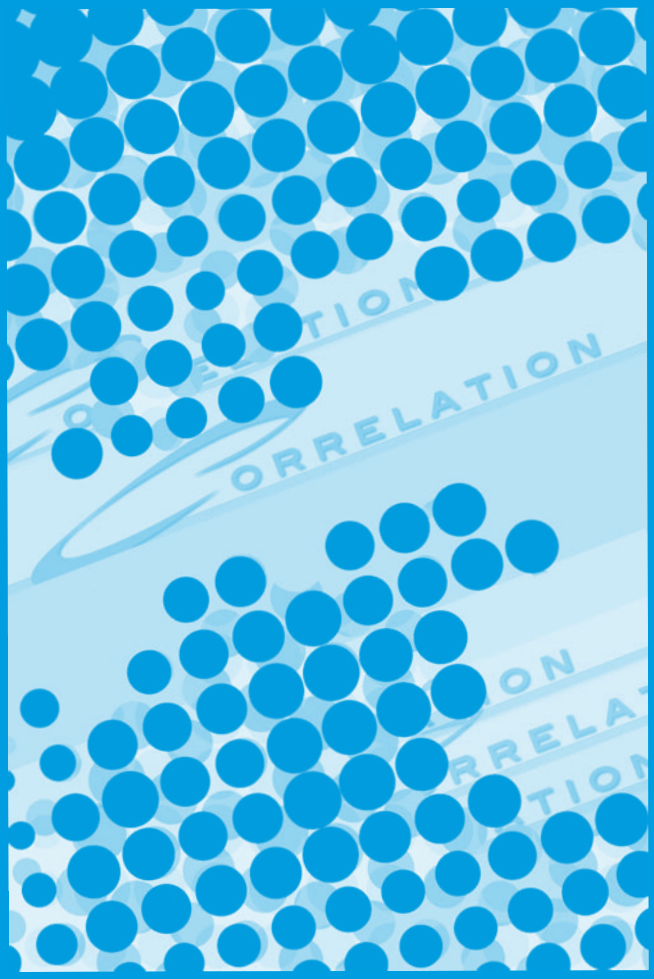
“MAKING VOICES HEARD”

STUDY AND TOOLKIT



ACCESS TO HEALTH AND SOCIAL SERVICES
FOR SUBSTANCE USERS

Colophon

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Amsterdam, March 2008

Ingeborg Schlusemann
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Foreword

Since 2006,The Institute of Public Health of the Republic of Slovenia has been working as a working group for monitoring and promoting health of labelled, isolated and especially threatened and vulnerable groups. Cooperation with members of the European network Correlation that covers social inclusion and health was especially helpful to us. Experiences gained through working within this network and by working with especially threatened groups extended to realisations in promoting health, ethics and protection of human rights. Within the cooperation of this network, we are stimulating the implementations on a different role of threatened groups when these appear as patients or clients in health care and social security. Scientific research and expert directions substantiated the benefits of including drug users in decision-making process on their health and other treatments. This form of participation in daily practice is not yet fully developed. Such approach, called by some a partnership in treatment, joint decision-making or active participation in treatment, is progressively integrated into the work of experts in different work areas of giving assistance to people in need. However, in the area of providing assistance to drug users and to some other especially threatened and vulnerable groups, they are less prevalent. It is assumed that inconsistency on including drug users in decision-making arises from emphasising their personal immaturity, illness, inconsistency and difference, which are the reasons given to justify a treatment without their significant involvement. Thinking that they are at own fault for their situation or that they could have chosen a better and healthier life-style are also contributing factors. For this reasons it is necessary to take away or significantly limit their freedom of decision-making on their own health or medical treatment. This relinquishes their status as an autonomous and thinking being which has a poor effect on the treatment and personal growth. Too frequently and mostly unjustifiably they are labelled as a threat to our environment. Such thinking is concurrent with repressive ideologies and policies towards this population. This is also the cause for different forms of ignoring, humiliating and excluding drug users that may end in imprisonment of patients. The essence of such approaches is not giving assistance but rather, to achieve a more conformable behaviour of individuals who are different.

Stigmatisation, as a moral judgement of selected individuals or groups of society, results in their more or less complete isolation. Labelling and exclusion increase their suffering, contribute to obstacles in accessing and attainability of health care, and limit gaining employment and housing. Stigmatised and isolated individuals, due to fear, lack of resourcefulness, inadaptability, poor past experiences with assistance systems and so forth, do not seek and do not know how to find help in traditional healthcare, social and other programmes. Aside from threat, members of these groups, due to their personal characteristics and social and economical conditions in which they live, are more vulnerable, susceptible to certain disturbances and illnesses. These are often ‘hidden’ individuals and groups for which we presume they are more susceptible to certain illnesses or have already fallen ill but the illness had not yet displayed its symptoms. Problematic drug users are a typical example of a vulnerable group, which is often not accessible to an official type of assistance. For a suitable prevention and elimination of their threat and vulnerability, it is important to understand these occurrences. Individualist explanations steer towards ascribing the reasons for threat of affected groups to their physical and psychological deficiencies or selected life-style that leads to threat or vulnerability. The consequence is the thinking that the country is not obligated to help such groups. And if help is given it is only under specific conditions. Social explanations hold that for an occurrence of threat, key social processes are those that limit people’s free choices, threaten them and cause suffering. Such a view transfers the burden of responsibility for solving drug problems onto the society or the state. The government alone

cannot be responsible for solving drug problems, rather such responsibility is shared between an individual drug user and the community in which he or she lives.

Thus, drug use must be treated according to scientific research and not an ideology. Ideology may only lead to a stricter repression, a breach of fundamental human rights or to apathy, ignoring calls to recognise science and profession as well as deficient actions. It is necessary to check appropriateness and effectiveness of existing assistance programmes for such groups. The present reports contain information on rights to health, appropriate health care and social security for vulnerable groups. Our publication intends to raise awareness on partnership communication under which a drug user and an expert together decide on a treatment suitable to their views and opportunities. It advocates cooperation and a balance of various high threshold and low threshold approaches, a greater involvement of outreach work as a method to approach 'hidden' populations and a larger investments into preventative approaches. We hope that the information collected on extremely moving stories on (not) overcoming obstacles will contribute towards better accessibility, attainability and acceptance of health care and social services for drug users. As drug users may also be co-creators of programmes and at the same time co-responsible for their challenges, the results of treatment are better. Empowering drug users, together with assistance on personal growth, acknowledges them as entities within different system frameworks. It means joint elimination of barriers and replacing obtrusive role of medicated or criminal entities, with a distribution of decision-making power and responsibility between all the subjects. To this end, it is necessary to enable setting up self-help groups for drug users. Within the context of respecting a democratic approach and human rights, it is important to also support organised meetings for individuals and groups who, due to their vulnerability and life deprivation, cannot help themselves. The reports draw attention to unsatisfied needs of 'hidden' drug users and their needs for social integration. Taking everything into consideration, we are aware of fundamental deficiencies. The book mainly reports on aspects of drug users and it does not take into consideration the needs of their extended family, as well as of experts and their organisations. One can refer to an old saying that 'everyone sees the world through his own eyes'. It will therefore be important to continue learning about the needs of all subjects in solving drug problems. We wish to stimulate a more constructive dialogue, improve the exchange of information between different partners, working on enforcing rights of all threatened and vulnerable groups, and at the same time, point to their shared responsibility for addressing difficulties.

Mag. Dušan Nolimal, Msc, Dr. med.,
Head and main researcher of the Slovenian team

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Executive summary

While the European Union (EU) is expanding and transforming, it is facing a great variety of challenges. Until today, marginalised populations in all EU member states do not have appropriate access to basic health and social services. They live permanently or temporarily outside mainstream society, because they belong to a stigmatised group (e.g. ethnic minorities, sex workers) or engage in unaccepted behaviour (e.g. drug users). The living conditions as well as health and social perspectives for drug users, sex workers and disenfranchised ethnic minorities are critical. This poses a threat to their own health and well-being and to public health in general.
As the EU is harmonising policies on many issues, it is important for civil society organisations in all EU member states to be united in order to learn from each other and to stand strong in following and where necessary criticising and improving European policies.

The Correlation network, which has been established in 2005, links different initiatives, focussing on marginalisation and exclusion. The network concentrates on the development and implementation of effective strategies to provide health and social services to socially marginalised and vulnerable populations. The overall goal of the project is simple as well as complex: improving the access to services for marginalised populations.
One of the fields of activity of the Correlation network over the past few years has been to stimulate and support the development of comprehensive national policies on social inclusion and health promotion targeting marginalised populations, by providing a dialogue platform for policy makers, service providers and interest groups. In order to do this, members of the network gathered concrete data through research and organised national debates for the distribution of results and for exchanging viewpoints with local and national policy makers.

The objective of the research that is summarised in this publication is to provide relevant information for the empowerment of marginalised groups. The information from the surveys was used in different national debates that took place after completing the surveys, and it strengthened the involvement of and the impact on clients and service providers. The various target groups have participated as much as possible in the design and implementation of the research process as well as in the national debates.

Partner organisations in five European member states developed and implemented the study in their own country, adapted to the local situation and to their specific target group. The organisation ***Enghaven in Denmark*** focussed its research on barriers to access to social and health services for homeless people, sex workers and drug users. Unfortunately, the report of this Danish study could not be included, due to problems in the process of the research.

The *Research Institute on Drug Studies (RIDS) in Hungary* centred its research on barriers to access to social and health treatment for problem drug users currently out of treatment. The goal of this study was to reveal the reasons why this high-risk group was denied any given form of treatment and needle exchange programmes – or if they did gain entry, what difficulties they were facing. The research sample of this study consisted of 67 problem drug users. The pilot test took place in March 2006 and data collection took place from April 2006 to July 2006.
The results of the Hungarian study showed that methadone maintenance treatment and drug rehabilitation services were particularly hard to access, while needle exchange services and day care were judged easily accessible. Long waiting lists were one hindrance mentioned

for all services. Besides strict accession criteria were named in connection with gaining entry to methadone maintenance and drug rehabilitation programmes. In general, data show that treatment and some harm-reduction activities (methadone maintenance) do not reach the target group they are meant for: those with the greatest needs, displaying the most harmful pattern of drug use.
Almost 100 Hungarian harm reduction service providers and researchers gathered at the European Youth Centre in Budapest on 30 & 31 October 2006 for the national debate organised by RIDS. Actors from various fields were represented at the conference, including drug users, service users, service providers, advocacy NGOs, policy makers, law enforcement officials and researchers.

The main goal of the survey carried out by ***Foundation Mainline in The Netherlands*** was to find out what barriers Moroccan hard drug users in Amsterdam encounter when they intend to enter different forms of (drug) care. Between October 2006 and February 2007, Mainline outreach workers interviewed 23 Moroccan drug users on their needs concerning health care and other services and on the accessibility of those services. The outcomes of the survey give an insight in the reasons why Moroccan drug users are under-represented in Dutch drug treatment clinics; the key message is that the Moroccan drug users of the sample do not expect to receive the help they need from drug treatment clinics. General practitioners and substitution treatment are described as being reasonably accessible; tuberculosis (TB) and hepatitis B (HBV) tests are easily accessible for drug users. The so-called 'low threshold' drug consumption rooms in Amsterdam only attract 43,5% of the respondents of the sample. Plausible reasons for this are that Moroccan drug users don't want to expose themselves as drug users, or that they don't want to be among other people who are using drugs.
Mainline organised a debate with the title 'Couscous and Coke' on 15 March 2007. An important part of this debate was dedicated to tackling the questions of how to communicate findings from the field to policymakers. Another vital issue for this day was how to translate theory into practice when working with clients that have a different (cultural) background. Prominent in their absence during the debate were both policymakers and members of the target group. This absence shows that a lot of work still has to be done in order to create a true debate between these two groups.

The survey of the ***Initiative for Health Foundation in Bulgaria*** aiming to identify means of treatment of drug dependencies and the barriers obstructing the access among problem drug users set forward two main goals:

- To assess the level of interest towards treatment of drug dependencies among the problem drugs users in Bulgaria;
- To assess which are the main barriers obstructing the access to treatment of such dependencies of problem drug users in Bulgaria.

As partners and subcontractors, this survey included seven Bulgarian non-governmental organisations (NGOs), working in the area of harm reduction. Together these partners interviewed 893 problem drug users (PDUs) in eight Bulgarian cities.
The analysis of the data within the framework of this survey identifies several problems and barriers, which give an explanation to why such findings are observed:

- Drug users assess the major part of the programmes available as inefficient, which does not motivate them to seek further treatment;
- There are not enough rehabilitation and re-socialization programmes;
- Regardless of the presence of certain treatment programmes, most of them are private

and therefore cost-prohibiting for most of the drug users;
- Great parts of the treatment programmes offered are concentrated in Sofia, and to some extent in Varna and Plovdiv. In the rest of the towns in Bulgaria, such programmes are not available and this is the main barrier for PDUs in those towns to receive treatment;
- The state financed programmes are often repulsive to drug users, because of the poor quality of the service offered.

The Bulgarian national debate 'The Treatment of Addictions in Bulgaria; Opportunities and Problems' took place on 25 and 26 June 2007. The debate was attended by representatives of the treatment system and policy makers in the area of drugs and drug addictions, representatives of the National Drugs Committee, Ministry of Health, The Parliament, Sofia Municipality and others. During the meeting the results from the study were presented, together with an overview of the care system for drug users in the country and the gaps it has.

The ***Institute of Public Health in Slovenia*** was especially interested in the possibility for participation of drug users in different research phases and in the final political discussion. On content level, key research questions were whether assistance programmes are sufficiently accessible to drug users and what the users experience as barriers to obtaining general and specialised help offered by the health care, social and non-governmental sector. Field research was carried out by two research specialists and one public health specialist, two outreach workers and four drug users.
The selected target group consisted of 49 problematic drug users who had previous experiences with assistance programmes on health care and social security as well as in seeking assistance from non-governmental high threshold and/or low threshold organisations. Besides, four focus groups were carried out, selecting qualitative data from 32 problematic drug users. Data were collected from the beginning of January to the middle of September 2007 in Ig, Celje, and Ljubljana.
The first conclusion of the study was that drug users wish the same things as those who do not use drugs; respect, a roof over their head, a respectful job and better living conditions. They wish to be healthy and happy, getting it through taking drugs that sooner or later stop making them happy.
Some recommendations, based on the study results, are:
- Reducing inequality in accessibility to health care, social services and other forms of assistance for illegal drug users;
- Supporting field work by non-governmental organisations;
- Supporting de-stigmatisation and social inclusion of illegal drug users;
- Supporting the opening of new shelters for homeless drug users;
- Including drug users' representatives in decision making process;

The most important conclusion shows to be cooperation with the Ministry of Health, other relevant governmental and non-governmental institutions working in public health and social security, as well as European network on social inclusion and health.

From the results and conclusions of the four studies it is evident that in all of the four member states where the research took place, some gaps exist regarding the access to care and treatment for those who are in most urgent need of this kind of services. Without wanting to draw preliminary conclusions, we can state that this is probably the case in the whole European Union. Therefore, it is necessary to continue the work carried out by these Correlation members. This book contains a toolkit for those organisations wanting to develop and implement research that supply grass roots data to service providers and policy makers, fuelling the debate to improve

social policies for marginalised populations.

In that matter, one of the first concerns – however trivial it may seem – is that research projects need both enough financial and human resources to be carried out. For grass roots organisations wanting to organise a successful research and debate, this means it is highly advisable to cooperate with a larger organisation. Another important issue is the involvement of the target group in the whole process. Even though grass roots organisations are often close to their target groups and know these groups very well, the highest level of empowerment is reached by involving the people concerned. This is not always easy, because the target group may actually not be a clear-cut group with a well-defined leadership. Therefore, sufficient time needs to be invested to define clear goals and select a representative team to work with. However, involving the target group does not mean blindly following their desires. Good grass roots organisations have the capacity to translate the daily reality of their target group to institutionally useful themes and they should use this capacity.

A last important remark is that organisations that strive to involve their target groups have to make sure that preconditions are met for the members of that target group. Working with drug users for example means that participants need to be able to fulfil their daily needs, like taking methadone. It may also mean paying them for their activities in order to boost their motivation.

1

Introduction

Ferenc Márványkövi, Ancella Voets

While the European Union (EU) is expanding and transforming, it is facing a great variety of challenges. Although most countries in the EU have a vast experience in policy targeting marginalised populations, the extent and nature of specific problems have reached new dimensions. Most European countries are dealing with persistent problems related with social issues, like drug use, (illegal) migration and sex work. Many persons in the EU do not have access to basic health and social services. They live permanently or temporarily outside mainstream society, because they belong to a stigmatised group (e.g. ethnic minorities, sex workers), engage in unaccepted risk behaviour (e.g. drug users) or find themselves in risk situations (e.g. youngsters experimenting with party drugs), in which they cannot appeal to the protecting safety structures of mainstream society. The living conditions as well as health and social perspectives for drug users, sex workers, disenfranchised ethnic minorities and vulnerable youth are critical. This poses a threat to their own health and well-being and to public health in general.

