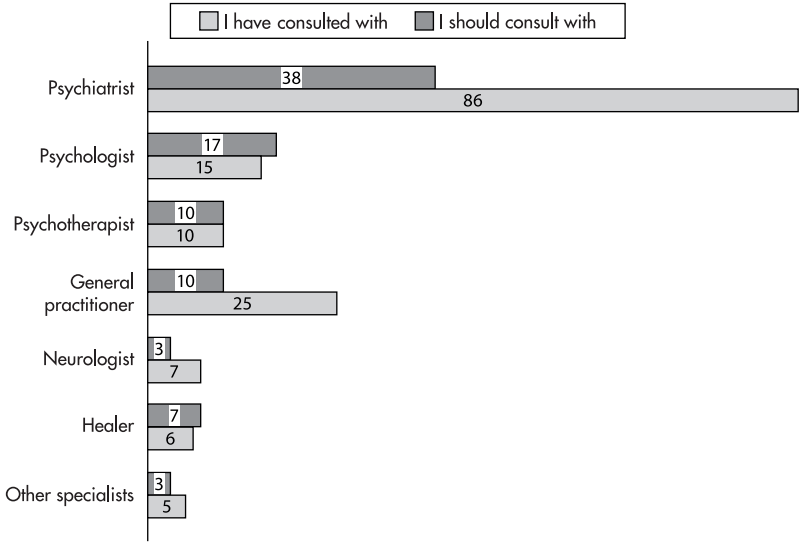
**Number of hospital patients who have received specialists' consultations over the last year and patients' opinion on consultations that would be still needed (%). (Question 1) N=266**



**Number of residents of social care homes who have received specialists' consultations over the last year and residents' opinion on consultations that would be still needed (%). (Question 1) N=142**



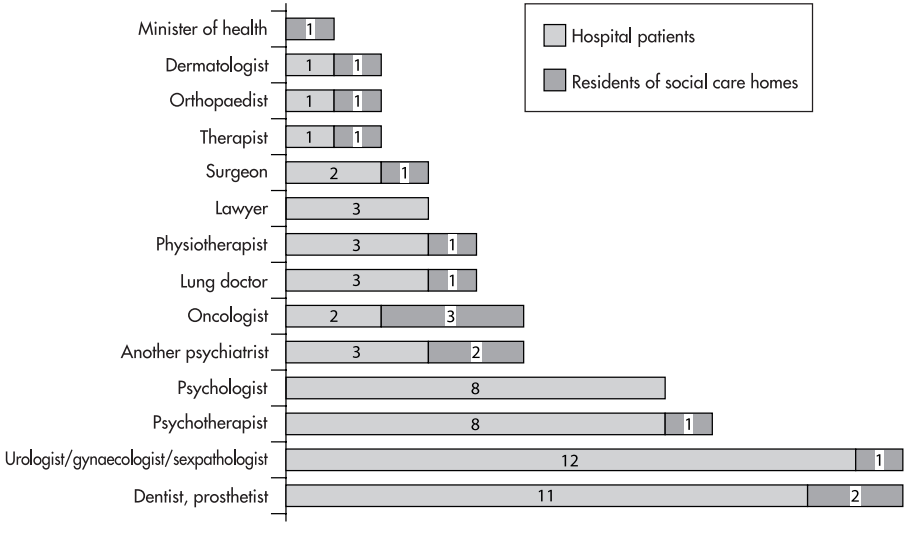

**Number of all respondents who have received specialists' consultations over the last year and their opinion on consultations that may be still needed (%). (Question 1) N=408**



care homes for consultation with a psychologist, psychotherapist and general practitioner is less than the number consulted by these specialists. Respondents' answers concerning consultations with a healer make one wonder. 9% of hospital patients have received consultations with a healer and 8% have expressed a wish to consult a healer. Hospital patients wish for consultations with a healer almost as much as for consultations with the family doctor and twice as much as for consultations with a neurologist. Residents of social care homes wish for consultations with a healer as much as for consultations with a neurologist and four times more than for consultations with a psychotherapist. In analysing answers of all the users together, we obtain the opinion of users that consultations with specialists fully ensures users' needs, and consultations with two specialists – psychiatrists and general practitioners – exceed the needs expressed by patients by more than twice.

In order to have more detailed information on users' needs for consultations with other specialists respondents' answers were obtained on necessary consultations with other specialists which had been unavailable to the users. The number of respondents who had expressed a need to consult other specialists is rather small. Hospital patients had named other specialists 59 times, and residents of social care homes – 15 times. The breakdown of needs of residents of social care homes for other specialists is even, thus indicating that the needs of residents for services of other specialists are not so

**Number of answers of users of mental health care services naming consultations with specialists which are needed but have not been available (Question 11) N=408**

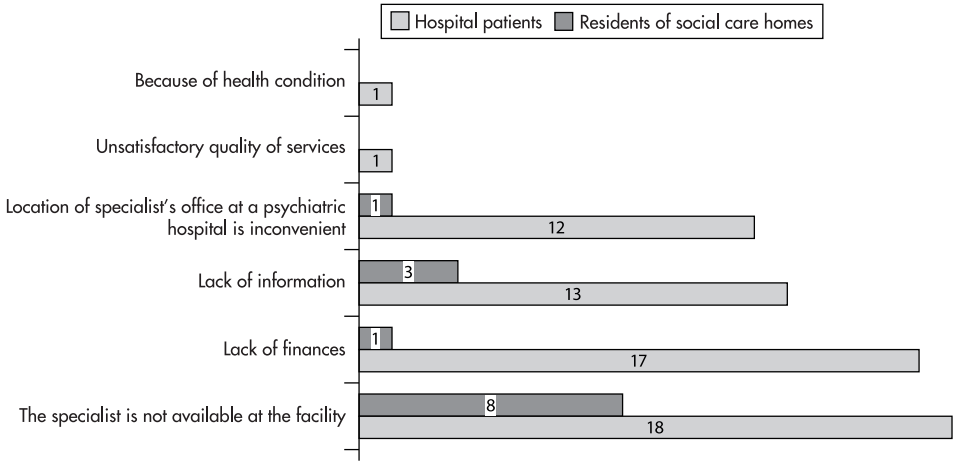


urgent. The needed specialists most often named by hospital patients are: dentists (11 answers), urologist/gynaecologist/sexpathologist (12 answers), physiotherapist (8 answers) and psychologist (8 answers). 3 hospital patients and 3 residents of social care homes expressed a wish to consult another psychiatrist.