The general tendency in the majority of European countries is to have public order prevail over public health and social inclusion. Experience indicates that main stakeholders (policymakers, research institutes and service providers) have limited communication with the final beneficiaries (individual members and representative bodies of marginalised populations), resulting in a gap between policies and practice and lack of information exchange between the main national and international actors. Therefore, it is important for civil society organisations in all European member states to be united in order to learn from each other and to stand strong in following and where necessary criticising and improving European policies that are being harmonised by EU member states.

The Correlation network, which has been established in 2005, links different initiatives, focussing on marginalisation and exclusion. The network focuses on the development and implementation of effective strategies to provide health and social services to socially marginalised and vulnerable populations. The overall goal of the project is simple as well as complex: improve the access to services for marginalised populations. The partners of the network cover a wide range of backgrounds and activities: National Health Institutes, research institutes, grass roots organisations, service providers and self organisations of service users. Correlation is coordinated by the Amsterdam-based Foundation Regenboog AMOC and receives funding from the European Commission (DG SANCO) and the Dutch Ministry of Health. The Correlation approach is to bring together experts from different professional backgrounds in order to discuss problems and solutions in the area of health and social inclusion, thereby crossing the borders of various fields of work and expertise.

One of the fields of activity of the Correlation network over the past few years has been to stimulate and support the development of comprehensive national policies on social inclusion and health promotion targeting marginalised populations, by providing a dialogue platform for policy makers, service providers and interest groups. In order to do this, members of the network gathered concrete data through research and organised national debates for the distribution of

results and for exchanging viewpoints with local and national policy makers.

So far, most research (Appel et al, 2004; Farabee et al, 1998; Marcus et al, 2004; Treolar et al, 2004; Weiss et al, 2004; Stein and Friedman, 2002) focussing on barriers to treatment has been conducted outside Europe. Members of the Correlation network found out that there is a lack of knowledge and data on the following issues:

- The needs of marginalised people who have no or very limited access to social and health services/treatment;
- The factors and possible reasons that hinder their access to social and health services/ treatment;
- The possible remedies suggested by service users and service providers, and;
- The ways in which existing policies (on drugs, sex work, and minorities in general) work in a counterproductive way for these target groups.

Besides, the members of the Correlation network considered it useful to provide a toolkit for health and social service providers on how to organise a study and a national debate in order to effectively gather and disseminate data on the issues stated above. The experience of the various surveys presented in the following chapters can be adopted and used by various marginalised populations such as problem drug users, sex workers or other minorities who are out of social and health services, or who have limited contact with these services. The toolkit will be useful for policymakers (at local, national and international levels) and service providers as well.

After this introduction you will find a general chapter on the Correlation study. Chapters 3 to 6 contain the reports from four members of the network, who have carried out the study in their respective countries and organised national debates to disseminate and discuss the results. After these reports some general conclusions of the study are drawn. In the last part of the publication, a toolkit is included on how to organise comparable studies and a national debate.

2

Framework of the study

Ferenc Márványkövi, Ancella Voets

The objective of the Correlation study that is presented here was to provide relevant information for the empowerment of marginalised groups. The information from the surveys is used in the different national debates that Correlation members organised after each survey and it strengthens the involvement of and the impact on client and service provider participation. The various target groups have participated as much as possible in the design and implementation of the research process as well as in the national debates.
The research had the following primary research objectives:

- To identify services that the various target groups are most in need of;
- To identify the level of satisfaction of service users;
- To detect barriers impeding the access to social and health services;
- To detect the reasons for having difficulties while trying to access services;
- To detect the level of participation and involvement of services users in the services used.

Five Correlation members co-developed and implemented the study in their own countries. The table below indicates the research focus for partner.

Organisation	Country	Research focus
Research Institute on Drug Studies	Hungary	Barriers to access to social and health services for problem drug users currently out of treatment.
Mainline	The Netherlands	Barriers to access to drug treatment services and general health and social services for Moroccan drug users in Amsterdam.
Initiative for Health	Bulgaria	Access to addiction treatment for heroin users.
Institute of Public Health	Slovenia	Intravenous drug users' access to general health and social services in Slovenia.
Enghaven	Denmark	Barriers to access to social and health services for homeless people, sex workers and drug users.

The original quantitative research tool was developed by the Research Institute on Drug Studies (RIDS) of the ELTE University in Budapest (Hungary). The tool was first tested in Hungary. Following this pilot test each partner contributed ideas to the common structure of the tool and adapted the questionnaire to the local situation. Before the actual start of the local studies, a RIDS representative visited all partners in order to assist in testing and where necessary modifying the tool. RIDS had written a manual for the local partners, with a protocol for using the questionnaire and the RIDS representative discussed the tool with all local interviewers during his visit. For the exact division of tasks see annex one.

The questionnaires that were used in the individual countries had the same, or very similar structure:

- Basic socio-demographic information;
- Treatment history;
- Substance use;
- Social and health services used by the target group;
- Satisfaction level of the target group with the social and health services;
- Barriers to access to social and health services;
- Level of user participation and involvement in the services used.

In annex two, the questionnaire of the Dutch study is included as an example.

During the data collection phase, RIDS acted as a counselling partner. However, the local partners carried out data collection and procession. The partners processed the data in ***Excel*** files. Where necessary, a simple code model and coding instruction were provided by RIDS. Local partners also took care of data analysis, with RIDS acting as a consultant. Each research partner was responsible for reporting on the results as well as for organising the national debates where the results of the studies were presented.

The first study was carried out in Hungary; the research was launched in January 2006 and finished in September of the same year. In the Netherlands the research period started in September 2006, with the main results ready to be presented in March 2007. In Bulgaria, the project started in January 2007 and was completed in July of the same year. January 2007 also saw the beginning of the study in Slovenia. Here, final results were ready for presentation in December 2007. The Danish study was also launched in January 2007 and was foreseen to be complete by September of that year. However, the study came to a halt and is still pending. For the timetable of the studies, also see annex three.

The following chapters present the results of the studies and the national debates in Hungary, the Netherlands, Bulgaria and Slovenia.

3

Barriers to treatment and needle exchange among problem drug users in Budapest

József Rácz, Ferenc Márványkövi, Katalin Melles

3.1 Introduction

Barriers and obstacles to obtaining social and health care is an area of study that has been disregarded unjustly by Hungarian drug research. One may point out a number of factors to justify more thorough knowledge on the nature, treatment needs, relation to the care system and attitude of out of treatment patients. One of the most important factors is that drug users – as opposed to the general population – tend to wait for some time before seeking social and health services. In many cases they need no further treatment than that offered by emergency care – nor is it typical of them to pay much attention to recommendations of health care specialists (French et al., 2000; McGeary and French, 2000; Pablos-Mendez et al., 1997). A careful study on barriers and obstacles to entering treatment enables Hungarian specialists to set and realize more reasonable objectives that also are easier to implement, such as: successfully reaching the target population; honing of the methods of contact; helping and motivating the target group to enter treatment; further developing existing forms of care and service and formulating new services which address real – not just presumed - demands of the client.

Albeit there have, during recent years, been a number of attempts to study this population (see the Literature Review below), one may safely state (and wonder) that the Hungarian – as opposed to the international – field of study completely lacks any ambition to map the demand for acute treatment and the barriers to and circumstances of obtaining social and health care. While not aiming at covering the full scope of the problem, the present research does take a throw at it. As this was an explorative - i.e. diagnostic - study, we preferred a descriptive approach, and tried to reveal basic relationships in connection to barriers to entering treatment. Accordingly, the issues of our research were the following:

- Describing treatment history of illicit drug users;
- Revealing acute (relating to the past year) treatment needs;
- Revealing and identifying barriers to, and any factors possibly influencing entering treatment.

3.2 Setting

Problem drug use: prevalence, infection and mortality rates

According to the ESPAD surveys carried out in Hungary since 1995, there was a small increase in the rate of heroin users among the 16-year-old age group at secondary schools from the mid-1990s until the late 1990s, then a small decrease and another small increase was experienced. Life prevalence of heroin use has never exceeded 3% among this age group (National Report, 2006). Regarding the adult population, life prevalence stood at around 0.5% in 2001 and 2003 (National Report, 2004).

Regarding the number of problem drug users, there have been two attempts to estimate their number in Hungary as well as in Budapest. In 2003, the number of opiate users (opiate is mostly

administered intravenously in Hungary) was estimated at 2.4 per 1000 inhabitants in Budapest (National Report, 2004), which is approximately 4,000 opiate users. In 2005, this figure was approximately 2,700. In 2005, the number of problem drug users was estimated at 21,000-24,000 in the 15-64 age group in Hungary, while intravenous users were estimated at 3,300-4,000 in the same age group (National Report, 2006). According to the latest estimate figures (National Report, 2006), the number of problem drug users was between 2,000-2,500 in Budapest in 2005. Despite the different methods used to estimate problem drug use, it can be said that this figure is well below the EU figures in the adult population (15-64) (National Report, 2005).
The HIV infection rate among injecting drug users (IDU) was 1% in the period between 1997-2004 (ECEMA, 2004). However, between 1997 and 2002, the proportion of hepatitis C (HCV) infected intravenous drug users (IDUs) treated in hospitals rose from 16% to 30% (National Report, 2002). Based on reported incidence data from 2006 and the HIV analysis of 300 intravenous dependent users, it can be concluded that the number of users infected with HIV is rather low in comparison with earlier figures. The 28.9 % HCV infection prevalence rate found among clients of outpatient centres and low-threshold agencies calls for the importance of secondary and tertiary prevention (OEK, 2007).
While in the new EU member states drug-related death increased between 1996 and 2003, Hungary is experiencing a decreasing rate with drug-related annual death figures, dropping from 40 to 28 in the period between 2001 and 2005. Most drug users dying from overdoses are injecting opiate users. Their mortality shows a small increase from 8 to 13 in the period between 2004 and 2005 (National Report, 2006).
In conclusion, it can be said that the number of problem drug users and the percentage of infected intravenous users as well as mortality rates are below the European figures.

Barriers to treatment

Hungarian research on factors hindering access to treatment and actual need for acute treatment of problem drug users is very insufficient. It is known that this population is characterised by high-risk behaviour, such as the sharing of needles and injecting devices or unprotected sexual practices; and that the number of those having been through a medical screening is extremely low (Rácz et al., 2003.). According to national data, the number of opiate users in treatment decreased significantly from 4,200 to 2,000 between 2001 and 2005 (National Report, 2006). This may suggest that although effective field education work helps, harm reduction messages do not reach this group easily , and problem drug users do not reach treatment. Previous research also suggests that low-threshold agencies have problems reaching problem drug users due to several factors (Márványkövi and Rácz, 2005).
Below, we present the limited number of research that targeted problem users and barriers to access to treatment.
Rácz and Ritter (2003) directed their research, among other factors, to those hindering access to treatment, as seen by service providers. They found that, according to professionals working in the field, of all barriers to entering treatment, the most characteristic are: under-motivation of the drug user; house rules of the institution providing the service; low accessibility of the service institution; lack of recognition of the particular condition of the drug user; misdiagnosing the symptoms of illicit drug use (in some cases, even an overdose case was not recognised); lack of knowledge on treatment methods; lack of proper personal and infrastructural conditions; and lack of communication and harmony amongst the processes making up the service provision system. Also very important is the fact that in many cases gaining access to residential services is a matter of who-knows-who.
In their 2003 research, Rácz et al. compared intravenous drug users in the street who had never

been in treatment with those who had been seeking treatment. The basic difference between members of the two groups is the length of their drug career: those seeking treatment had been using drugs for a longer period of time – that, presumably, is the reason why they are seeking help.

3.3 Methods

Problem drug use

According to the EMCDDA definition, the problem drug user is one who uses a drug intravenously and/or one who has been using opiates, cocaine and/or amphetamine related substances regularly and for a long time (EMCDDA, 1999.).

Drug use treatment

When using the definition of problem drug use, we made use of EMCDDA guidelines (EMCDDA, 2002.). According to these, any provision aimed at health- and/or psychosocial disorders so that complete or partial abstinence from drugs is reached, is qualified as treatment, as long as it takes place in a well-defined environment. Using this definition, we may define as treatment the following: outpatient services; residential services; drug rehabilitation; day care/provision; methadone maintenance; and psychosocial forms of care offered by low-threshold services. Although needle and syringe exchange does not qualify as treatment, we have looked at circumstances of and obstacles to accessing this service as well.

3.4 Sample

The sample consisted of 67 problem drug users. Sample criteria were as follows:

- The prevalence criterion:
  - The interviewed person has been taking opiates or amphetamine for at least 3 years, 3-4 times a week (self-declared);
- The treatment pyramid criteria:
  - Patient has never been in treatment;
  - Patient had received some sort of treatment, but at least a year earlier;
  - Patient just entered treatment, but has not had any earlier;
  - Patient just entered treatment, and had received some earlier, but at least a year earlier

Needle exchange and/or drop-in service (warm food, bath, washing etc.) recipients, detoxification recipients, or the recipients of any medical treatment not arising out of drug use, such as that of the family doctor, were not accounted for as having been in treatment.

- Socio-demographic criterion
  - The interviewed had to be at least 18 years old.

3.5 Sampling methods

In our research we used two methods of a sort that had purposely been developed for target groups of hiding nature. Such a target population is that of intravenous drug users where

traditional sample- and data collecting probability methods would not, or would only limitedly work. A number of sample collection methods had been developed that lower or minimize data distortion resulting from data collection. Snowball techniques offer an easy and fast way to reach members of a sub-population, although its improper use may lead to substantial data distortion during the collection phase: propagation may flow towards targets who belong exclusively to the peer group of the person in question (Heckathorn 1997, 2002). To eliminate this error, we started data collection from four independent cores (Kék Pont: Contact Café; Kék Pont: street needle exchange; Baptista Foundation: needle exchange bus; Drug Prevention Foundation: local needle exchange; Drog Stop Foundation).
The other sample collection method we used – which is tightly connected to the one above – is the sampling technique based on service/treatment location (Caiaffa et al, 2003; Fauziah et al, 2003). It only allows into the sample those who are either clients of needle exchange programmes or those recommended by these clients, provided they also fit other sample criteria.
Interviewees were invited to participate in the snowball sampling process. They were asked to bring along friends and mates from their networks that met the sampling criteria.

3.6 The research tool

The questionnaire used in the research consisted of two parts: a face-to-face and a self-completed section. Completion time for the face-to-face questionnaires was about 40 minutes, while the self-completed questionnaires took only 10 minutes. The face-to-face questionnaires had been compiled by the research team; during its development we took into consideration the treatment needs of other problem drug users, along with international measuring tools used to examine barriers to treatment (Appel et al., 2004; Treloar et al., 2004; Stein and Friedmann, 2002). The face-to-face questionnaire had an index that had been validated and used both in international studies and in Hungary: that of heroin dependence (Severity of Dependence Scale, Gossop et al., 1995; Rácz et al., 2003). Some of the questions of the self-completed questionnaire came from a measuring tool developed by NIDA, which had been validated for Hungarian research earlier (Rácz et al., 2003).

Thematic questions of the face-to-face questionnaire were the following:

- Background data (socio-demographic background; marital state; residential state; state by level of education; state of employment);
- Peer network (close friends, both drug users and non-users; friends who were in treatment in 2005.; family support contentedness);
- State of health (subjective opinion on general state of health; having been screened for HIV and hepatitis; perceived risk of HIV and hepatitis);
- Factors hindering access to treatment, perceived need for treatment (treatment history; treatment needed during the last 12 months; barriers to treatment; judging the difficulty of entering treatment);
- Severity of Dependence Scale.

Thematic units of the self-completed questionnaire:

- Criminal involvement;
- Alcohol- and drug using preferences;
- High risk behaviour: needle sharing and sexual practices.

Pilot test

The pilot test took place in March 2006 among problem drug users. Users were explained why the pilot test took place and were invited to comment on the questions. Following the test, certain questions aimed at barriers to treatment were deleted and modified, while others were added based on users' comments.

Data collection

Data collection took place at NGOs providing needle exchange and providing outreach programmes from April to July 2006. Staff providing services were also invited to inform users about the survey. Of the 6 interviewers, one worked as a social worker and one was a former problem drug user.

Ethical aspects of the research

As part of the questioning process, our partners signed an informed consent in all cases; this ensured that the anonymous data collection could be interrupted at any time, and that both the questionnaires and the database would be destroyed, once data procession would be complete.

3.7 Results

Socio-demographic background

The average age of the sample population was 27,4 years. The age group distribution looked like this: those aged 18-24 years took up 32,8%; the 25-29 years group spread across 37,3%; the rest -29,9%- was aged over 30. Almost three quarters of our sample group were male, only a quarter female. Regarding their origins, they predominantly (close to 75%) proclaimed themselves to be Hungarian; 22,4% declared they were Roma. From the point of view of education, the sample was practically homogenous, since more than half of the participants had not finished secondary school and the average number of grades completed was 10. The low level of education may not be put down to age, as nearly 60% of those not attending any kind of educational institute at the time of the questioning had not finished secondary school either. Another characteristic trait of those in the sample was that most of them had no permanent work, and made their living out of odd jobs. Nearly two-thirds of the questioned had had a lawsuit against them, and 30% had already been in prison, doing, on average, 2,2 years' term. More than a third of the questioned had been prosecuted on charges of drug abuse and trafficking; 34% had been prosecuted on charges of crime against property (as well).

Drug use

98,5% of those in our sample had tried marijuana; 94% had taken amphetamine; 91% had experienced heroin and more than two thirds of them had used cocaine. During the 30 days just before our survey took place the drugs used mostly had been heroin and marijuana (80,6% and 53,7% respectively), while injection prevalence for the same period of time had been highest in the case of heroin (82,1%). Nearly two-thirds of the questioned had taken a number of problem drugs during the 30 days examined, and almost all of them had had some of those substances injected. For the last two days before our interview it had been also heroin that had been preferred, all subjects having had taken it, following the last-30-day prevalence, intravenously.
The age at the first exposition to amphetamine, cocaine and heroin were almost the same: 19-20 years; it can be said that this was also true for the age when regular drug use generally began.

The age of first contact with marijuana also nearly coincided with the age when regular use of this drug started (16,5 and 16,7 years respectively). We may also safely lay down the fact that, looking at marijuana and the former three drugs, the age of contact and that of starting to use them regularly did practically coincide, which suggests that once drug contact was established, regular use set in almost immediately. The average length of problem drug use career in our sample was 7,6 years.

According to the Addiction Severity Index which measures from 1 to 15, subjects in our sample averaged level 9, which is associated with a medium degree of dependency regarding heroin / amphetamine. More detailed analysis of the distribution revealed that slightly more than half of those in our sample were drug dependent more severely.

When we considered common needle usage of those in the sample, we found that a substantial part of these problem drug users had shared needles when injecting the substance: 28% of them had done so even during the relatively short period of 30 days before the interview. When we looked at sharing of injecting tools in general, this figure was even higher: 40,3% during the month before the questioning took place.

Treatment history

Slightly more than half of those in our sample had been treated in one of the institutes providing services to cure drug use problems: most of them had received outpatient services (37,3%) and resident hospital services (35,8%). 39,4% had received psychological provision, and 29,9% had been offered labour-related counselling. 76,1% had obtained sterile needle and syringe via a low threshold service provider. At the time of our survey 16,4% of our subjects had been receiving, for less than 30 days, an ongoing hospital treatment. Somewhat less of them were being given drug counselling. Regarding needle and syringe exchange, we found that more than two-thirds in our sample obtain sterile injection tools either locally or via street needle and syringe exchange, although the former way is more characteristic.

Barriers

Judging the difficulty of entering treatment

Table 1: Judging the difficulty of entering treatment, by type of treatment*

	Average	N	Standard Deviation
Outpatient services	1,98	49	1,31
Methadone maintenance	4,28	50	1,33
Day care / provision	1,50	28	1,04
Residential services	2,39	49	1,50
Drug rehabilitation	3,03	39	1,50

** The questioned had to mark off on a five-point scale the perceived difficulty of entering any given treatment (1: not hard at all; 5: very difficult).*

Problem drug users indicated methadone maintenance programmes as the hardest to join (average: 4,28), while getting into day care was judged easy (average: 1,5) – although the latter was the least known among drug users. Obtaining outpatient hospital services were seen by most as greatly hindered by long waiting times and the large number of applicants. Among the number of barriers to drug treatment, there was one that we received more information on than on the rest: methadone maintenance treatment. Most of the interviewed found this difficult to

access because of long waiting lists; they also named as a barrier the tough conditions drug users must meet in order to participate, and to stay in treatment – that is, the strict accession and treatment criteria. In the course of our questioning we found that, according to those questioned, methadone maintenance programmes were the most popular form of treatment: there was such a demand for them that the sheer number of applicants made it difficult to even sign up for them. In our sample we only had seven persons who had an opinion on obstacles to accessing day care services - naming, other than long waiting times, admittance capacities of these communities and difficulties of obtaining the necessary documentation. Resident hospital services were seen as moderately hard to enter, naming the high number of problem drug users treated in these hospitals as the most serious obstacle; another phenomenon that in our subject's opinion hampered admittance was that, as they stated, these institutions "prefer not to admit too many addicts at the same time". Other than long queuing times it was low standards of the service and problematic administrative entrance procedures ("cutting the red tape") that were also mentioned. The difficulty of entering drug rehabilitation was valued, on average, 3,03. Most had marked the insufficient number of rehabilitation institutions as the culprit, but long waiting times and an entrance condition that required a "proper drug user's record" were also named as retarding factors.

Factors influencing difficulty of entering treatment

Table 2 contains those factors that affect judgement on how difficult it is to enter treatment of different types:

Table 2: Factors affecting degree of difficulty of entering treatment, by type of treatment: a linear regression analysis

		Level of significance	Coefficient B***
Outpatient services	Roma / non-Roma origins	0,0105*	0,9767
	Opinion on quality of life	0,1205	0,2379
	General state of health	0,0309*	0,3263
	Contentment with friends' support	0,0113*	-0,2805
	Worried about AIDS infection	0,1008	-0,1781
	Using different kinds of drugs (Bivariate)	0,0054**	-0,8377
	Severity of drug dependency	0,0022**	0,1287
Methadone maintenance programmes	Owning necessary documentation	0,0498*	-0,7585
	Severity of drug dependency	0,0061**	0,1412
Resident hospital services	Reliable (regular) income (Bivariate)	0,0309*	-0,3263
	Worried about AIDS infection	0,0555	-0,2945

Values of the continuous dependent variable were between 1 and 5.

*** Strongly significant (t-Statistic below 0,01)*

** Significant (t-Statistic below 0,05)*

Variables not marked with an asterisk did not reach significance.

**** Coefficient B: this coefficient of linear regression tells us about the magnitude of influence of the individual variable on the dependent variable, and what is the polarity of this effect.*

It is apparent from the table above that judgement on the difficulty of entering outpatient services was affected by Roma origins, general state of health, problems with secondary socialization contacts (partner, spouse, friends), the use of different kinds of drugs and a more severe drug dependency. This meant that those subjects of the survey who thought of themselves as Roma, who judged their general state of health as inferior, who were not satisfied with their friends, who were using more kinds of drugs and/or were -according to the Severity Scale- more addicted to the drug(s) would say that gaining access to outpatient services was not easy. Of these background variables two effects proved, on a 0,01 level, to have been significant: using different kinds of drugs and severity of drug dependency. When comparing the influence of these two variables, one can see that based on their coefficients, using different kinds of drugs had –slightly, but- greater effect on how the subject judged the level of difficulty of accessing outpatient service.

Looking at the figures on methadone maintenance treatment, it is evident that judgement was solely influenced by severity of drug dependency; this influence was there even at significance level 0,01: accessing methadone maintenance programmes was deemed more difficult for those who were, according to the Severity Scale, more addicted to the drug. Interesting also is the fact that those without any / proper documentation necessary for entering maintenance treatment also opined that methadone programmes were less easy to get into – although this relationship was very weak. Therefore, according to the statistical indicators, this background variable had its own influence; this effect was probably due to such factors that were outside the scope of study of our research.

In the case of resident hospital services, the opinion on the difficulty of gaining entry to this type of service was biased significantly by job security only: those not having a regular job serving them as a secure source of income, would find entering resident hospital services more problematic than those with a regular job. This relationship, however, is not reliable.

Perceived treatment needs and entering treatment

Table 3:
Treatment requirements during the last 12 months: frequency distributions (%)

(N=67)	Outpatient	Resident	Rehabilitation	Day care	Methadone	Total
Yes	22.4	19.4	14.9	10.4	34.3	61,2
No	76.1	80.6	85.1	89.6	65.7	38,8
Totalling	100	100	100	100	100	100

For the span of the previous year, the treatment sought after most was methadone maintenance, yet almost a quarter of our responses to this question also indicated a need for outpatient services. Altogether it was 61,2% of our sample that, during the year before, expressed the need for at least one form of service. More than three quarters of our sample had asked for needle and syringe exchange.

It was those applying for admittance into outpatient services that had the largest rate of success. Drug rehabilitation services and methadone maintenance programmes, however, were characterised by markedly low rates of entry. Those indicating their need for needle exchange were largely successful in obtaining sterile injection tools via an organisation.

Perceived factors influencing treatment requirements

Table 4 displays figures on factors that, as seen by those questioned in our research, affect their needs for treatment of different sorts

Table 4: Factors influencing treatment requirements: a logistic regression analysis

		Level of significance	Odds ratio***
Treatment requirement	Being unemployed *(Bivariate)*	0,0568	0,2586
	Subjective opinion on general state of health / on physical condition	0,2225	1,6314
	Contentment with family support	0,4917	0,8076
	Contentment with friends' support	0,0878	0,6056
	Common needle usage (for last 30 days) *(Bivariate)*	0,1000	4,2095
	A friend using intravenous drugs *(Bivariate)*	0,0448*	4,0768
	Treatment history *(Bivariate)*	0,0173*	5,0674
Needle exchange programme	General state of health / physical condition	0,0228*	0,4200
	Roma / non-Roma origins *(Bivariate)*	0,1784	0,2234
Treatment of social nature	Having received psychological counselling *(Bivariate)*	0,0868	4,3128
	Having received labour-related counselling *(Bivariate)*	0,0051**	12,4974
	Using different kinds of drugs simultaneously *(Bivariate)*	0,0018**	0,0487

****The Odds Ratio is an index on how our independent and dependent variables relate to each other: here it tells us that, in the case of those where the independent variable is equal to 1, how many times their chances are to have needed some sort of treatment during the year before.*

Values of the bivariate dependent variable:
0, when no treatment of any sort was required for the last 12 months; 1, when some kind of treatment was needed during the year past.
0, when there was no needle exchange during the last 12 months; 1, when the needle exchange programme was utilized during the last 12 months.
0, when no psychological, nor labour-related counselling was needed for the last 12 months; 1, when counselling of psychological or labour-related nature was needed during the past 12 months
*** Strongly significant (Wald value below 0,01)*
** Significant (Wald value below 0,05)*
Variables not marked with an asterisk did not reach significance

Expressing treatment needs was influenced by two factors, both having their own effect: treatment history and the presence of a friend using intravenous drugs. Those problem drug users who had attended some kind of treatment at an earlier time were more likely to have asked for some sort of service during the previous year. Those with friends on intravenous drugs also expressed their wish to enter treatment more frequently – while the latter variable is less significant. Considering our data on socio-demographic background factors and on general drug use (length of drug career; number of drugs presently used; sharing of needles), it is important to note that from these points of view there was no difference between those who did perceive the need for treatment and those who did not.
Regarding the need for needle exchange, we found that the major factor here was the general health as the drug user perceived it: those who esteemed their physical condition as inferior

would request this service less often than those who found themselves fit enough.
When it comes to demand for treatments of social nature (psychological, labour-related) we also found treatment history and the use of many drugs to be key factors: those who have already had received counselling, or who were using more than one problem drug were more likely to have asked for these. Comparing the effect of the two variables, it can be seen that having received labour-related counselling had the greater influence.

Chances to enter treatment

As a last step during our study of factors hindering access to treatment, we had two subgroups of our sample compared with each other. These were: those who had already taken part in any of the five forms of treatment under scrutiny before – and those who had never succeeded in getting into treatment of any kind. The table below summarizes our results.

Table 5: Factors influencing prospects to enter treatment: a logistic regression analysis

		Level of significance	Odds ratio
Treatment history	Roma / non-Roma origins ***(Bivariate)***	0,3875	0,4530
	Age	0,0989	1,1919
	Education (number of grades completed)	0,0288*	1,5610
	Length of drug career	0,0066**	1,4107
	Severity of drug dependency	0,4350	1,0818

Values of the bivariate dependent variable: 0, when no treatment of any sort has ever been required; 1, when some kind of treatment has been requested in the past

*** Strongly significant (Wald value below 0,01)*

** Significant (Wald value below 0,05)*

Variables not marked with an asterisk and the dependant variables are correlated, but in our model they show no significant relationship with earlier treatment history.

The simultaneous study of several background variables had led us to the conclusion that access to treatment was influenced to a significant degree by two factors: the client's length of drug career and his/her education: those with a longer drug career and those with a higher level of education gained entry to any given treatment with a higher probability than those who had regularly used amphetamine or heroin for a shorter period of time, or those less educated. Of these two influencing factors the former – length of drug career – is strongly significant.
Where the statistical distribution of the variable allowed this, we examined the five forms of treatment one by one. Of the several background factors, the probabilities of getting into outpatient and resident hospital services were affected significantly by the length of drug career only: a longer career predicts getting into treatment. With needle exchange the influential factor was the person's origin in that Roma drug users were less likely to access this service – yet the influence did not reach statistical significance.
To sum it up: what we have found was that the drug using career proved to be a predicting factor on the likelihood of gaining access to treatment. Users with a longer drug history stood a better chance to enter some sort of treatment as a result of their drug-related problems.

3.8 Discussion

Our research was aimed at problem drug users who were either out-of-treatment at the time of the study, or who just got into treatment at that time, and had not been in treatment for at least a year before the survey took place. This meant that their needs for treatment and their experiences and opinion regarding access to treatment were limited by this time frame. Our goal was to reveal the reasons why this high-risk group was denied any given form of treatment and needle exchange programmes – or if they did gain entry, what difficulties they were facing.

It had become manifest from socio-demographical and sociological characteristics of the sample group that problem drug using was associated with serious drawbacks in other aspects of life, such as education, housing, unemployment or criminal involvement (some of these crimes having been not drug-related crimes as such). Drug using tendencies in the sample group and the level of drug addiction (as measured by the Severity of Dependence Scale), themselves being criteria for the sampling, drew a profile of problem drug using. Also important factors are multiple drug use, the injection method, and frequent sharing of needle and syringe.

As our research indicated, it was a total of 41 persons (61,2% of the sample) who wished to access some sort of treatment; 10 of these (14,9%) succeeded in receiving some sort of provision. Most of those questioned *would have liked to enter* methadone maintenance treatment, but the number of those intending to receive outpatient or resident hospital services was also relatively high. However, considering that our clients were who they were (i.e. highly dependent problem drug users with their typical psycho-social profile), then it became evident that these proportions were in fact low: lacking any bases of comparison with similar proportions in other drug using populations, it was hard to tell; yet again, looking at the graveness of the problem this was what we felt. It is not easy to draw a parallel between data on similar populations in other countries and those in Hungary: the average age of the problem drug user in Western countries is higher, and the service provision system is also different. In their research on problem drug users in the US, Appel et al. (2004) found that 17,7% of the subject group was not inclined to undertake treatment, meaning 82% ***was*** willing; and this proportion is way higher than what we found in Hungary. When we see that 76% seek needle exchange services, the figure may appear to be high – but then again, there is no basis for comparison. The very need for needle exchange programmes indicates that the questioned do not, or would not, wish to abandon drug use and this fact may be instrumental in them avoiding treatment.

Our results showed that methadone maintenance treatment and drug rehabilitation services were typically hard to access, while those indicating their need for needle exchange were largely successful in obtaining sterile injection tools. These results – along with what we have inferred regarding the need for the services – establish the fact that methadone maintenance programmes do not succeed in admitting those who need them. According to our sample group, accessing any of the five treatment forms, with the exception of outpatient treatment, was hindered by some kind of organisational/institutional barrier. As pointed out by other studies before (Farabee et al., 1998; Marcus et al., 2004; Treolar et al., 2004), blaming the provision/service side on the part of the problem drug user is understandable – yet, for reasons detailed above (different sample size; partially different sample group and different provision systems) comparison with research results obtained in other countries is only possible in a limited way.

We also saw that the realisation of treatment needs was influenced by two factors, both with their own effect: treatment history and on the presence of friends using intravenous drugs. Those problem drug users who had attended some kind of treatment at an earlier time were more likely to have asked for some sort of service during the previous year. Those with a friend using intravenous drugs expressed their wish to enter treatment more frequently as well. Treatment

history as a factor that positively influenced (boosted) the need for drugs could be explained by a sort of socialising effect of the earlier treatment session(s): if there was trouble, there was the need for treatment; and the person knew where to go, what to do. The drug use boosting effect of intravenous drug user mates may be interpreted by the like-age group effect in initiating treatment, but it may also indirectly indicate social exclusion, a psycho-social condition that has deteriorated so far that all that is left are the friends with the needle. These assumptions cannot be verified by existing data; further research is needed to analyse the details and polarity of these relationships.

The need for needle exchange was mostly influenced by the general health condition as the drug user felt it – in a paradoxical way, it is those with a better state of health who utilized needle and syringe exchange programmes more often. This may be explained by a number of factors as well. Perhaps those with ill health are awaiting more intensive treatment; or they ceased to carry on their harm-reduction behaviour (as well). In scientific literature this state of affairs is characterized – among other things – by powerlessness (e.g.: Laudet, 2003.). When it comes to demand for treatments of social nature (psychological, labour-related) we found treatment history and the use of many drugs to be key factors; the former might also be a sign of socialisation for drug provisions.