## Reasons for limited availability of specialists' consultations

Reasons for limited availability of specialists' consultations for hospital patients were indicated 62 times, but for residents of social care homes only 15 times, which shows that specialists' consultations are more available for residents of social care homes than for hospital patients after discharge from the hospital. The reasons for limited specialists' availability for hospital patients and residents of social care homes differ only in quantity and the most differences concern the answer of lack of funds for specialists' consultations. Answers of residents of social care homes mention lack of funds as the reason only once while hospital patients mention this reason 17 times. Hospital patients have mentioned 12 times the location of the psychiatrist's office at the psychiatric hospital as a reason for limited availability of a psychiatrist. This certainly shows the need to continue de-institutionalisation and develop community care and other community based support forms for users of mental health care services. It also shows the need to reduce obstacles caused by the availability of services which is limited by finances.

**Number of respondents' answers on reasons for the limited availability of out-patient specialists (Question 12) N=408**



# V. SATISFACTION AND NEEDS OF INTERVIEWED USERS OF MENTAL HEALTH CARE SERVICES

Assessment of satisfaction and needs of persons with mental disorders is related to issues of quality of life. Researchers *J. Wing, C. R. Brewin, G. Tornicraft* (2001) indicate that quality of life can be measured by such physical needs as heat, light, shelter, food and security, etc., which must be provided for people who cannot procure them otherwise. Measuring the quality of life is concerned with the quality of such provisions themselves, in particular in terms of the quality of environment and the choice available. And lastly, quality of personal life to such an extent that a disabled individual can maintain self-respect and autonomy, keep up interests, make a recognised contribution to society and increase his or her self-knowledge.[11] In turn *A. Bowling* (2001), speaking of the quality of life in respect to health, notes that it is essential to include in the definition assessment of the level of the patient's satisfaction with treatment, outcome, and health status and future prospects.[12]

The working group drafting the questionnaire chose the following as the most important indicators of satisfaction of users of mental health care services: mental health, physical health, present employment situation, financial security, dwelling, relations with family, relations with friends and colleagues at work, and opportunities for recreation and entertainment. The following diagrams show separately the satisfaction of hospital patients and residents of social care homes with each of the chosen criteria. Hospital patients are most satisfied with their dwelling (74%), relations with friends and colleagues at work (66%), opportunities for recreation and entertainment (62%) and relations with family (62%). In turn, the least satisfaction hospital patients have with material well-being (60%), mental health (52%) and present employment situation (49%). Residents of social care homes are most satisfied with recreation and entertainment opportunities (75%), mental health (73%) and relations with friends (71%), but are least satisfied with material well-being (51%), physical health (32%) and relations with family (26%).

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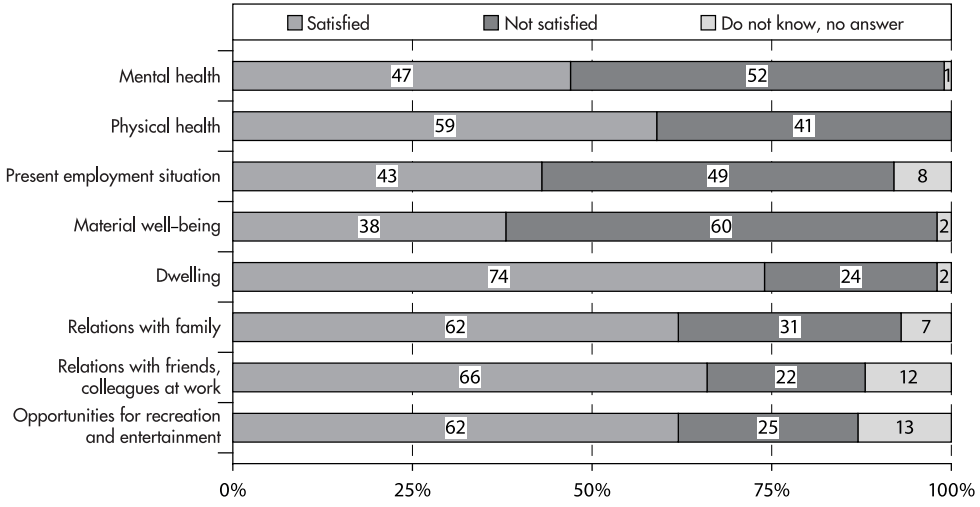
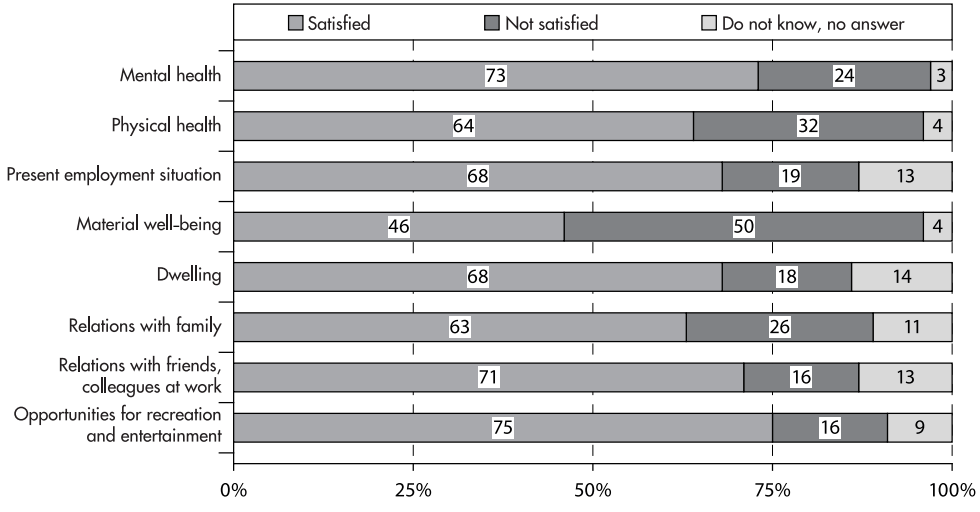
[11] John Wing, Chris R. Brewin and Graham Thornicraft. *Defining Mental Health Needs, **Measuring Mental Health Needs***, 2001, http://www.rcpsych.ac.uk/files/samplechapter/60_9.pdf (accessed on 7 July, 2006).

[12] Ann Bowling, ***Measuring Disease, A Review of Disease-Specific Quality of Life Measurement Scales***, 2nd edition, Open University Press, Buckingham, Philadelphia, 2001, pp. 69–74.

**Satisfaction of hospital patients with various areas of life (%)**
**(Question 38) N=266**




**Satisfaction of residents of social care homes with various areas of life (%)**
**(Question 38) N= 142**



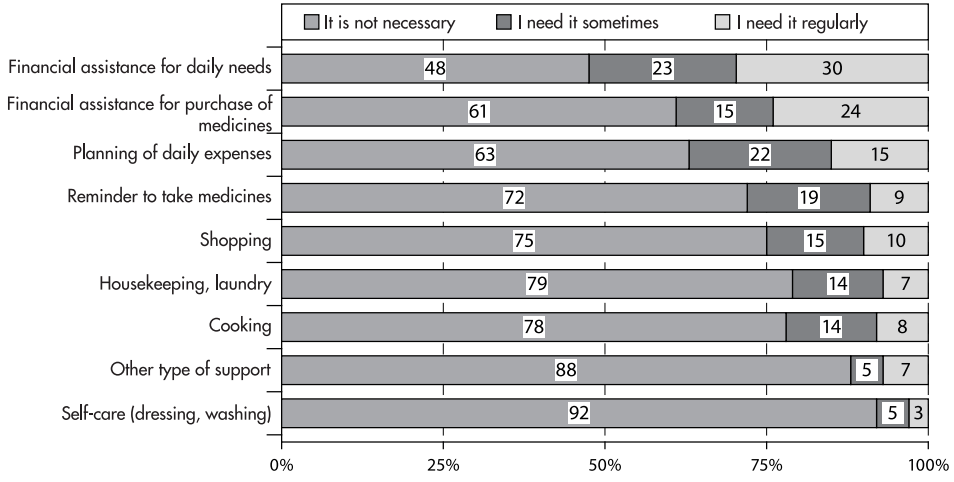
The table below shows priority areas which do not satisfy hospital patients and residents of social care homes:

| **Dissatisfaction of hospital patients** | **Dissatisfaction of residents of social care homes** |
|---|---|
| Material well-being 60% | Material well-being 51% |
| Mental health 52% | Physical health 32% |
| Present employment situation 49% | Relations with family 26% |
| Physical health 41% | Mental health 25% |
| Relations with family 31% | Present employment situation 20% |
| Opportunities for recreation and entertainment 25% | Dwelling where he/she lives 18% |
| Dwelling where he/she lives 24% | Relations with friends, colleagues at work 16% |
| Relations with friends, colleagues at work 22% | Opportunities for recreation, and entertainment 16% |

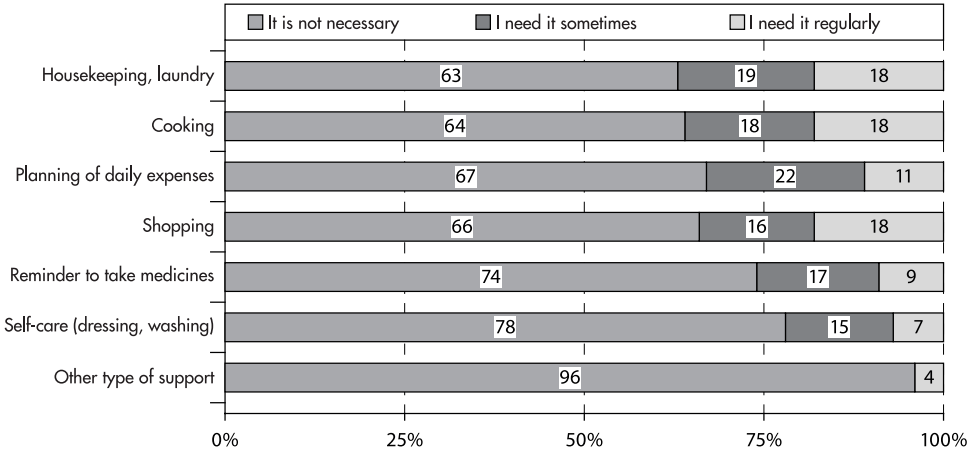
The question of satisfaction of users of mental health care services is related also to self-evaluation of necessary types of every day support. In analysing both target groups separately, it was found that hospital patients need most of all the offered types of financial assistance support for every day needs, financial assistance for purchase of medicines, assistance for planning of daily expenses and reminders to take medicines. For their part residents of social care homes need the most help with housekeeping chores and laundry, cooking, shopping and planning daily expenses. It would help to ensure the above mentioned types of support for hospital patients and residents of social care homes if training would be provided at all mental health care facilities according to the programme "Life skills"[13], which was developed in 2002 by Latvian Union of Psychiatric Nurses in cooperation with patients and personnel of Aknīste psychiatric hospital. The programme is regularly used at Aknīste and Strenči psychiatric hospitals.