Our sample group voted methadone maintenance programmes as the hardest to join, while getting into day care was judged easy – although the latter was the least known among drug users. Long waiting lists were one hindrance mentioned for all services; strict accession criteria were named in connection with gaining entry to methadone maintenance and drug rehabilitation programmes; and problematic entrance administration procedures were brought up often. Data on low accessibility of methadone maintenance programmes were really interesting: as a basic harm-reduction technique this service ought to be (more) readily available (depending on which treatment paradigm we side with); yet a number of datasets indicated it was everything, but: methadone maintenance programmes were the hardest to join. It was also here that we found that the more dependent a user was, the less easy he/she found access to be. The fact that the very target group finds treatment access so difficult appears to be a problem; as a result they (may) refrain even from trying to join these services.

An inferior state of health as a disadvantageous factor regarding access to treatment is justified under certain circumstances: drug users in a bad shape require more intensive treatment. Outpatient hospital service may be the gateway to this sort of intensive treatment; however, as drug users see it, the service is not up to this role.

The drug user's race raises many thoughts as well; it is not easy to interpret Roma origins as a factor rendering access to drug treatment more difficult: outpatient contact workers really cannot be accused of racism. Roma origins may be a kind of psychosocial-cultural background of those questioned in this particular milieu, which might fuel mistrust towards this form of treatment. However – the connection we revealed suggested that hiding behind the significant relationship were not dissimilar socio-economic factors – that is, it was not the influence of a possibly prejudicial socio-economic status that manifested itself through Roma origins. To fully examine this aspect of our results we'd need to involve more Roma in our sample group.

In the case of resident hospital services having a reliable source of income proved to be significant: those not having a regular job serving them as a secure source of income, found entering resident hospital services more problematic than those with a regular job. We saw earlier that the level of education generally influenced accession rate - and our present findings regarding entry into resident hospital services show how important employment is. This phenomenon guides our attention to the interrelationship among health services and social inequalities: in relation to resident care, those with better education and -employment status are invariably in a better

position. This sort of discrimination is also there when we look at the – as yet unexplained – effect of racial origins on gaining entry to outpatient services: to what being a Roma may bring about, when the client wishes to enter this service. Considering drug career, we see that certain treatment types (methadone maintenance programmes, outpatient services) are more readily available for those candidates with better health condition; the system works in such a paradoxical, discriminative way that drug users in a better shape (who might need less intensive treatment) are preferred. This can be explained by the belief that these clients do still have the potential to be "healed", while "hopeless cases" do not. All these show that treatment and (in our research: in the case of methadone maintenance service) harm-reduction does not reach the target group: those with the greatest needs, displaying the most harmful pattern of drug use; therefore the treatment's role in drug policy is limited.

Finally, the connections between a lengthy drug career, higher level of education and treatment history is also interesting to think about. The influence of the length of drug career can be explained with problems induced by taking problem drugs over a long period of time – problems that ask for treatment, mostly of outpatient and resident hospital nature. Using the possible connection between health-behaviour and the level of education as factor of inference is questioned by the fact that those users with a higher level of education are more likely to have been through treatment of some sort. Education may be looked at as a measure of socio-economical status. In this case we can interpret our results in the context of the relationship as it was seen between lower social status and unfavourable health attitude (Borell et al., 2000; Pomerlau et al., 1997). Other studies pointed out the connections among several dimensions of disadvantageous social status (bad financial and housing conditions) and access to drug treatment (Mullins et al, 2005; Deck and Carlson, 2004; Wood et al, 2005). Finding and examining further relations binding these factors, as they are experienced amongst Hungarian problem drug users may form the basis of a future research.

3.9 National policy debate - Harm Reduction Conference, 30-31 October, 2006, Budapest

Almost 100 Hungarian harm reduction service providers and researchers gathered at the European Youth Centre in Budapest on 30-31 October, 2006 for the two day event, with only 10 persons having failed to turn up despite former registration. The Open Society Institute and Correlation Network sponsored the conference.

The main objectives of the national policy meeting could be summarized as the following:

- To provide legal and media training for harm reduction service providers;
- To hold workshops to point out the major problems of harm reduction in Hungary and make proposals for policy makers;
- To present new research findings on the major gaps in access to services;
- To contrast different views and opinions on how to improve harm reduction by presenting national and international speakers at a round table discussion partly based on the research results of the study.

There were actors coming from various fields represented at the conference, including drug users, service users, former drug users, service providers and advocacy NGOs, policy makers, law enforcement officials as well as researchers. The conference consisted of both plenary sessions and workshops.

On the first day, HCLU staff members provided legal and media training for the participants,

later in the afternoon three workshops discussed the problems and challenges in the three important fields of harm reduction (substitution therapy, needle and syringe exchange and rave party services). Members of the three workshops drafted proposals and recommendations for decision makers and researchers. This was the first time that the seven NGOs working in rave-dance scenes in different parts of the country could meet; therefore they expressed the need for stronger cooperation in the future and they called for the establishment of professional standards. Party service providers unanimously criticised police raids against young people participating in rave parties – they pointed out that there are positive public health alternatives to repressive law enforcement measures. Participants also urged the government to create legislation which obligates rave party organizers to allow entrance for social workers and encourage them to cooperate with service providers in order to develop a safer environment for young people. The workshop on methadone maintenance stated that the coverage of substitution treatment is very low. Therefore they urged the government to open new clinics all around the country. The so called TÁMASZ drug care network has 78 local centres in Hungary; if all these centres provided methadone maintenance, there would be access to treatment for all people in need, concluded Dr. József Csorba, head of the biggest methadone centre in Budapest. In their consensus statement, needle and syringe exchange providers called for a new legislation, which facilitates and normalizes the work of these programmes and respects the human rights of clients.

On the second day, researchers from the Research Institute for Drug Studies (RIDS, ELTE University, Budapest) presented their findings from a new quantitative and qualitative study on the access to treatment among Budapest injecting drug users. According to the researchers, most IDUs found it „difficult" to get into a rehabilitation programme and „very difficult" to participate in a methadone maintenance programme - even if 33 percent of IDUs demanded this type of treatment last year, only a small minority could finally enter a programme. 40 percent of research participants reported that they shared injecting equipment in the last 30 days – these alarming data point out that the access to sterile needles and syringes is very limited. Speakers concluded that there are serious barriers to treatment for injecting drug users in Hungary, and these barriers are even stronger in the case of more addicted and more marginalized people. Different participants pointed their fingers to other factors then themselves: service providers claim it is the lack of funds which limits the access to treatment, law enforcement officials say that it is the law that should be changed, while policy makers say there is no consensus in the society to change the law.

After the presentation of the findings, HCLU organized a round table discussion where service providers discussed the proposals with political decision makers and law enforcement officials. Here the representative of the Office of Prosecutor General repeated her position that needle exchange has to be considered a crime according to recent legislation. She said the parliament has the responsibility to create a new legislation to regulate harm reduction services. Other participants criticised this position because it derives from a false interpretation of the current Criminal Code. They said what is needed is not change in legislation but change in the attitudes of law enforcement officials. Katalin Felvinczi, the national drug coordinator of the government said that without social consensus the government can not be expected to decriminalize drug use. She called for more public dialogue and debate to change public attitudes. Opponents from HCLU emphasized that drug use needs to be addressed as a public health issue and that the government has to ensure that the human rights of drug users are not violated, even if this does not meet with public expectations. The organizers invited a guest speaker from the Open Society Institute, Mauro Guarinieri, who made an impressive presentation about the importance of user involvement in designing and maintaining services.

A number of different presentations were held at the plenary session with the following topics:

- Legal issues concerning harm reduction services;
- Media work;
- Challenges for harm reduction;
- Access to treatment;
- Efficacy of methadone maintenance;
- User involvement;
- Concepts of addiction.

Access to treatment and its legal and financial barriers were a central issue in almost all presentations. The role of drug legislation and law enforcement generated the most discussion at the meeting.

As far as the written outcome / product of the event is concerned, the proposals of the workshops and the results of the study were formulated in an official text which consists of the recommendations of the Hungarian Harm Reduction Association to policy makers and various other key stakeholders.

Below we present the recommendations that were partly based on the results of the study:

- There is a need to diversify programmes aiming at reducing risk and harms of drug use. It is also needed to extend these programmes to secure proper coverage.
- Agencies should aim at providing condoms, HIV/AIDS and HCV consulting in addition to providing needle exchange.
- Agencies should aim at assisting their clients in gaining free, anonym and easy access to tests regarding HIV, HAV, HBV, HCV and other blood-born and sexually transmitted diseases.
- In order to monitor the work of syringe exchange centres, the profile and the needs of their clients, there is a need to develop a standardised data collection system. This system should harmonize with the current concepts of EMCDDA's regarding data collection on low-threshold agencies.
- The Ministry of Health should initiate the popularisation of methadone maintenance programmes among general practitioners and doctors.
- The Ministry of Social Affairs and Labour, in cooperation with other ministries, should increase the current number of methadone maintenance centres in Hungary.
- The Ministry of Justice should secure the access to methadone maintenance programmes for opiate dependent users in prison.

There is no reliable data on the needs of methadone among the injecting population in the different regions of the country. There is also little reliable data on the number and extension of injecting drug users in the country.

The methadone black market is rather intensive in Hungary. The participants of the conference concluded that this phenomenon is mainly due to the fact that there is few maintenance programmes, and opiate dependents buy methadone to do their own self-therapy. General Practitioners and doctors do not know methadone maintenance therapy and they do not indicate it to their clients.

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4

Barriers to services for Moroccan drug users in Amsterdam

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4.1 Abstract

This article presents a survey carried out by foundation Mainline among Moroccan drug users in Amsterdam. The survey was carried out within the programme of the Correlation network, a network of organisations aiming at the social inclusion of marginalised persons in the European Union. The main goal of the survey is to find out what barriers Moroccan drug users encounter when they intend to enter different forms of (drug) care. Between October 2006 and February 2007, Mainline outreach workers interviewed 23 Moroccan drug users on their needs concerning health care and other services and on the accessibility of those services, using a questionnaire developed in co-operation with the Research Institute on Drugs Studies of the University of Budapest (RIDS). Respondents were found during outreach work, in drop-in centres, in drug consumption rooms, in the streets, in a hostel, in a methadone dispensary and in prison.

The outcomes of the survey give an insight in the reasons why Moroccan drug users are under-represented in Dutch drug treatment clinics. The main problem is not that respondents can't find their way to these clinics, although a minority of the respondents state they have never heard of detoxification or motivation clinics. This being remarkable in itself, the key message is that the Moroccan drug users of the sample are not interested in the help of drug treatment clinics. Most respondents stated either that they were not ready to quit drugs, or that they could kick the habit without professional help. It becomes evident that these drug users do not expect to receive the help they need from drug treatment clinics.

Some striking results from the survey are that 65,2% of respondents considers themselves homeless and 39,1% report having slept in the street during (part of) the thirty nights preceding the interview. At least 26,1% of the sample has passed time in prison during the past month. Furthermore, one of the three most popular income-generating strategies – after prison fees and together with stealing – is sex work.

At the time of the interview, fourteen respondents were still using at least one substance regularly; eight respondents were using two or more substances on a regular basis. In line with expectations cocaine is not only the drug most used by the sample, but also the drug that is used most frequently.

Blood testing is considered the easiest service to gain access to according to respondents. 78,3% of the sample has been tested on tuberculosis (TB) during the past five years. 69,6% has been tested on hepatitis B (HBV). On the other hand 56,5% of all respondents has not been tested for hepatitis C (HCV) during the past five years and 52,2% has not been tested for HIV. The survey shows that once respondents start testing, most of them have themselves tested regularly.

Noteworthy is that less than half of the respondents (43,5%) have made use of drug consumption rooms in the past three years, although these rooms are numerous in Amsterdam and should be easily accessible. Quite some respondents (13,6%) consulted a psychologist or a psychiatrist in the past three years, confirming the numerous 'problems in the head' they report to outreach workers.

The knowledge level of the sample of Moroccan drug users on infectious diseases appears to be rather low; 40,9% of respondents don't know how TB is transmitted, 68,2% don't know how HBV is transmitted and 68,2% don't know how HCV is transmitted. As a result most respondents don't know how to protect themselves against these infections. Moreover, some respondents fail to distinguish between the different infectious diseases.
As a follow up on the survey among Moroccan drug users, Mainline organised a debate with the name 'Couscous and coke'. An important part of the debate was dedicated to tackling the questions of how to communicate findings from the field and form an effective link between the target group and policymakers. Another vital issue for this day was how to translate theory into practice when working with clients that have a different (cultural) background. Prominent in their absence during the debate were both policymakers and members of the target group. Interesting as the day was, this absence is significant and shows that a lot still has to be done.

4.2 Introduction

Since many years, Dutch drug treatment institutions have signalled difficulties in attracting drug users of foreign origins. They tend to wait longer than Dutch drug users before seeking help and once they do ask for help, they often drop out of treatment before the end. In the Background Study of the National Drug Monitor of 2001 (Eland, A., Rigter, H.) possible reasons for not seeking help mentioned by Moroccan drug users in the cities of Amsterdam and Utrecht are:

- Insufficient knowledge of available help and how to reach drug treatment institutions;
- Dislike for certain types of therapy (e.g. group discussions);
- Language barriers;
- Taboo on drug use makes it difficult to ask for help outside the circle of close relatives.

Furthermore the study concludes that:

- Foreign drug users are underrepresented in ambulant group drug treatment;
- Foreign drug users have a relatively larger drop-out percentage;
- Foreign drug users seem to be underrepresented in intramural drug treatment.

A joint study by IVZ and IVO shows that between 1994 and 1998 the number of drop-outs among Dutch and foreign drug users decreased, except for Moroccan drug users; their drop-out rate increased with 13% between 1994 and 1998 (Vrieling, I., Alem, V.C.M. van, Mheen, H. van de). The reason for this is unclear.
The following article presents a survey carried out by foundation Mainline among Moroccan drug users in Amsterdam. The article starts with the objectives of the survey, followed by a description of the setting in which the survey took place. Subsequently the methods and the results of the survey are presented ending with the discussion and conclusions of the survey.

4.3 Objectives of the survey

The above mentioned signals give reason to wonder what makes Moroccan drug users in the Netherlands so hard to reach, compared to other sub-groups of drug users. In order to learn more about the under-representation in drug care institutions of Moroccan drug users, Mainline carried out a survey on this subject, asking the opinion of the Moroccan users themselves. This survey

was carried out within the programme of the Correlation network, a network of organisations aiming at the social inclusion of marginalised persons in the European Union. General concerns of the Correlation network are:

- Do various groups of marginalised people have access to the support they need?
- Do they have access to information, prevention materials, health and social care and support?
- Are they able to empower themselves and take over the steering wheel of their lives?

The aim of the network is not to gain scientific knowledge, but to provide relevant information for empowerment, to be used in the political debate. This Correlation research can be called a kind of satisfaction research. The fact that drug users are asked their opinion on services is in itself revolutionary. Focussing on Moroccan drug users even more so. This makes the current survey an important tool for empowerment of this specific group.
The main goal of the described survey is to find out what barriers Moroccan drug users encounter when they intend to enter different forms of (drug) care. Therefore, Mainline chose to focus on Moroccan drug users who have not completed treatment in a drug clinic during the twelve months preceding the interview.

4.4 Setting

Dutch situation[1]

The Netherlands has a population of approximately 16 million inhabitants. The number of problematic drug users is estimated at 33.500. This number has a rather large margin of uncertainty, varying from 24.000 to 46.000. Most drug users are poly-drug users, using opiates, (crack) cocaine, sedatives and alcohol, and have an average age of around 40 years old. Approximately 80% of these users are male, 20% are women.
It is estimated that 10% to 15% (2.400 to 6.900 persons) of the population of problematic drug users consume (crack) cocaine, without using heroin. When cocaine use is mentioned it concerns mainly the use of the ready-made so called ‘cooked cocaine’ or crack. Mostly the users smoke it from a small (metal) pipe. The euphoric effect is mind blowing but last only a few minutes. This makes it a substance that is very hard to control for many users. Problematic crack users tend to neglect themselves, not eating or sleeping for days and getting totally exhausted.
Since the mid-nineties, crack became the number one drug for problematic drug users in the Netherlands. Between 1994 and 2004 the demand for help of drug users with cocaine dependence as primal problem increased from 2.500 to 10.000. However, the exact number of problematic cocaine users is difficult to estimate. This is due to the fact that not all problematic users of crack are in sight of the drug care facilities, which is because these services have less to offer to them than to opiate users. Proper treatment for the group of problematic cocaine users has yet to be developed.
Apart from treatment services, there is a large range of low threshold services in the Netherlands, like drop-in centres, user rooms, night shelters and syringe & needle exchange programmes. In most cities combined services are developed with substitution maintenance treatment, a user room, drop-in, social and medical aid, night shelter and activity programmes under the same roof. Over the last years the implementation of outreach and assertive community treatment (ACT) teams has increased in order to reach drug users who don’t find their way to treatment services.

1 Source: National Drug Monitor 2005

This policy is inspired by the wish of the Dutch government to incorporate all problematic drug users into existing treatment services.

Amsterdam[2]

The capital of the Netherlands, Amsterdam, with a population of 727.000 inhabitants, counts around 5.100 problematic users of hard drugs of which 14% are injecting their drugs. From the total group of drug users approximately 2.000 are Dutch and around 1.350 are from Surinam, Antillean (mainly from Curaçao) and Moroccan descent; approximately 1.750 users are from other European countries (mainly Germany and Italy) The number of problematic drug users in Amsterdam is decreasing and the average age of the drug using population increases, from 26,8 years in 1981 to 39 in 1999. The share of drug users under 22 years decreased in the same period from 14,4% to 1,6%.

Crack is the number one drug for most problematic drug users in Amsterdam. It is estimated that 510 to 765 users (10% to 15% of the population of problematic drug users) consume crack without using heroin. Around 40% of all drug users in Amsterdam are in methadone treatment. Most of these drug users have been using for at least 20 years. The health problems they have are increasing in connection with their age. Apart from infectious diseases as HIV/AIDS, hepatitis C (HCV) and tuberculosis (TB), various lung diseases are diagnosed among these drug users.

4.5 Methods

Target group

The Mainline target group for the Correlation survey consists of Moroccan hard drug users in Amsterdam. Through outreach work activities, Mainline learned that nearly all these users are men. Most of them are between 30 and 45 years of age. Younger Moroccan users are difficult to contact, as they are constantly on the move and don't identify themselves as problem drug users (yet). Most Moroccan drug users have been in the Netherlands for quite a while and speak Dutch reasonably or well.

Almost all of these users smoke crack cocaine. Quite a number of them also smoke heroin or are in methadone programmes (or both). Thirdly tranquillizers are not unpopular in this target group. In general drug users who use opiates do not perceive opiate dependence as problematic. Crack on the other hand makes some of the users desperate, because they cannot control it.

Most Moroccan drug users that hang around in the street are homeless. They sleep in low threshold night shelters, at friends' houses or in squats. The main health problems are exhaustion, malnutrition, negligence and so-called self-reported 'problems in the head': psychological problems, varying from restlessness to severe depression. However, most Moroccan users mention as their most urgent problems the lack of a residence permit, which excludes them from almost everything in Dutch society (financial support, health insurance, substitution therapy, entrance to many shelters, etcetera), or when they do have a residence permit, homelessness, the lack of financial support, joblessness and therefore financial problems. Often these problems are so severe and attention consuming that talking about drugs and health seems not appropriate.

Both parties perceive contacts between Moroccan drug users and Dutch service providers as difficult. Older drug users are more used to Dutch service providers and their way of working than younger ones, but even they have problems staying in services, other than those with a low threshold.

The Moroccan drug users form an open group, not isolated or closed to others. But one can see

2 Source: Local Government, council policy 2006

they are more interlinked than other ethnicities (such as Dutch or Surinam drug users, who are more individualists).

Sampling

In the framework of the survey the target group was specified along the following criteria:

- At least 18 years old;
- Identifying oneself as Moroccan;
- Using either cocaine, heroin or methadone at least three times a week for the last three years;
- Not having completed any inpatient drug treatment in the last twelve months;
- In case of detention, the respondent should be detained since no more than six months.

The sample of respondents consisted of 23 Moroccan drug users meeting the above-mentioned criteria. Outreach workers had to establish contact with approximately four drug users in order to complete one interview. Besides, it could take as many as three attempts before an interview could really take place. These are the main reasons for the relatively low number of respondents; within the time available it was not possible to complete more interviews. One of the 23 respondents did not complete the interview.

Research tool

The survey was performed using a questionnaire that was used in face-to-face conversations by Mainline outreach workers. The questionnaire was developed by Mainline and the Research Institute on Drugs Studies of the University of Budapest (RIDS). Most interviews lasted between 30 and 60 minutes, with some exceptions varying from 10 to 105 minutes.

Data collection

The interviews took place from October 2006 to February 2007. Respondents were found during outreach work in drop-in centres, drug consumption rooms, in the streets, in a hostel, methadone dispensary and in prison. In most cases, the outreach worker initiated a conversation with the drug user; sometimes contact was established by a social worker, or by the respondent himself.

After the interview respondents received remuneration, consisting of a set of self-control playing cards and a small box containing a lighter, a condom, plasters and filters for crack pipes.

4.6 Results

Socio-demographic background

All respondents in the sample are male. Respondents are between 20 and 57 years old; the medium age is 40,4 years.

Respondents came to the Netherlands between 1956 and 1994. None of them is born in the Netherlands.

Thirteen respondents (56,5%) have an elementary education or less, seven (30,4%) completed an intermediate vocational education, two (8,7%) finished secondary school and one respondent (4,3%) completed higher education.

Nearly all respondents have some (legal) documents; an identity card, a residence permit or a passport. Two respondents (8,7%) had no documents at all at the time of the interview; one of them lost his, the other one is an undocumented immigrant.

Only four respondents (17,4%) of our sample mention their own house as a place where they

spent (part of) the last thirty nights before the interview. The place mentioned most often (by ten respondents; 43,5%) is a friend's house, which is twice as often as a relative's house (five respondents or 21,7%). Not less than nine respondents (39,1%) report having slept in the street during the latest thirty nights.
Fifteen respondents (65,2%) consider themselves homeless, seven (30,4%) don't. One respondent did not answer this question. All respondents who consider themselves homeless do so for more than a year, and nine respondents report being homeless for five years or more.
The most reported income resource in the past thirty days is 'prison fee' (26,1%), showing that at least six respondents have passed time in prison during the past month. The second most popular income generating strategies over the past thirty days were sex work and stealing (17,39%). Eighteen respondents (78,3%) mentioned more than one resource type. Eleven respondents (47,8%) mentioned 'other' resource types. These included 'taking clients to drug dealers' (5), 'guiding tourists' (2), 'hustling' (2), 'advance payments of my social welfare benefit' (1) and 'performance artist in the streets' (1). A total of ten respondents (43,5%) obtained (part of) their income through drug trade during the thirty days preceding the interview.

Drug use

Age at first use	Average	Nº.	N.A.
Cocaine	24.1	22	1
Heroin	25.4	19	4
Methadone	30.6	15	8
Alcohol	17.8	20	3
Tranquilizers	25.8	9	14

Age at starting regular use	Average	Nº.	N.A.
Cocaine	25.2	22	1
Heroin	26	18	5
Methadone	31.6	13	11
Alcohol	20.2	16	7
Tranquilizers	24.8	5	18

The survey reveals that respondents started their 'career' with alcohol, at the age of 18. The first use of cocaine was at 24 years. Methadone use started at the age of 30. Thirteen respondents never used tranquilizers (one interview was ended before reaching this question). For respondents using cocaine, heroin, methadone and tranquilizers, regular use began shortly (within one year) after the first use. The time span between first and regular use of alcohol was fairly larger (2,5 years).

Age at ending regular use	Average	Nº.	N.A.
Cocaine	40	13	10
Heroin	42.5	9	14
Methadone	41.4	10	13
Alcohol	34.2	11	12
Tranquilizers	35.5	2	21

At the time of the interview, fourteen respondents (60,9%) were still using at least one substance regularly; six (26,1%) respondents were still using alcohol, tranquilizers, cocaine or heroin on a regular basis, while eight respondents (34,8%) were using two or more substances on a regular basis. Respondents who ended their regular use, did so at the beginning of their 40s in the case of cocaine, heroin and methadone, while their regular use of alcohol ended in their mid 30s.

Respondents had the shortest career with methadone (ten years); use of alcohol (fourteen years), cocaine (fifteen years) and heroin (sixteen years) lasted longer.

Nº. of days substance used in the past thirty days	Average	Nº.	None	N.A.
Cocaine	23.8	15	7	1
Heroin	21	14	8	1
Methadone	19.2	12	10	1
Alcohol	13.3	13	9	1
Tranquilizers	21.6	3	19	1

Leaving aside the respondents who hadn't used the substance asked for at all ('none'), it becomes clear that cocaine is the drug most frequently used, followed by heroin and methadone. Tranquilizers are used more often than heroin and methadone, but only three respondents used them during the past thirty days. No one in the sample had injected any of the drugs in the past thirty days. In fact, all respondents stated they had never injected drugs in their lives.

Substance use in the past 48 hours	Yes	No	N.A.
Cocaine	10	11	2
Heroin	11	10	2
Methadone	8	14	1
Alcohol	8	14	1
Tranquilizers	2	20	1

Cocaine and heroin were the most frequently used substances in the past 48 hours, followed by alcohol and methadone. Only two respondents used tranquilizers.

Health status

Nº. of times tested in past five years	TB	HBV	HCV	HIV
None	5	7	13	12
Once	2	7	4	4
Twice	1	2	1	2
More than twice	15	7	5	5
Total	**23**	**23**	**23**	**23**

Eighteen respondents (78,3%) have been tested on tuberculosis (TB) during the past five years. Seven respondents (30,4%) report to be tested ten times on TB over the past five years, which comes down to two tests a year. Sixteen respondents (69,6%) have been tested on hepatitis B (HBV). On the other hand thirteen respondents (56,5%) have not been tested for hepatitis C (HCV) during the past five years and twelve (52,2%) have not been tested for HIV. Three respondents (13,0%) report having been tested on sexually transmitted infections (STIs) during the past five years.

Latest test in	TB	HBV	HCV	HIV
2007*	1	0	0	1
2006	14	10	6	6
Before 2006	2	5	3	4
Don't know	1	1	1	0
Total	**18**	**16**	**10**	**11**

** As stated earlier, interviews took place between October 2006 and February 2007, accounting for the low number of people tested in this year.*

Of those respondents tested, most had their latest test in 2006; 83,3% of the respondents who tested on TB did so within the past year. For HBV this is 62,5%, for HCV 60% and for HIV 63,6%. All three respondents who reported being tested on STIs, had their test in 2006.

Result of latest test	**TB**	**HBV**	**HCV**	**HIV**
Positive	1	1	1	1
Negative	16	14	8	9
Don't know / no answer	1	1	1	1
Total	**18**	**16**	**10**	**11**

For each infection one respondent reported a positive testing result. One respondent refrained from answering this question. The three respondents who have been tested on STIs all reported a negative testing result.

Treatment / service history

Who do you ask for help*	**Relatives / friends**	**Institutions**	**Other**
When you are out of money	14	3	12
When you have no place to sleep	14	4	10
When you are out of food	3	19	2
In case of drugs-related health problems	1	12	7
In case of general health problems	0	23	1

* *More than one answer was possible for this question.*

When they need money or a place to sleep, the Moroccan drug users in the sample prefer to turn to their relatives, friends or partner. In the category 'other' respondents answered 'nobody', 'I don't have this problem' or mentioned they turn to God. In the case of money, they reported they would 'make money' by begging or hustling.
When respondents are in need of a meal, they mainly ask for help at drop-in centres. This can be a drop-in centre for homeless people or one attached to a low threshold drug service, such as a drug consumption room.
With both drug related and general health problems respondents most of the time turn to institutions for help. The institutions mentioned by respondents are the emergency department of a hospital, municipal health services, a general practitioner or *Médecins du Monde*, an organisation offering medical help to people that cannot access other medical services.

Services used in the past three years	**Yes**	**No**	**No answer**
Meal distribution	20	2	1
Day shelter	19	3	1
Social work	16	6	1
Social welfare	15	6	2
General hospital	14	8	1
Night shelter	13	9	1
General practitioner	13	9	1
Consumption room	10	12	1
Paid day activity	10	12	1

Substitution treatment	10	12	1
Income assistance	10	12	1
Juridical assistance	7	15	1
Housing assistance	6	16	1
Social hostel	5	17	1
Psychologist	3	19	1
Psychiatrist	3	19	1
Drug treatment clinic	2	20	1
Self help group	2	20	1

Almost all respondents have on occasion made use of meal distribution (90,9%) or day shelters (86,4%) during the past three years. Ten respondents (43,5%) have made use of drug consumption rooms in the past three years. Drug treatment clinics and self help groups were used the least (9,1%) by this sample.

Perceived needs and barriers

Services used in the past twelve months*	**Didn't look for help**	**Looked for help; didn't receive it**	**Looked for help and received it**
Detoxification clinic	22	0	0
Motivation clinic	21	0	1
Rehabilitation clinic	21	1	0
Substitution treatment	12	1	9
General practitioner	10	1	11
Blood testing	9	0	13
Mental health treatment	17	2	3
Social counselling	5	3	14

** One respondent had disrupted the interview before reaching this question, which makes the sample size 22.*

Respondents were selected on not having completed any drug treatment during the past 12 months. Results show that most respondents didn't even look for such treatment. None of the respondents sought for help of a detoxification clinic in the year preceding the interview. The main reason (31,8%) for this is that respondents state they can quit drugs without the help of a clinic, if they wish to. Other reasons mentioned are that respondents don't know this type of clinic (18,2%) and that they quit before, but started using drugs again (18,2%).

One respondent entered a motivation clinic[3] in the past year, but he left when he found out that he was not allowed to quit drugs gradually. The other 21 respondents didn't look for help in a motivation clinic, again mainly because they claim to be able to quit drugs without help of a clinic, when they want that (33,3%). Other important reasons for not turning to this type of clinic are because 'they can't offer the help I need' (19,0%) and because 'I'm not ready for it yet' (19,0%).

At the time of the interview, one respondent was in the process of entering a rehabilitation clinic. However, his appointment was cancelled by the clinic and no date was established yet for a new

3 Motivation clinics are places where drug users are motivated and prepared for drug treatment. The main goal of these clinics is to reduce nuisance caused by drug users in the street.

appointment. Of the other 21 respondents, seven (33,3%) answered they can quit drugs without help of a clinic. Eight respondents (38,1%) said they were not ready to quit at the time of the interview.

When it comes to substitution treatment, nine respondents (40,9%) say they are on methadone treatment and all of them are quite satisfied about this service. One respondent (4,5%) didn't receive the help he asked for, because he doesn't have a residence permit. However, twelve respondents (54,5%) don't want methadone, mainly because they don't want to have another addiction (22,7%) or they don't want to depend on drug care institutions (9,1%).

Eleven respondents (50%) consulted a general practitioner (GP) in the past twelve months. Seven of them were very satisfied, two were quite satisfied and two respondents were not satisfied; one said the GP had prejudices towards drug users, the other one said the GP wanted him to quit drugs. Ten respondents (45,5%) didn't look for help from a GP. Three of them said there was no need to visit a GP; three respondents do not have a health insurance. One respondent (4,5%) is actually looking for a GP at the time of the interview.

Thirteen respondents (59,1%) participated in some sort of blood testing (mostly for hepatitis B) in the past year. Six of them were very satisfied about this service, six were quite satisfied and one respondent valued the service neutrally. Of the nine respondents (40,9%) who didn't ask for blood testing, three said they don't need it, because they are sure they are healthy.

Five respondents (22,7%) looked for mental health treatment during the past year. Two of them didn't receive this treatment (yet); one respondent was referred elsewhere and didn't go yet, one respondent was refused treatment because of his drug use. Of the three respondents who did receive treatment, two were very satisfied; one was quite satisfied. Seventeen respondents (77,3%) said they didn't look for this type of help, most of them (14) because they don't need it.

Fourteen respondents (63,6%) used social counselling in the past year. Five of them were very satisfied, five were quite satisfied, three were neutral about this service and one respondent was not satisfied; he said the social worker wanted him to enter treatment in which he had to quit drugs, take methadone and live in the premises of the organisation offering the social counselling. Three respondents (13,6%) tried to access social counselling services but didn't succeed; one respondent said it was because of his addiction, one respondent didn't go to his second appointment and one is still looking for help. Of the five respondents (22,7%) who didn't look for social counselling, four said they don't need it. The other respondent doesn't know whom to turn to for this kind of help.

How difficult is it to get into the following services?*	**Average**	**Number**	**Don't know**
Detoxification clinic	3,6	9	13
Motivation clinic	3,3	9	13
Rehabilitation clinic	3,3	15	7
Mental health	3,3	8	14
General practitioner	2,4	22	0
Social advice	2,1	21	1
Substitution treatment	1,9	16	6
Blood testing	1,9	21	1

** 1 = very easy, 5 = very difficult*

Blood testing is considered the easiest service to gain access to according to our sample. On the other hand respondents find it slightly difficult to access the various types of drug clinics. Respondents mentioned waiting lists as an obstacle to entering these services.

Knowledge about health issues

Mainline, being an organisation focussing on health education, considers it important to learn what respondents know about infectious diseases. Therefore a number of questions were included on (prevention of) transmission of these infections4.

Tuberculosis (TB)

To the question "Can you tell me how tuberculosis (TB) is transmitted?[5]" nine respondents (40,9%) answered they didn't know. Eight respondents answered TB is transmitted through coughing, seven think TB is (also) transmitted by sharing crack pipes and six respondents answered TB is transmitted through infected people's breath. Four respondents think TB is transmitted through sputum, the same number thinks it is transmitted by blood and two respondents think the infection is transmitted through unprotected sex.