[13] The programme "Life skills" is available in full on the Latvian Human Rights Centre website http://www.humanrights.org.lv/html/lv/jomas/28804.html (last accessed on 10 July, 2006.)

**Answers of hospital patients on types of support needed every day while not in hospital (Question 30) N=266**




**Answers of residents of social care homes on types of support needed every day (Question 30) N=142**



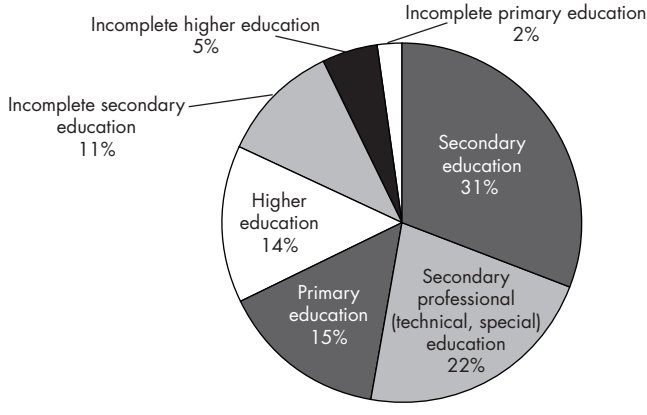
**Comments from residents of social care homes on their needs:**

- They are going to build new blocks for young people, but we need smart people who work with them.
- We need smart management to see what is going on here.
- There is nothing to do during the day, it is boring. I go to look at the ducks.
- It is bad that at a small care home there are also very ill people who continuously shout and brawl. There is never any peace. It would be better in another home, where there are people of the same illness.
- It troubles me and so I am not comfortable that there is a terrible smell of urine at the care home and that I have to be in the same building with seriously ill people with disabilities (imbecile clients who shout).
- I do not like it that I have no private life.

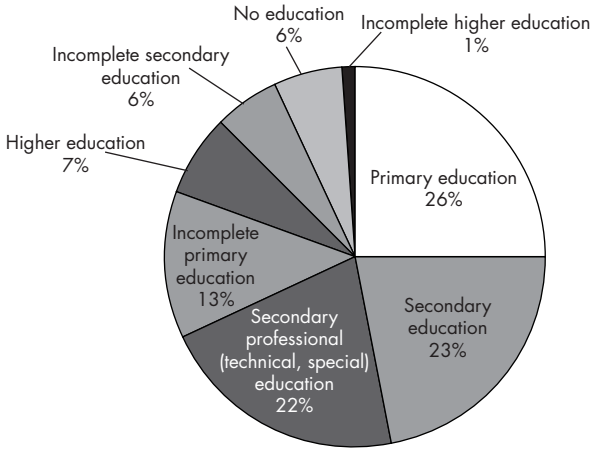
## Assessment of employment situation and need for support in addressing employment situation

In analysing the employment situation of users of mental health care services it is essential to look at it in the context of the level of education and employment of users of mental health care services. The following diagram shows that most hospital patients, or 53% have secondary or secondary professional education, 19% of patients have higher or incomplete higher education. Similarly most residents of social care homes, or 45% have secondary or secondary professional education and 1% has higher or incomplete higher education, but 26% have primary education.

**Education of hospital patients (Question 31) N=266**

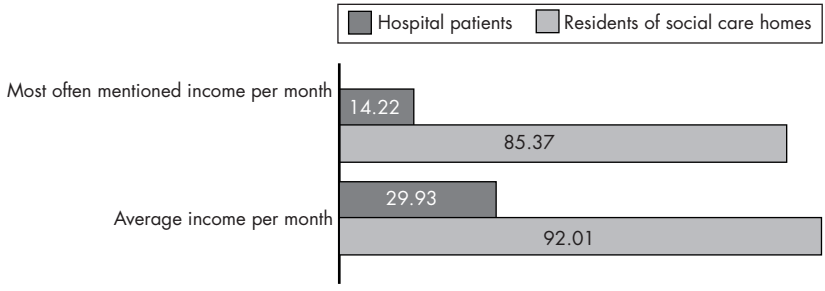


**Education of residents of social care homes (Question 31)**




In assessing monthly income, the average income of residents of social care homes is LVL 21.04 (or EUR 29.93) per month, in most cases receiving LVL 8 to LVL 10 (EUR 11.38 to EUR 14.22) a month (53% of residents). In its turn, average income of hospital patients is LVL 64.67 (EUR 92.01) a month, most often receiving LVL 50 to LVL 60 (EUR 71.14 to EUR 85.37) a month (33.5% of hospital patients). These data, obtained at the interviews, correspond to average disability pensions which is the main source of income for most residents of social care homes (according to *Social Services and Social Assistance* Law they are entitled to 15% of pensions while staying in social care homes) and hospital patients.