To the question "How can people protect themselves against TB?" ten respondents (45,5%) answered they didn't know. Six respondents answered sharing crack pipes should be avoided, three respondents advised 'covering your mouth'. Two respondents think vaccination against TB exists.

Asking respondents how they protect themselves against TB, eleven (50%) answered they don't know. Seven respondents say they don't share their crack pipe; three have check-ups twice a year.

Hepatitis B (HBV)

Fifteen respondents (68,2%) answered the question "Can you tell me how hepatitis B (HBV) is transmitted" negatively. The seven respondents, who did have an answer, said HBV is transmitted by unprotected sexual contact (5) and by blood (3). Two respondents also mentioned sharing crack pipes as a possible route of transmission.

Sixteen respondents (72,7%) said they don't know how one can protect oneself against HBV. Three respondents named using condoms as a protection against HBV; two respondents named using your own gear while taking drugs. One respondent named the HBV-vaccination as a possible protection.

To the question "How do you protect yourself against HBV?" fifteen respondents (68,2%) said they don't know. Three respondents said they are vaccinated against HBV and three said they always practice safe sex.

Hepatitis C (HCV)

Fifteen respondents (68,2%) could not tell how hepatitis C (HCV) is transmitted. Four respondents mentioned blood-to-blood contact as a route of transmission; two respondents mentioned unprotected sex.

Sixteen respondents (72,7%) said they don't know how one can protect oneself against HCV. Of those who did answer, two respondents said using clean needles & syringes helps prevent HCV and the same number mentioned not sharing smoking utensils as prevention strategy. Two respondents also mentioned practicing safe sex as prevention against HCV. One respondent answered that not staying in a confined space with others prevents transmission of HCV.

On the question "How do you protect yourself against HCV?" eighteen respondents (81,2%)

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4 To all questions of this section, more than one answer was possible.

5 This and the following two questions concern so-called 'open' lung tuberculosis in the Dutch context, where daily two of such cases are discovered. It is not about other forms of tuberculosis, because these hardly exist in the Netherlands.

answered they don't know. Three respondents said they always practice safe sex; two answered by 'being careful'. None of the respondents mentioned any protective measure to avoid blood-to-blood contact.

4.7 Discussion

The Mainline target group for the Correlation survey consists of Moroccan hard drug users in Amsterdam. In the sample of 23[6], all respondents are male. Their medium age is 40,4 years, which corresponds with the larger target group. Also consistent with the general image of the target group are the relatively high rate of homelessness (65,2% in the sample) and the fact that all respondents came to the Netherlands more than 10 years ago.
Ten respondents (43,5%) reported having spent (part of) the past thirty nights in a friend's house. Again, this coincides with the image of the larger target group. A striking result is that not less than nine respondents (39,1%) report having slept in the street during the latest thirty nights. At least six respondents (26,1%) have passed time in prison during the past month.
Respondents appear to use a wide range of income generating strategies, varying from formal to informal and illegal strategies. One of the three most popular income-generating strategies – after prison fees and together with stealing – is sex work.
This is noteworthy because Mainline outreach workers hardly ever heard of (the relatively older) Moroccan drug users earning money with sex work. A total of ten respondents (43,5%) obtained (part of) their income in drug trade during the thirty days preceding the interview.
In line with expectations cocaine is not only the drug most used, but also the drug that is used most frequently; fifteen respondents (65,2%) stated they had used cocaine on an average of approximately 24 of the thirty days preceding the interview. Heroin takes a second place with fourteen respondents (60,9%) having used this drug on averagely 21 of 30 days preceding the interview. Three respondents (13,0%) report use of tranquilizers during the past thirty days. All respondents state they have never injected drugs.
The first use of cocaine was at 24. Regular use of cocaine, heroin, methadone and tranquilizers all began within one year after the first use. At the time of the interview fourteen respondents (60,9%) were still using at least one substance regularly; eight respondents (34,8%) were using two or more substances on a regular basis[7]. Respondents who ended their regular cocaine, heroin or methadone use, did so at the beginning of their 40s.
Respondents, who take blood tests, mainly do so for TB testing (78,3%). Seven respondents (30,4%) actually report to be tested ten times, which comes down to two tests a year. The municipal health services oblige drug users receiving methadone to participate in TB testing twice a year, which explains this relatively high number. The second most used blood test among respondents is the test on HBV (69,6%). For this result there is also a logical explanation; municipal health services have put a lot of effort in reaching as many drug users as possible for HBV testing – and vaccinating – and have called upon Mainline to motivate the group of drug users that is hardest to reach. For hepatitis C (HCV) and HIV testing these types of obligations or

6 One respondent did not complete the whole interview; therefore the sample consisted of 22 for some of the questions.

7 It is generally known that people tend to trivialise their substance use. This is not expected to be different for our sample of Moroccan drug users. Therefore this number should be considered as a minimum.

motivational efforts don't exist[8], which shows in the relatively high numbers of respondents who have never tested on those infections.
Of those respondents tested on TB, 83,3% had their test within the past year. For HBV this is 62,5%, for HCV 60% and for HIV 63,6%. For so-called 'risk groups' it is advised to test at least once or twice a year for the above mentioned infections. The survey shows that once respondents start testing, most of them have themselves tested regularly.
When they need money or a place to sleep, the Moroccan drug users in the sample prefer to turn to their relatives, friends or partners. When respondents are in need of a meal, they mainly ask for help at drop-in centres. This can be a drop-in centre for homeless people or one attached to a low threshold drug service, such as a drug consumption room. With both drug related and general health problems, respondents generally turn to the emergency department of a hospital, municipal health services, a general practitioner or *Médecins du Monde*.
Almost all respondents have on occasion made use of meal distribution or day shelters during the past three years. Many respondents also find their way to social workers, social welfare benefits, general hospitals, night shelters and general practitioners. Strikingly, less than half of the respondents (43,5%) have made use of drug consumption rooms in the past three years, although these rooms are numerous in Amsterdam and are (or at least should be) easily accessible.
Quite some respondents consulted psychologists (13,6%) and psychiatrists (13,6%) in the past three years, confirming the numerous 'problems in the head' they report to outreach workers.
When asked for the needs of respondents for services and the barriers impeding them to use these services, respondents provide a clue for their under-representation in drug treatment clinics. The main reason they don't look for help of these clinics is because they are convinced they can quit drugs without the help of a clinic, if they want to. When it comes to substitution treatment, nine respondents (40,9%) say they are on methadone treatment and all of them are quite satisfied about this service.
Eleven respondents (50%) consulted a general practitioner (GP) in the past twelve months. Two respondents were not satisfied; one said the GP had prejudices towards drug users, the other one said the GP wanted him to quit drugs. Ten respondents didn't look for help from a GP. Three of them said this is because they do not have a health insurance.
Five respondents (22,7%) mention they looked for mental health treatment during the past year; three of them also received treatment. Fifteen respondents (68,2%) said they didn't look for this type of help, because they don't need it.
The service most used by the sample of respondents is social counselling. Fourteen respondents (63,6%) used this service in the past year. Five of them were very satisfied, five were quite satisfied, three were neutral about this service and one respondent was not satisfied. Three respondents (13,6%) tried to access social counselling services but didn't succeed; one respondent doesn't know whom to turn to for this kind of help.
The knowledge level on infectious diseases appears to be rather low among the sample of the survey; 40,9% of respondents don't know how TB is transmitted, 68,2% don't know how HBV is transmitted and 68,2% don't know how HCV is transmitted. As a result most respondents don't know how to protect themselves against these infections. Moreover, at least some respondents fail to distinguish between the different infectious diseases.

8 The municipal health services asked Mainline to participate in a new HCV testing project, which was to start in January 2008. Due to lack of funds the project has not started yet.

4.8 Conclusions

The main goal of the current survey is to find out what barriers Moroccan drug users encounter when they intend to enter different forms of (drug) care. In a period of five months, 23 Moroccan drug users have been interviewed on their needs concerning health care and other services and the accessibility of those services. The results show that some services are well used by this group, while others are either hard to access, or of no interest to them, for a variety of reasons.
General practitioners and substitution treatment are described as being reasonably accessible. Thanks to the efforts of the municipal health services and their partners, TB and HBV tests are easily accessible for drug users. HCV testing is less used by the sample of this survey, but that might change in 2008, if the municipal health service and Mainline start their project on this issue. For HIV testing several incentives have been developed in the past, but it is clear that they have not reached many Moroccan drug users; less than half of the sample was tested on HIV in the five years preceding the interview. It might be wise to rethink current HIV testing programmes. On the other hand, once drug users have found their way to testing facilities, the return rate for repeated testing is quite high; up till 83,3% for TB testing.
Although respondents state they prefer to turn to relatives, friends or partners when they need a place to sleep, most of them also find their way to night shelters. Social welfare benefits are harder to obtain. The main problem for those not accessing this service seems to be the lack of proper documents. Many respondents have used meal distribution services during the past three years, either in homeless day shelters, or in drop-in centres attached to drug services. On the other hand, the so-called 'low threshold' drug consumption rooms in Amsterdam only attract 43,5% of the respondents of the sample, even though some of them are in the same building as the day shelters where the Moroccan drug users are found. Plausible reasons for this are that Moroccan drug users don't want to expose themselves too openly as drug users, or that they don't want to be among other people who are using drugs. Fact is that drug users with Dutch or Surinamese origins mainly populate drug consumption rooms in Amsterdam[9].
When faced with drug related or general health problems, a just majority of respondents find their way to one of the health care institutions in the city. When going to hospital however, some respondents state turning to the emergency department, which may indicate they have no other place to go to or they wait too long before searching medical help. This assumption is supported by the fact that a few respondents mention the organisation *Médecins du Monde*[10] as the service they use when facing health problems. It may be clear that (public) health institutions do not function as low threshold services. It is important however that those in need of medical help receive this. The results of this research give rise to doubts concerning the accessibility of these institutions. Besides, some respondents reported their drug use caused their general practitioners to treat them in an unsatisfactory way.
The outcomes of the survey give an insight in the reasons why Moroccan drug users are under-represented in Dutch drug treatment clinics. The main problem is not that respondents can't find their way to these clinics, although a minority of the respondents state they have never heard of detoxification or motivation clinics. This being remarkable in itself, the key message is that the

9 Except from one drug consumption room focusing specifically on European drug users. Apart from many German and Italian users, more and more users originating from Central and Eastern European countries are found here.

10 As stated before this organisation offers medical help to people who have no access to medical services elsewhere.

Moroccan drug users of the sample are not interested in the help of drug treatment clinics. Most respondents stated either that they were not ready to quit drugs, or that they could kick the habit without professional help. It becomes evident that these drug users do not expect to receive the help they need from drug treatment clinics. This poses a challenge, on the one hand because they have problems that are connected with their drug use, and therefore could use help if it was tailored for them. On the other hand, drug treatment clinics have a lot to offer, but don't know how to reach these drug users or how to prevent dropout once they are in treatment.
Over the past two years, Mainline has carried out a project in which outreach workers paid special attention to reaching Moroccan drug users[11]. The most important lesson learned from this project was that outreach work among Moroccan drug users is a matter of longstanding presence in the scene and establishing relations of trust – just like outreach work among other groups of drug users. It follows that drug treatment clinics could be more successful in reaching and treating Moroccan drug users, if they invest more time and efforts in reaching and understanding this group, that will not ask for help spontaneously. This research does not pretend to provide a clear-cut answer on the question how to reduce the under-representation of Moroccan drug users in drug treatment clinics and it certainly takes more than just time to be successful. But one thing that has become clear from this survey is that Moroccan drug users can be reached, when attention is paid to personal contact, trustful relationships and tailored care[12].
However, this survey also reveals that the work of Mainline is far from being finished. Thanks to the previously mentioned project ***Echt Contact***, Mainline outreach workers reach the group of Moroccan drug users now. But that's only the first step. Results show that most Moroccan drug users have little or no knowledge on infectious diseases and on how to protect themselves from being infected. Mainline considers it its task to pass and repeat the messages of health education to this group of drug users until they have the knowledge needed to protect their health.

4.9 Policy debate

One of the major goals of the Correlation policy stream is to distribute findings from grassroots organisations to policymakers. With this aim, Mainline has organised a debate with the name '***Couscous and coke***' as a follow up on the survey among Moroccan drug users. An important part of this debate was dedicated to tackling the questions of how to communicate findings from the field and thus form an effective link between the target group and policymakers. Another important issue for this day was how to translate theory into practice when working with clients that have a different (cultural) background.
A large part of the morning was filled by an interesting and animated round table discussion on the question of tailored care. Participants agreed that tailored care is an important policy issue for drug services. Unclear however is how tailored care should be designed. The round table panel mainly existed of professionals working in the field and the discussion focussed on very practical solutions; multi-cultural expertise teams, intercultural brokering, outreach work, peer education and working together with the target group and its surroundings (relatives of clients)

11 This project that started in 2005, is called '***Echt Contact***' (real contact) and aims to improve contact between Mainline and Moroccan drug users, in order to provide them with information on health and drugs.

12 Taking into consideration the variety of problems of this specific group, it could be necessary to offer integrated services, addressing medical, social, housing, financial and other problems. However, this discussion is outside the scope of this article.

were mentioned as important building stones of tailored care for Moroccan drug users. It was stressed that working on a relationship of trust is very important for success and that service providers have to actively reach for members of the target group.
Other issues that were addressed during this round table discussion were the gap between service providers and policymakers and the emphasis on results on the side of policymakers and donors. The importance of convincing policymakers and politicians was stressed and the moderator, local councillor in Amsterdam, encouraged all those present to actively engage in setting the agenda on the level of institute management as well as on the level of local and national politics.
The morning was concluded by an interesting presentation on the intercultural paradox. The presentation gave an extensive argumentation on why cultural differences are not the right starting point for dealing with cultural minorities and proposed a new attitude towards culture in which humanity, justice and creativity are more important than power.
During the afternoon three workshops covered a range of themes connected with the survey and its outcomes. One workshop was dedicated to lobbying: how can relatively small (grassroots) organisations, that are closest to the target groups, make effective use of their findings? In the workshop, three different ways of lobbying were presented, targeting the public, the political or the policy agenda. The workshop presented the need for a lobby plan for organisations that decide to start lobby activities as well as the importance of coalitions.
The second workshop focussed on various aspects of working with different cultures in a clinical setting. Attention was paid to differences is perceptions of drug users and service providers and some models to explain these perceptions were presented. The outcomes of the Mainline survey were discussed in the third workshop.
Striking in their absence were policymakers and members of the target group; of both groups there was only one representative. Interesting as the day was, this absence is significant and shows us a lot still has to be done in order to create a true debate between the two groups and to guarantee a meaningful exchange that is interesting for both parts.

4.10 References

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5

Treatment of drug dependencies in Bulgaria: Survey on the treatment demand and barriers to access among problem drug users in Bulgaria

Atanas Rusev

5.1 Introduction

During the last years in Bulgaria, the subject of drug use holds the spotlight of the common public attention. Unfortunately, mainly the criminal aspect of the phenomenon rouses the media interest, and the actual problems connected with provision of treatment for the drug dependents fall behind in the background. At the same time experts ever more frequently signal about the deficiency of options and alternatives for treatment, which could be accessed by the group. Assessment shows that there are between 20,000 and 30,000[13] heroin-dependents, whereas there are 1,605 places in methadone programmes, 641 places for hospitalisation, 75 in rehabilitation facilities, and 50 - in different therapeutic communities[14], which makes it obvious that this is far from enough.

In February 2003, the Council of Ministers of the Republic of Bulgaria adopted the National Anti-Drug Strategy, and in April, 2003 – the Action Plan for the implementation of this strategy. The measures underlying both of these documents provide for the elaboration of a system of easily accessible, efficient and varied treatment and rehabilitation programmes for people using drugs. Unfortunately, although existent, this adequate legislative framework does not contribute to a sufficient degree to achieve the goals and tasks traced out, due to the fact that financing for these measures is lacking. For example, there have been six new programmes open for substitution and supporting treatment in total in Bulgaria, where four of them are private and located in Sofia, and only two outside the capital. One of the treatment methods, which have proved effective for drug dependencies, is the residential treatment method (e.g. therapeutic communities). But in Bulgaria only two of these are in function, with a total capacity of 50 people. This is only a small example of how good ideas often remain simply good intentions, without turning into actual policies and actions.

Against the background of deficiency of the state institutions, during the last two years there has been an increase of newly discovered HIV-positive persons within the intravenous drug addicts group. The statistics compiled under the Programme for Prevention and Control of HIV/AIDS of the Ministry of Health account for 13 newly found HIV-positive persons within this group for 2005, 32 new cases for 2006, whereas for the first seven months of 2007 only, new cases of HIV are 13. Along with that, according to information submitted by the National Focal Point on Drugs and Drug Addictions, the drug use connected mortality rate has tripled for the 2002 – 2005 period (from 13 death cases in 2002 to some 40 in 2005).

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13 NFPDDA (2006). Annual report of drug and drug dependencies related problems in Bulgaria.