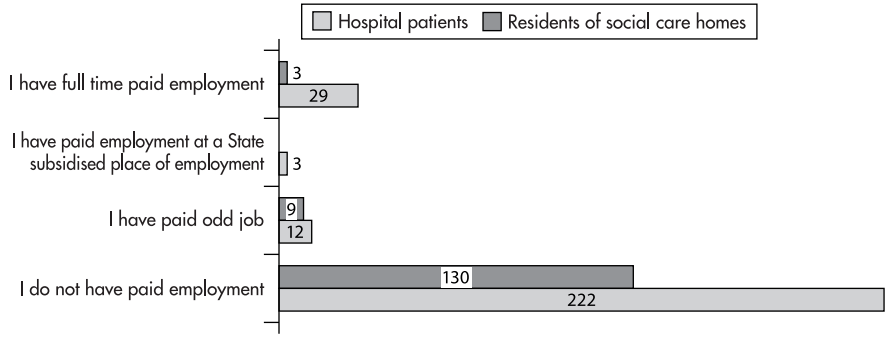
**Information provided by users on average monthly income (EUR) (Question 45) N=408**



In analysing the employment situation of users of mental health care services it was found that most respondents, or 352 users of mental health care services at the time of the interview did not have paid employment. The employment situation was a little better in the case of hospital patients, 29 of whom had a full time paid job, 3 had paid employment at a state subsidised place of employment, and 12 had paid odd jobs. Of the interviewed residents of social care homes only 3 had full time paid employment and 9 had paid odd jobs. Most of those hospital patients who had paid employment, or 19 persons had found it with the help of friends or relatives and only 4 persons had found work with the help of the State Employment Agency. 10 persons had found jobs with the help of hospital personnel and social workers. For their part, the working residents of social care homes had found employment with the help of personnel of care homes.

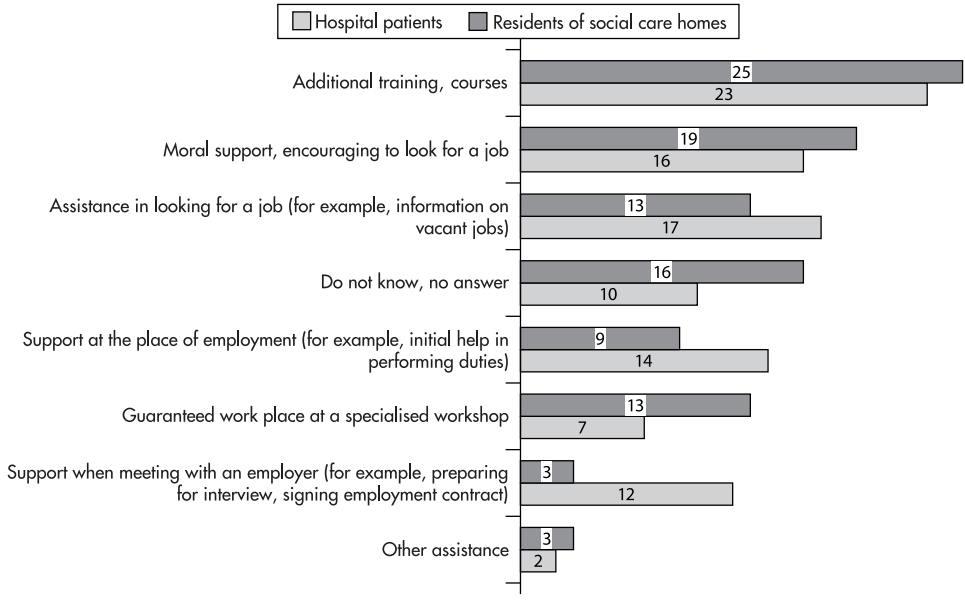
When asked about their attempts during the past year up till July (2005) to find work, 87% of residents of social care homes and 51% of hospital patients indicated that due to their health condition they are unable to work. 31% of hospital patients and only 1% of residents of social care homes indicated that they had shown an interest in finding employment. Information provided by hospital patients also shows that users of mental health care services had rarely applied to the State Employment Agency (only 5% of 266 respondents), where 6 hospital patients had obtained information on subsidised employment and 8 patients had registered for unemployed status.

**Employment of users of mental health services (absolute numbers) (Question 32) N=408**



When asked about needed assistance in finding employment, users of mental health care services indicated that the most necessary assistance would be additional training and courses (23% of hospital patients and 25% of residents of social care homes); moral support and encouragement to look for work (16% of hospital patients and 19% of residents of social care homes); assistance in looking for work, for example, information on vacant jobs (17% of hospital patients and 13% of residents of social care homes). Hospital patients indicated that initial support at the place of employment is important for them (14%), important as well is the assistance in meeting with an employer and signing the employment contract (12%).

**Opinion of users of mental health care services on necessary assistance in finding employment (%) (Question 37) N=408**




At any rate, altogether the situation of users of mental health care services in the employment situation can be considered as very unsatisfactory and these obtained data should provide sufficient background and reason for state policy planners and government officials who planning active employment measurements for people with disabilities to address employment problems of users of mental health care services more actively in both assessing whether it would be useful to develop the supported employment system for people with mental illness (similar to that already developed for persons with intellectual disability).

# VI. INVOLVEMENT OF USERS OF MENTAL HEALTH CARE SERVICES IN DECISION MAKING

Involving users of mental health care services in policy decision making and planning, organising and quality assessment of mental health care services is still a challenge and rarely encountered in post-Soviet countries. Analyzing the activities of organisations of users of mental health care services in the context of the Baltic states, the most active and developed movement of users of mental health care services can be found in Lithuania. For their part, users of mental health care services in Latvia have started to organise comparatively recently – about 3 years ago, thus for the time being it is difficult to speak of a developed movement of users of mental health care services in Latvia, and thus there have been relatively few publicly noticeable activities of users of mental health care services. In this context, the World Health Organization's (WHO) Mental Health Declaration and Action Plan for 2006–2016 signed in Helsinki in 2005, and which the Latvian Minister of Health also signed, is very important. The WHO Helsinki Declaration's Action Plan calls to consider organising comprehensive preventive and care services around the needs of and in close cooperation with users.[14]

Involving users of mental health care services in decision making should be encouraged on at least two levels: influencing decisions at government and local government levels and influencing every day life at institutions. In assessing present activities of users of mental health care users in Latvia, it should be taken into account that at first there was a tendency to form parent/professional organisations, which later involved also users of mental health care services. There are two such organisations in Latvia: the organisation "Gaismas stars" (A Ray of Light) and the organisation "Paspārne" (Shelter):

- The organisation "Gaismas stars" was established in 1997 as a support group of relatives (mainly relatives of schizophrenia patients). The organisation organised various activities for users of mental health care services (for example, art workshops and summer camps). Since 2005 the organisation "Gaismas stars" provides services at a day centre for persons with mental illness (capacity about 30 clients a day). Users of mental health care services living in Riga may visit

[14] World Health Organization. Mental Health Action Plan for Europe, Area 8 on Establishing partnerships across the sectors, http://www.euro.who.int/Document/MNH/edoc07.pdf (accessed on 10 July, 2006).

specialists at the Day centre (for example, psychologist, occupational therapist and social rehabilitator) for consultations and group workshops, art and music workshops, sports activities, a training kitchen, support and self-help groups, training programme "Life skills" and various joint projects.