14 Raycheva, Tsveta (2007). Treatment of drug dependencies in Bulgaria. Presentation at the PUBLIC DEBATE ON: "TREATMENTOF DRUG DEPENDENCIES – POSSIBILITIES AND PROBLEMS", 26.06.07

All these worrying facts and tendencies urged the Initiative for Health Foundation to conduct a major survey as to what the ways are to treat drug dependencies and respectively the barriers obstructing the access to treatment among problem drug users. The survey was conducted within the framework of the European Correlation project, "European network for social inclusion and health". The very survey took place with the methodological support of RIDS, the Research Institute on Drug Studies at the ELTE University in Budapest and the National Focal Point on Drugs and Drug Addictions, as well as with the kind financial support of the National Centre for Addictions. As partners and subcontractors, this survey included another seven Bulgarian non-governmental organizations, working in the area of harm reduction – "Bulgarian Red Cross – Ruse" (Ruse), "Panacea" Foundation (Plovdiv), "IGA" regional Fund (Pazardzhik), "Bulgarian Red Cross – Kyustendil" (Kyustendil), "Better Mental Health" Foundation (Varna), "Dose of love" Association (Burgas), "Alternatives" Association (Blagoevgrad).

5.2 Objectives, design and methodology of the survey

This survey aiming to identify means of treatment of drug dependencies and the barriers obstructing the access among problem drug users initially set forward two main goals:

- To assess the level of interest towards treatment of drug dependencies among the problem drugs users in Bulgaria;
- To assess which the main barriers are obstructing the access to treatment of such dependencies of problem drug users in Bulgaria.

By 'barriers' here we mean 'the reasons that could prevent drug users from searching or availing of drug dependencies treatment", i.e. the obstacles as the very drug users see them.

As a data collecting method, we used the standard interview with respondents (face-to-face). For the purposes of the survey also a questionnaire was used, elaborated by the RIDS Institute, which was later on edited, supplemented and adapted for the Bulgarian situation with the expertise and support of the National Focal Point on Drugs and Drug Addictions. The questionnaire is a compilation of 46 questions grouped into four sections – "Social and demographic characteristics", "Use of psychoactive drugs", "History of treatment and the need for treatment", and "Communication with various institutions and organizations".

When determining the target group of this survey, as a benchmark the EMCDDA definition for problem drug user was used: *persons who inject themselves with heroin and/or drugs, or have used those in a way, other than self-administered injection, but on a regular basis during the last three years, at least ten times during the last year and at least three times during the last month.*

5.3 Results of the survey

A total number of 893 people were interviewed – problem drug users, in eight Bulgarian cities (see Table 1). The clients of harm reduction programmes were used as recruiting basis. The formulation of the sample was performed by means of quotas, where the quotas were formed based on an expert assessment for each client who has had access to the programmes. Of the 1100 initially planned respondents, 893 were actually questioned. When selecting the interviewees, we strictly respected the anonymity principle. This is why all participants were registered only via a personal, seven-digit identification code, by means of which they take part in the programmes for

exchange of needles and syringes. This code encrypts the sex of the respondent, the first letter of the name, the first letter of a parent's name and the date and the month of birth. This code is used in the said programmes for the purposes of traceability of the respondent's everyday on-site contacts. The interviewers were social workers engaged under these programmes for exchange of needles and syringes, because the survey relates to specific task, such as history of drug use, risk behaviour, interest for different types of treatments of drug dependencies. These are all issues, requiring specific skills, a regular interviewer may not have.

Table 1. Distribution of respondents according to city of residence

City	Initially planned respondents	Interviewees	Per cent of the sample
Sofia	300	188	21,1 %
Ruse	100	69	7,7 %
Plovdiv	200	121	13,5 %
Pazardzhik	50	47	5,3 %
Kyustendil	50	73	8,2 %
Varna	200	196	21,9 %
Burgas	100	99	11,1 %
Blagoevgrad	100	100	11,2 %
Total	***1100***	***893***	***100 %***

Demographic, social and economic characteristics of problem drug users

Traditionally, surveys within the group of problem drug users face difficulties to cover the entire group; therefore, we can hardly speak of representative results. The lack of accuracy of the assessment of the size and the characteristics of the group is a main hurdle before formulating a statistically valid representative sample. Nevertheless, during the last few years, enough data have been accumulated from surveys conducted at a national level, which allow for an average estimation to be made of the demographic and the socio-economic profile of the group[15]. The data compiled under this survey, conducted in eight large and medium-size Bulgarian cities, to a great extent confirm this profile, while simultaneously they provide for the capturing of some new tendencies within this group.

Firstly, the comparison according to sex confirms the 1:4 proportion in favour of men using drugs. The stability of this distribution is clearly traceable if we compare these results with the results from two previous subsequent surveys conducted by the Initiative for Health Foundation in the years 2003 and 2005 (see Table 2). These data once again confirm the cultural grounds of the said specifics.

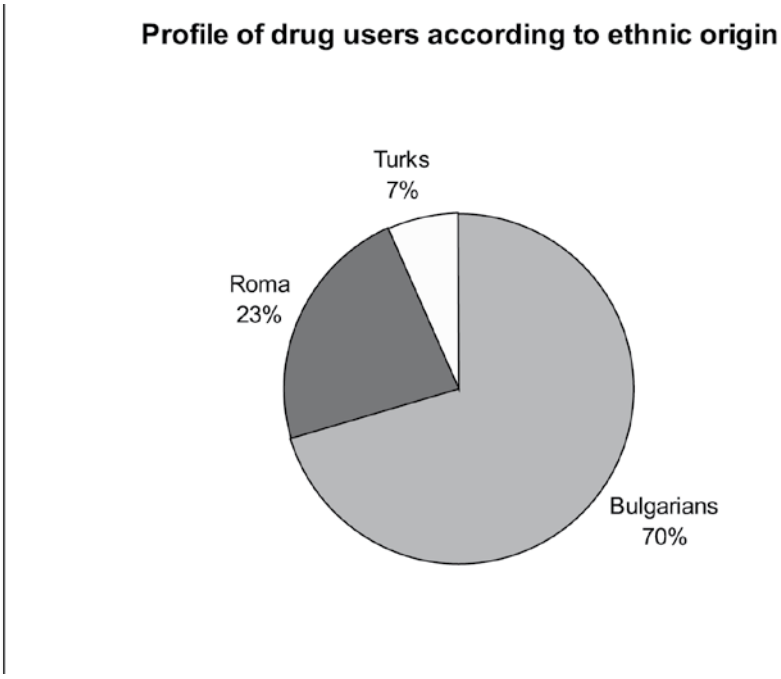
15 Annual reports of the NFPDDA (2002, 2003, 2004, 2005 and 2006), Drug Market in Bulgaria - CSD, 2003; Injection drug users in Bulgaria. Profile and risks - IHF, 2004; Heroine users one year after outlawing the does for personal use – IHF, 2005

Table 2. Distribution of drug users according sex

Sex	Survey 2003	Survey 2005	Survey 2007
MEN	80%	83%	83%
WOMEN	20%	17%	17%

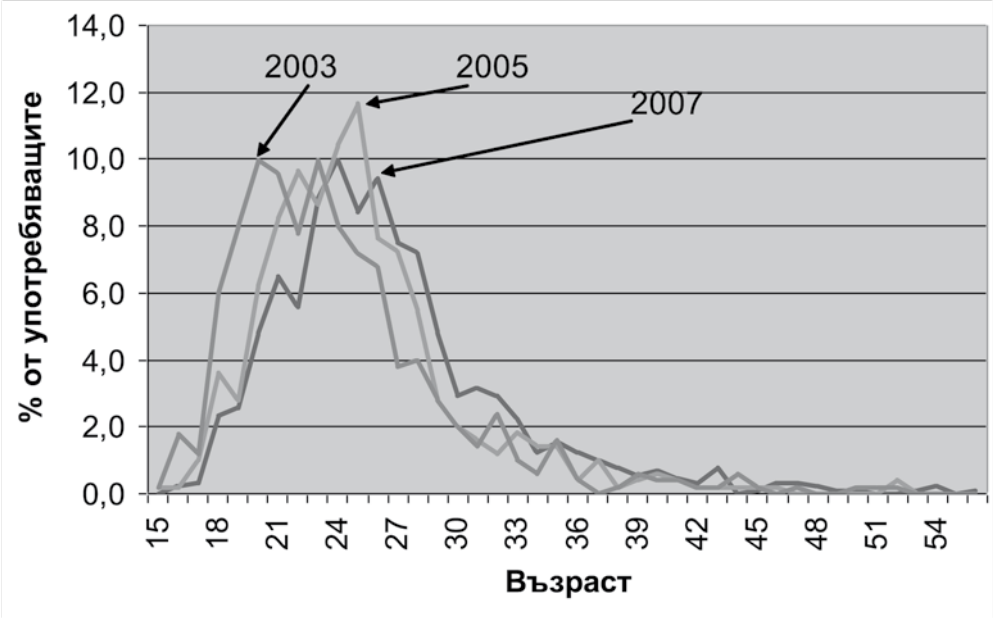
Regarding the ethnical profile of the group, we were unable to draw out some specific tendencies, neither were we able to make direct parallel with other data, because no previous officially published surveys are available conducted among drug users recruited on site of the same geographical area. The two previous surveys of IHF cover only the cities of Sofia, Plovdiv, Burgas, Pleven and Veliko Tarnovo. This present survey, on the other side, includes two other cities with compact Roma population, among which there is a widespread drug use – Varna and Kyustendil. This obstructs the making of parallel with the previous surveys conducted. In this survey the distribution according to ethnicity shows that approximately 23% of the sample are Roma people, where most of them live in Sofia, Plovdiv, Varna, and Kyustendil (see Figure 1). 7% of users declare Turkish ethnicity, where most of these are again Roma people, only this time, with self-definition as Turkish.

Fig.1. Profile of drug users according to ethnicity groups



Somewhat different is the situation with age related to drug use. In contrast to distribution according to sex, as far as age is related we observe a gradual change of the structure of the group towards increase of the injection adult drug dependents as compared to younger ones (see Fig.2)

Fig.2. Tendencies among the drug users according to age



Legend: Axis Y: % of drug users
Axis X: Age

This tendency towards overall aging of the group is ever more pronounced when compared to the mean age within the group in the years 2003, 2005 and 2007 (See Table 3). It can be clearly seen that the mean age has risen by some three years for this period. This process is connected first and foremost with the fading of the heroin outbreak peak, which is an issue discussed extensively among competent experts[16]. This tendency results to fewer new, respectively young people starting to use drugs in Bulgaria.

Table 3. Mean age of drug users

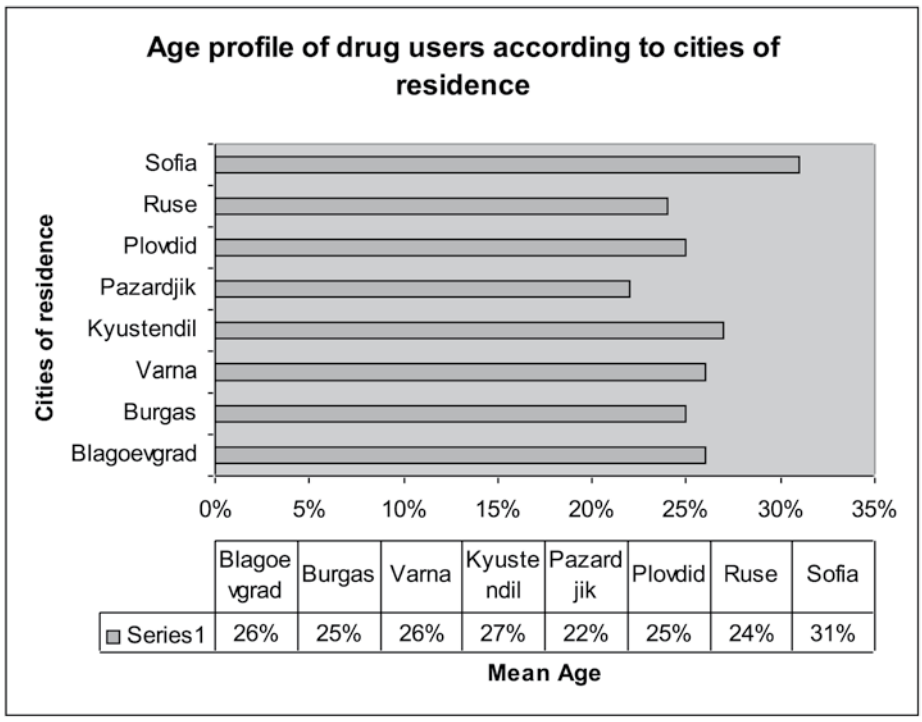
Indicator	Survey 2003	Survey 2005	Survey 2007
Mean age (Mean)	24 years	25 years	27 years
Mean age (Median)	23 years	24 years	26 years

Of course, the process of aging of this group takes a different course in the different cities. Differences result from the fact that the boom of heroin distribution starts at different times in the different cities. It is not by accident that in the bigger cities the process has progressed further than in the smaller ones and respectively there the mean age of the drug users with problems

16 Heroine users one year after outlawing the dose for personal use - IHF, 2005, page. 7

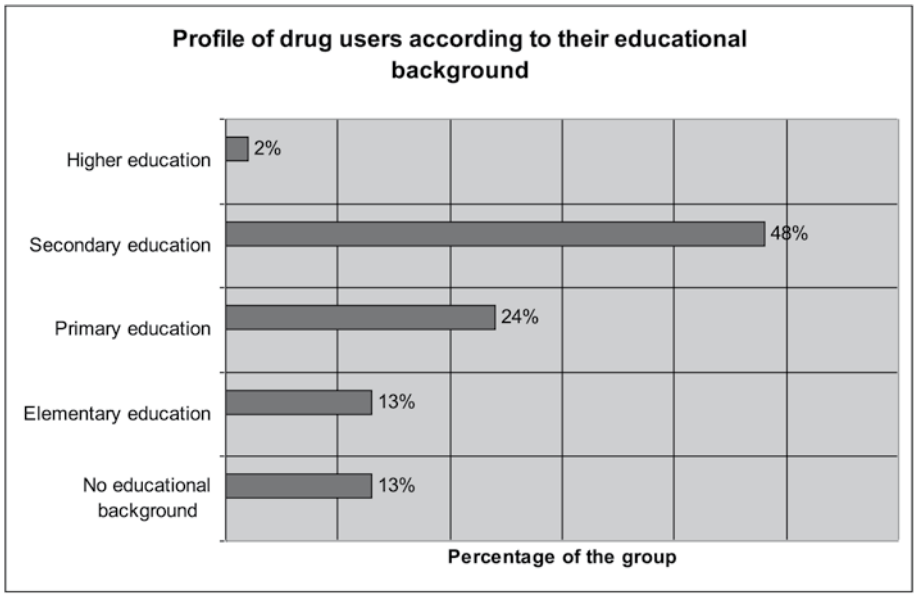
is the highest (see Fig.3). This means that the process has most extremely progressed in the capital, where the mean age is 31 years.

Figure 3. Age profile of drug users according to cities of residence



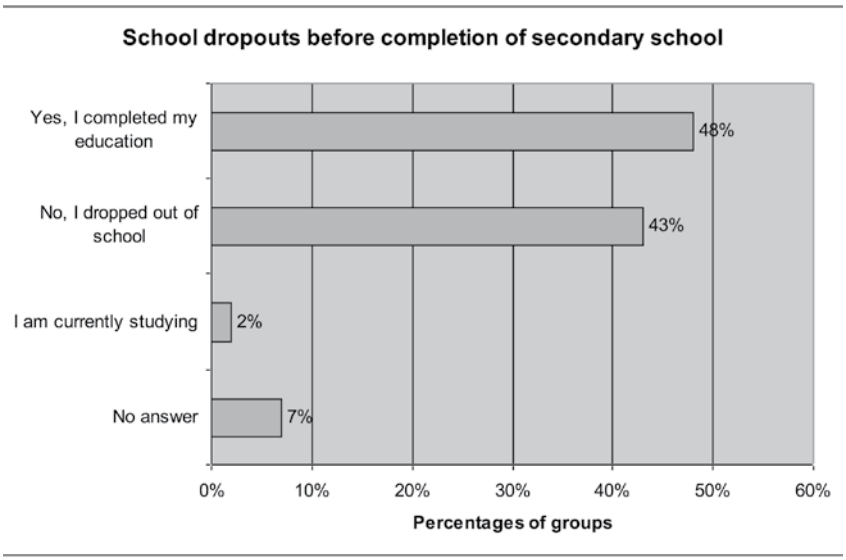
With respect to the aging of the group of drug users, there are some worrying facts and tendencies that are gradually outlined. These are related to the socio-economic status of the group and indicate an increasing marginalisation of the group. Reviewing the profile in terms of the education background of its members, we can say that half of the group has primary or even lower degree of education (see Fig.4), where 13% of the PDU have not completed secondary education.