- The organisation "Paspārne" was established in 2002 to provide help for mentally ill persons to improve the quality of their lives. The main priority of the organisation is to promote alternative care, employment and protection of interests of mentally ill persons. The organisation has 137 members, uniting 113 patients, 20 employees from Aknīste psychiatric hospital and 4 representatives of the local community. Representatives of Patients' Council of Aknīste psychiatric hospital also are actively involved in "Paspārne". With the financial support of the Mental Health Initiative of the Open Society Institute (Budapest) and Soros Foundation-Latvia, "Paspārne" has established a step-by-step programme for integration of patients of Aknīste psychiatric hospital into society, establishing a half-way house[15], community based employment programmes (café and a shop of users' arts work)[16] and developing a project of a group home which would permit users of mental health care services who have lived at the hospital for years and have nowhere to go, to leave the hospital.

Quite recently the first organisations of users of mental health care services have developed, among which the Patients' council of Aknīste psychiatric hospital should be mentioned, as well the organisation "Dzirksts" (Spark) and the just recently created organisation – "Latvian Initiative Group in Psychiatry".

- The organisation "Dzirksts", established in 2005, is operating in the Preiļi region. In 2005–2006 with the support of the Mental Health Initiative of the Open Society Institute (Budapest) and Soros Foundation-Latvia the organisation arranged activities for users of mental health care services in the Preiļi region, offering regular consultations with a psychologist and involvement in various craft workshops (for example, silk painting, leather work, painting, ceramics, etc.).
- At the beginning of 2006 the organisation "Latvian Initiative Group in Psychiatry" was established which included only users of mental health care services. The purpose of the organisation is to ensure observance of patients' rights,

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[15] For more information on the half-way house project see the article by Ieva Leimane-Veldmeijere "A Cat in the Window", http://www.humanrights.org.lv/upload_file/KakisAizLogaLV.pdf (accessed on 10 July, 2006).

[16] For more information on these projects see Mental Disability Advocacy section in the LCHR website http://www.humanrights.org.lv (accessed on 10 July, 2006).

improving quality of mental health care services and educating the public in issues of psychiatry. From December 2006 the organisation plans to organise a course of 10 workshops for 15 of the most active users of mental health care services with the support of the Mental Health Initiative of the Open Society Institute (Budapest) and the Soros Foundation-Latvia. The workshops will cover such themes as the rights of users of mental health care services in Latvia and international human rights standards; influencing the policy process at the levels of government, parliament and local government; advocacy for users of mental health care services – peer advocacy; problems and opportunities of mental health care in Latvia; interaction in a group and development of a successful dialogue; strategies for resolving conflicts, NGO participation in Cabinet of Ministers' State Secretary meetings and cooperation with local governments in social services area; a medical and social model of disability.

No less important in national and every day decision making is to involve users of mental health care services who currently receive long term institutionalised care – at specialised social care homes and long term care at psychiatric hospitals. The best known form of involvement is residents' and patients' councils. Of all the psychiatric hospitals in Latvia, patients' councils operate at Aknīste, Strenči and Vecpiebalga hospitals. The oldest and most active patients' council operates at Aknīste psychiatric hospital, where in 2000 an all-hospital Patients' Council was established on the basis of the Patients' Council of the Rehabilitation department, to which representatives are elected from all 6 departments of the hospital.

A Regulation of Patients' Council has been drawn up, regulating activities and giving it a place in the administrative structure of the hospital. The Council works with the hospital administration, addressing issues of daily regime, patients' meals, analyses the needs expressed by patients, assesses patients' living conditions and receives patients' complaints.[17]

According to requirements of the Law on Social Services and Social Assistance, since 2003 there have been Social care councils established at social care homes. Social care councils usually include 1–2 residents. Although one should value positively the drafted *Sample Regulations of Social Care Council at long term social*

[17] Aknīste psychiatric hospital. Patients' council – it is a challenge, 2002. http://www.humanrights.org.lv/upload_file/Mental%20Projektu%20Atskaites/PaspalidzibasGrupasIII.pdf (accessed on 10 July, 2006).

*care and social rehabilitation* institutions, approved with the Ministry of Welfare's Order No. 24 of 19 February 2003, we believe, however, that this model does not sufficiently ensure involvement of residents of social care homes and we would recommend that establishing Clients' Councils at social care facilities should be encouraged, using as an example of good practice the experience of Patients' Council of Aknīste psychiatric hospital, which at the beginning of 2007 will be compiled in an informative brochure and distributed to all mental health care facilities.

Experience of other countries, for example, the Netherlands, in involvement of users of mental health care services in decision making could also be of interest to Latvia.

Since 1996 there is a law in force in the Netherlands on the involvement of users of mental health care services.[18] The purpose of the law is to encourage users, give them opportunity to influence policy and decision making at facilities. According to the law, practically all mental hospitals have Patients' Councils. At one of the three mental hospitals in Amsterdam – *Buitenamstel*, there is a Patients' Council established consisting of five members. Three professionals support the Council. The Patients' Council consults the Board of the hospital on policy of the facility. Members of the Council receive no pay, except for the Chairman of the Council. Members of the Council are not elected, but are appointed by hospital management. The Council meets twice a month and once a month meets with the hospital Director. Activities of the Council are targeted to advocacy for group interests rather than addressing of complaints of specific individuals. The Councils discuss various issues of the internal hospital policies, for example, smoking, light, quality of food, patients' rights to contact the family, etc.

[18] *Health Care Clients Participation Act.*

# VII. RECOMMENDATIONS TO POLICY MAKERS AND HEADS OF MENTAL HEALTH CARE FACILITIES

1. In drafting policy documents and legislative acts in the area of mental health care, and planning development of new social or medical care services, it is necessary to take into account opinion of users of mental health care services.

2. It is necessary to implement the statements of the WHO Mental Health Declaration and Action Plan concerning involvement of users of mental health care services.

3. It is urgently necessary to begin development of community based mental health care services. According to international human rights standards users of mental health care services are entitled to care in the least restricting environment.

4. It is necessary to poll at mental health care facilities users of mental health care services on the quality of care services offered. It is advisable to ensure regular feedback of clients' opinions on the quality of services provided by the facility.

5. It is necessary to provide users of mental health care services with all necessary information on their rights and treatment process. Medical personnel must provide all necessary information in order that the user may give his/her *informed consent* to the treatment process.

6. It is necessary at mental health care facilities to draft an individual rehabilitation plan for each user of mental health care services. The user of mental health care services must be informed of the content of his/her rehabilitation plan and must be involved in drafting and implementing the plan. It is advisable to review periodically the individual rehabilitation plan together with the user of mental health care services.

7. It is necessary to assess repeatedly the suitability for residents of social care homes to life at long term social care institutions and develop alternative community based care forms for those clients who may be able to live in society, and to transfer to psychiatric hospitals those clients who need regular specialized psychiatric assistance.

8. It is necessary to develop and support financially programmes for training of users of mental health care services in order to raise their level of knowledge in human rights issues and promote their ability to fight discrimination.

9. In the future it is desirable to involve organisations of users of mental health care services in training of police officers and professionals of mental health care because experience of users of mental health care services may be best explained by themselves.

10. It is necessary to provide employment opportunities for both those users of mental health care services living at facilities and those living in society.

# APPENDICES

## *Appendix 1*

**Contact Information of Organisations of Users of Mental Health Care Services**

*Organisation* "Latvian Initiative Group in Psychiatry"
Pērnavas street 62
Rīga, LV – 1009
e-mail: antrasilina@yahoo.com
Telephone: +371 7272873

*Organisation "Dzirksts"*
Brīvības street 7
Preiļi, LV - 5301
Preiļi district

*Patients' Council of Aknīste psychiatric hospital*
Aknīste psychiatric hospital
"Alejas"
Gārsene
Jēkabpils district
LV – 5218

*Organisation "Gaismas stars"*
Pērnavas street 62
Rīga, LV – 1009
Telephone: + 371 7272873
e-mail: gaismasstars@yahoo.com

*Organisation "Paspārne"*
"Kraujas" 4–2
Gārsene
Jēkabpils district
LV – 5218
Telephone: + 371 29154838
e-mail: pudane@apollo.lv

## *Appendix 2*

**Questions included in the questionnaire**

1. What specialists have you consulted over the last year and what specialists, in your opinion, you should consult concerning your MENTAL health?

2. How often do you visit and how often in your opinion you should visit an out-patient psychiatrist?

3. Has any of the following circumstances ever prevented you from receiving an out-patient psychiatric assistance?

   *Limited choice of doctor; the doctor has visiting hours very rarely; doctor's visiting time is very limited; lack of money to purchase medicines; unacceptable out-patient environment (no privacy, have to wait in line for a long time at the doctor's office); the doctor's office is far away from place of residence; transport problems; difficult to get to the doctor; other circumstances.*

4. How regularly have you had treatment over the past 3 years and whether in your opinion, you should have treatment at a psychiatric hospital?

5. How long is it since your previous treatment at a psychiatric hospital?

6. How long are you presently undergoing treatment at the hospital or are staying at the social care home?

7. In which of the following activities have you been involved while undergoing treatment at the hospital or while staying at the social care home?

   *Various classes (music, drawing, cooking, etc); handing out meals; collecting and washing dishes; bringing out garbage, etc.; helping in housekeeping tasks; helping in maintaining hospital's/care home's territory; involvement in the Life Skills programme; passive recreation; occupational therapy; active recreation.*

8. Do you have the following consultations with specialists available while undergoing treatment at the hospital/staying at the social care home?

   *Psychiatrist; psychologist; psychotherapist; neurologist; general practitioner; dentist; gynaecologist; urologist; occupational therapist; rehabilitation specialist; social worker.*

9. Which of the following specialists have you visited during the past 3 months while undergoing treatment at the hospital/staying at the social care home and/or while residing outside of these?

   *Psychologist; psychiatrist; neurologist; family doctor; occupational therapist; rehabilitation specialist; social worker.*

10. Is there a specialist(s) whose consultations or services should be necessary for you at present, but such a specialist(s) is not available?

11. What specialist's consultations should be necessary for you but is not available?

12. Why is this specialist(s) not available?

13. Are the following services for persons with mental disorders available at your place of residence?

    *Day centre; half-way house; group apartment; mobile treatment team; alarm button; users' self-help group.*

14. Have there been cases when you were involuntarily placed in a psychiatric hospital?

15. Who initiated placing you involuntarily in a psychiatric hospital?

16. Who explained to you why and how you were placed involuntarily in the psychiatric hospital?

17. Were you examined by a doctors' commission within three working days since involuntary admission to the psychiatric hospital?

18. Were you informed on the decision of the doctors' commission?

19. How often, while undergoing treatment at the hospital or staying at the social care home have you encountered the following situations?

    *The doctor decides without your participation what method of treatment to use; the doctor and you decide on the most suitable method of treatment; during treatment the doctor and you review your treatment plan; too much medicine is used during the period of treatment; you have been treated with electro-*

*convulsive therapy; during treatment restraints were used; during treatment a special strait-jacket was used; handcuffs were used during treatment; you have been given injections to reduce upset and aggression (chemical restraint); you have been placed in a strict supervisory ward during treatment.*

20. While undergoing treatment at the hospital/or staying at the social care home, who usually explains to you the following questions?

    *Diagnosis; method of treatment; therapy used; course of illness and reasons for aggravation; need to take prescribed medicine and its effect; possible side effects and actions needed if such appear; use of medicines while living at home.*

21. Have you ever encountered any of the following situations while undergoing treatment at the psychiatric hospital or staying at the social care home?

    *You have heard offensive, rude remarks directed against you; you have been shouted at; you have been threatened; you have been physically coerced (pushed, hit, beaten, etc.); you have not encountered such situations.*

22. What persons have treated you like that?

23. Do you have information available at the unit on patients' rights in a brochure or in the form of informative material on the notice board?

24. Do you know where to go if you are not satisfied with the admission procedure at the hospital/care home, treatment, and attitude of the doctor or personnel, living conditions at the hospital/care home? Please name these institutions!

25. Have you suffered from violations of human rights while staying at and/or during admittance to the hospital or social care home?

26. If you have suffered from violations of human rights, please describe how it happened:

    *Physical coercion; emotional coercion; I was involuntarily hospitalized; I was involuntarily treated; my questions related to treatment were not explained; there were unsatisfactory living conditions; use of restraints; use of compulsory injections to reduce aggression; forbidden walks in fresh air; others.*

27. If your human rights were violated during your treatment and/or admission to the hospital or social care home, where did you look for assistance?

*The attending physician; Head of the facility; Inspection of Quality Control of Medical Care; Social Services' Board; Ministry of Health; National Human Rights Office; Patients' Rights Office; Latvian Centre for Human Rights; other institution; have not applied anywhere.*

28. How many people are there in your hospital ward or social care home room?

29. Please evaluate from your own experience whether descriptions of living conditions at the hospital or social home are true?

    *In your ward you have everything necessary (locker for private items, night-light); you always have clean clothing available and an opportunity to clean it; you always have clean bed linen available; you have an opportunity to have a shower or bath several times a week; hospital rooms are clean and tidy; hospital rooms are ventilated; you have free access to a telephone in your unit; telephone is located in a sufficiently private location so that others may not listen in to your conversations; you have available everything necessary to write letters (paper, envelopes, stamps and other items); you may mail letters without the intervention of personnel; written letters have to be handed in to personnel opened; you have the opportunity to be alone if you wish; meetings with visitors usually are without the presence of others; you have TV, radio and publications of the press available; hospital's/care home's rooms are suitable for users with physical disabilities (in wheelchairs).*

30. Do you need any of the following types of assistance on a daily basis?

    *Assistance in self-care (dressing, washing); help in preparing meals; help with housekeeping chores, laundry; help in shopping; reminder to take medicine; advice on planning daily expenses; financial help for purchase of medicines; financial help for daily expenses (paying bills, purchase of food, etc.) other assistance.*

31. What is your education?

32. Do you have a paid job at present?

33. How did you find this job?

34. Have you tried over the past year to find work using one of the following ways?

    *Asked friends, relatives or acquaintances if they know of any vacant jobs; looked in employment advertisements in newspapers and/or internet; went to*

*the State Employment Agency; gone to private employment agencies; used other ways; I have not tried to find paid employment; I have not had the need for employment; I cannot have paid employment due to health reasons.*

35. At the State Employment Agency you have:

    *obtained information on job vacancies; obtained information on State subsidised places of employment for people with disabilities; obtained information on qualification courses and re-qualification opportunities organised by the Agency; obtained advice on choice of profession; registered as unemployed; received other assistance; I have not received any kind of assistance.*

36. What kind of assistance would you need in the future to become more involved in the labour market?

    *More information (on employment opportunities for the disabled, job vacancies, on a profession); additional training, courses (help in obtaining education, learning a profession, additional training, computer courses, re-qualification courses, qualification courses); no need for assistance; moral support from peers (friends, relatives); support of professionals (doctor's help in improving health, support of social workers, psychologist, legal assistance, lawyer's consultations, support of a knowledgeable and helpful person; help in improving health); special work conditions (own workshop, guaranteed work place in a specialised workshop, suitable place of employment, part time work, light, simple work); change the attitude of employers.*

37. Do you need any of the following types of assistance to become more successfully involved in the labour market?

    *Moral support; encouragement to look for work; additional training courses; help in looking for work; guaranteed work place in a specialised workshop, help in meeting with an employer (for example, getting ready for interview, signing the employment contract), help at the place of employment (for example, initial help to perform tasks); other assistance.*

38. Please evaluate by saying "satisfied" or "not satisfied" to your present situation in the following areas of life:

    *physical health; mental health; present employment situation;*
    *material well-being; dwelling where you live; relations with family; relations with friends, colleagues at work, etc.; opportunities for recreation and entertainment.*

39. What is your gender?

40. What is your age?

41. What is your diagnosed illness?

42. How long have you suffered this illness?

43. You are permanently residing at

    *a private house; privatised apartment; rented apartment; apartment in a local government's social house; at social care home; at hospital for long term stay; other.*

44. How many people are in your household?

45. What is your average monthly income?

46. What are the main sources of your income?

    *Salary; disability pension; elderly pension; unemployment benefit; social benefits; child care benefits; other sources.*

47. Your place of residence is in:

    *town, village.*

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