Figure. 4. Profile of drug users according to their educational background



Additional analysis of the data shows that approximately half of the group – 43% - have left school before completing their secondary education (see Fig.5). Dropping out of the educational system is a prerequisite for these people for the further marginalisation away from society, as far as this deprives them from a very important social resource, if, at a certain stage of their life, they decide to make the choice and fight their problem, so as to be again included in society as fully fledged individuals.

Fig.5. School dropouts before completion of secondary education



The profile of the PDU in terms of employment shows that approximately 60% of them are unemployed, where most of these people are not even registered in the Regional Recruitment Offices (see Table 4). Along with that 20% of the users say that they do not have any identification documents whatsoever. The situation is even worse with respect to health insurances: While in the 2003 survey of the Initiative for Health Foundation some 49% of the respondents had an health insurance, the 2005 survey indicated that only 39% of the respondents were insured.

Table 4. Profile of drug users according to employment

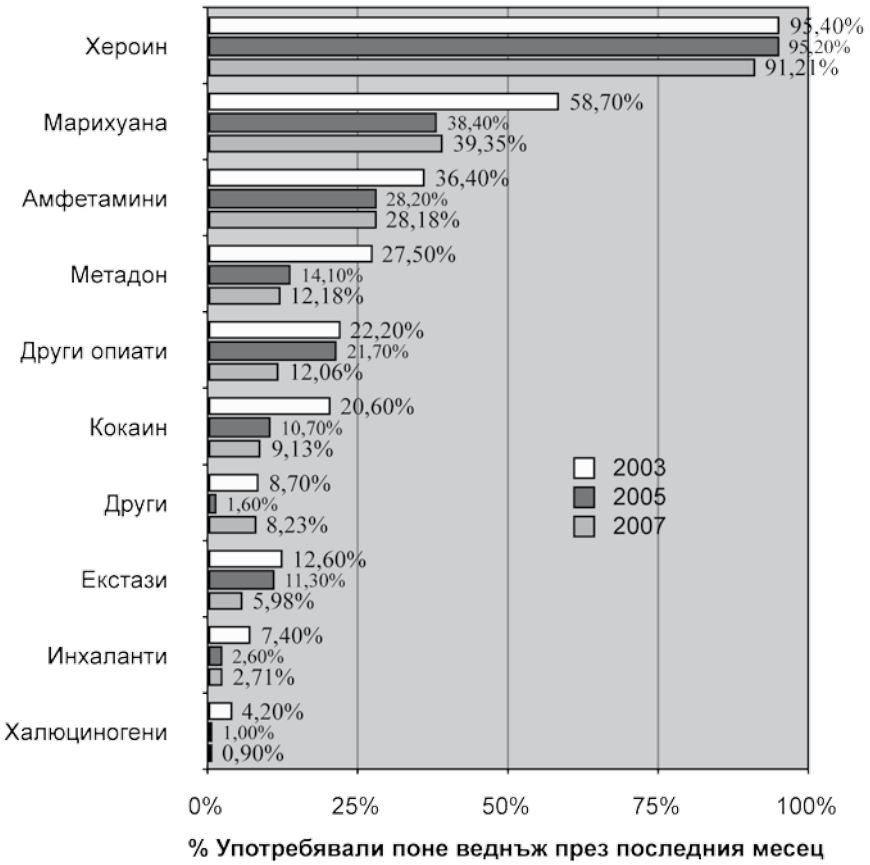
Employed currently	**Persons**	**% of the group**
Unemployed, not registered	515	57.7
Unemployed, registered	51	5.7
Emplyed, no labor agreement	154	17.2
Employed, full-time	113	12.7
Employed, part-time	18	2.0
Studying	33	3.7
Disability retirement	5	0.6
Other	4	0.4
Total	893	100.0

All these figures unequivocally show a tendency towards increasing marginalisation of drug users and a further intensifying process of dropping out of most of the important social systems, such as the educational, the health and the labour systems. In the near future this observed marginalisation shall result into a severe multiplication of drug use related health and social problems, and will further obstruct the rehabilitation and re-socialization of drug users. As far as access to drug dependencies treatment is available, the dropping out of PDU from the said systems to a great extent restricts them from getting access to treatment, and consequently lessens their chance to re-integrate successfully back into society as fully valued individuals.

Models of use of psychoactive drugs and risk practices

Comparing the use of psychoactive substances with the information from the Initiative for Health Foundation studies in 2003 and 2005, we can see a trend for stabilization of the mode of drug use in the last two years. Heroin remains the main and preferred substance, where the use of the other PAS – cocaine, ecstasy, other opiates has even decreased a little (see Fig.6).

Fig.6. Ranking of PAS according to frequency of use during the last month

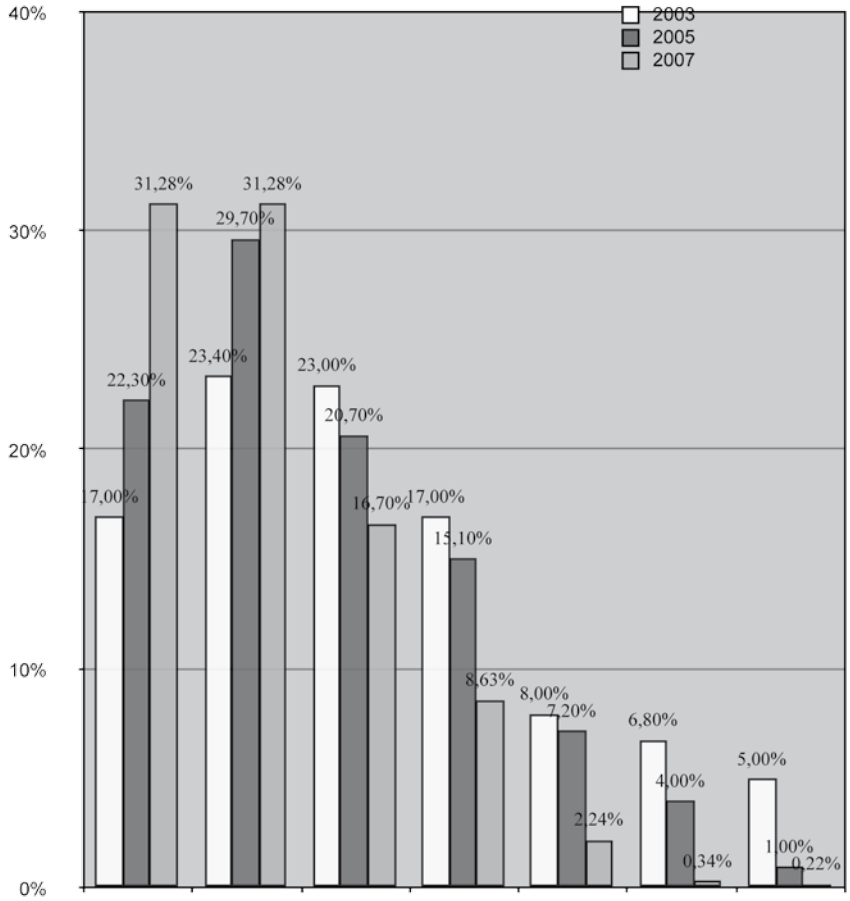


Legend: *Axis X:* *% of those who have used at least once in the last month*

Axis Y:
Heroin
Marijuana
Amphetamines
Methadone
Other opiates
Cocaine
Other
Ecstasy
Inhalants
Hallucinogens

The multi-drug use established in previous surveys continues to a great extent within the group this time as well. Average of 70% of PDU uses at least one other substance in addition to heroin. Nevertheless, the comparison with earlier data shows that there is a stable trend for going back and sticking mainly to heroin (see fig.7). Moreover, the share of those who said they use only heroin has risen by almost 10%. This trend can be explained mainly with the increased quality of the heroin sold on the streets. This is why users no longer have the need to search for substitutes or “improvers”.

Fig.7. Multi-use of PAS



Legend: Axis X: only heroin, +1 more PAS, +2 more PAS, +3 more PAS, +4 more PAS, +5 more PAS, +6 and more PAS

As the second preferred substance marijuana is most frequently mentioned, immediately followed by amphetamines (see Table 5). This means that the most widespread mode of use is heroin and marijuana, or heroin and amphetamines. In the last mentioned case the two substances are taken together in the form of the so-called "Gypsy speed"

Table 5. Most frequently used PAS together with heroin

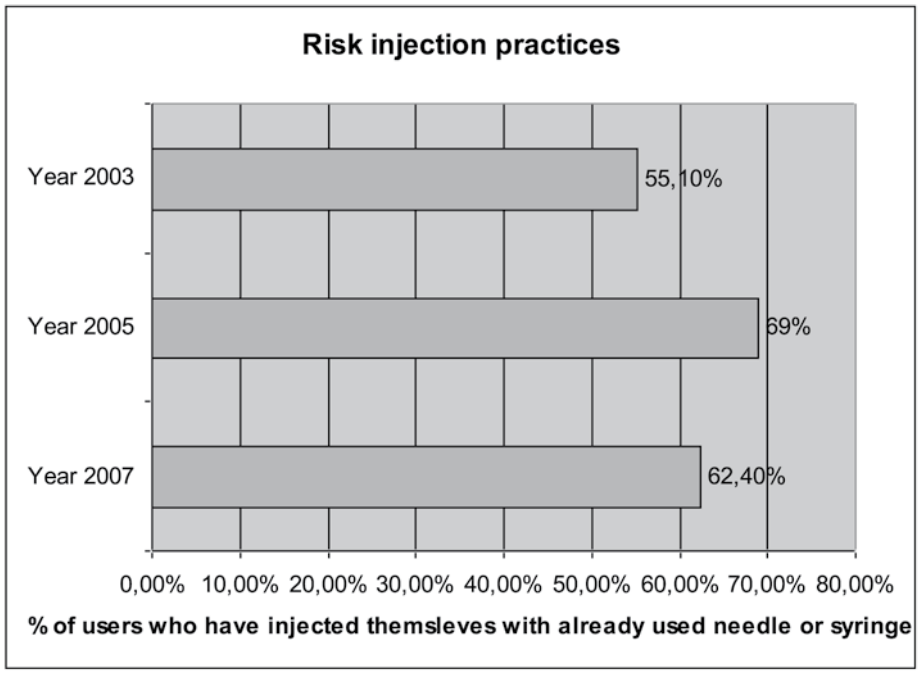
Second substance	% of heroine users
Marijuana	63,0%
Amphetamines	41,5%
Other opiates	17,0%
Cocaine	13,4%
Other	12,1%
Methadone	10,9%
Ecstasy	9,4%
Inhalants	4,0%
Hallucinogens	1,3%

The widespread practice of using two or more substances at the same time, which is observed ever more frequently in the last 4-5 years, is a true challenge for the Bulgarian treatment system. The multi-drug use is a new problem to the narcologist doctors, because they have to treat a patient's dependency not to a specific substance, but to a number of several PAS simultaneously. Furthermore, most of the already existing treatment programmes target at treating of opiates dependencies, where observation data shows that the problematic use of stimulants has preserved a stable level for several years in a row.

Along with multi-drug use, risk behaviour continues to be of justified concern. The current survey data indicate that risk practices are still widespread – 62% of the respondents have at least once in their life injected themselves using someone else's needle or syringe, 74% have used other people's cap, filter, or water, and 56% have shared narcotic in one single syringe. Comparing these data with the results form the previous two surveys shows just a slight decrease of sharing of instruments, yet still in general the percentage of individuals with risk behaviour remains high (see Fig.8).

Fig. 8. Risk injection practices – tendencies during the last four years

The above data clearly indicate the risk for the health system, if not enough means of treatment are



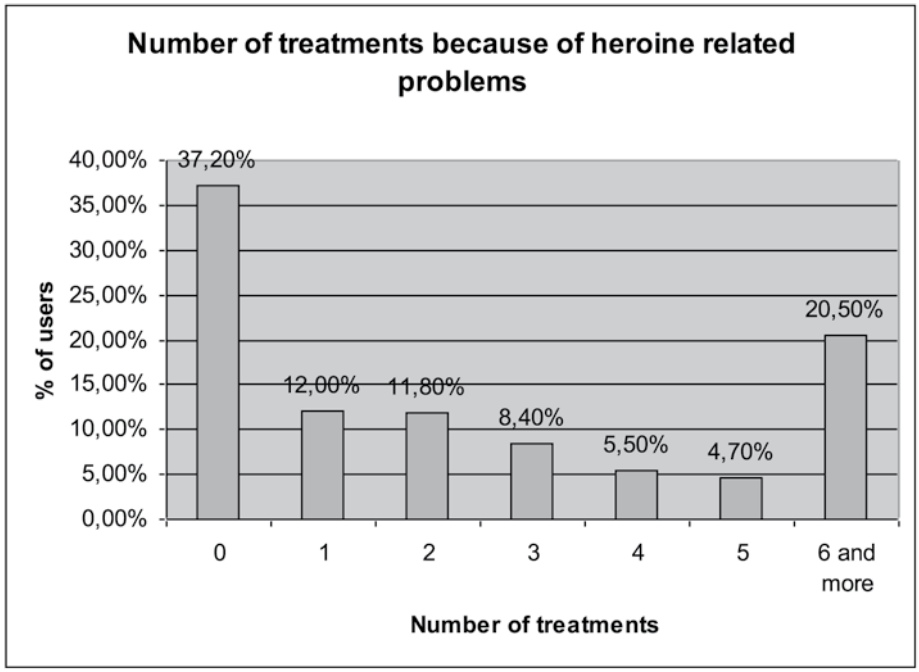
made available to deal with dependencies of the drug users group. Harm reduction programmes cannot act as a self-contained instrument to limit the spread of HIV and blood-borne diseases. It is not by accident that the number of HIV positive injection drug dependents continues to progress during the recent years, regardless of the existent and the newly initiated programmes for exchange of needles and syringes – in six new cities of Bulgaria, during the last three years.

History of treatment

The status of the drug dependencies treatment system is under constant monitoring by the National Focal Point on Drugs and Drug Addictions, and apart from that it is an issue of public discussions on a regular basis. Nevertheless, we have only scarce information of what the actual search for and access to treatment there is by PDU on the street. Here namely the group of users who presently very actively use drugs is meant. This survey gives valuable information on this particular aspect, as much as in its greater part the data published, related to treatment search, is relevant to people, who have established contact with the healthcare system.

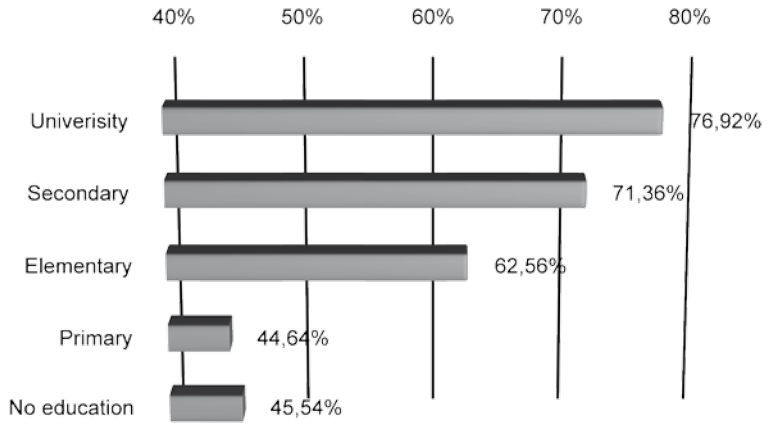
The survey results show that approximately 1/3 of the users have never availed of drug related treatment. This is not surprising, considering that one part of the PDU have started using drugs somewhat recently and at this stage they still lack motivation to seek treatment for their dependency. What is more worrying is that almost half of the respondents indicated they have already undergone two or more courses of treatment throughout their life, which had obviously been unsuccessful, because presently they continue to use drugs (see Fig.9). The mean number of treatments undergone for the group as a whole is 3.

Fig. 9. Number of treatments because of heroin related problems



The analysis of the information about treatments over the last 12 months shows that 62% have not been treated, 25,5% have undergone one course of treatment, and 12,8% report two or more courses of treatment. 85 % of the treated in 2006 had at least one more course of treatment at an earlier stage of their life. A main factor influencing the liability of PDU to undergo treatment appears to be the educational background. The higher the level of education is, the bigger the probability to undergo treatment. This fact tells us that the process of marginalisation within the group only further decreased the chances of PDU forever getting a treatment for their drug dependencies.

Fig. 10. Share of treated users according to completed educational degree



% treated within the group

The information received for those who underwent treatment imminently poses the question of that could the problem be, so that such large per cent of drug users undergo more than two courses of treatment, and still can not overcome their problem. As a fact alone, this information signals very distinctively the efficiency of the services offered in Bulgaria in general.

In part, the answer can be found in the supply of drug treatment options in Bulgaria. Analysing the types of treatment programmes, which the drug users have undergone for the last five years reveals that half of them have received detoxification in hospitals or elsewhere (see Table 6). Some 1/5 underwent a substitution therapy. On the other hand those who underwent rehabilitation programmes – either daytime centres or therapeutic communities are under 10%.

Table 6. Percentage of treated during the last five years according to the type of treatment

Type of treatment	State	Private	Total
Detoxification in hospital	32,4 %	1,1%	33,5%
Out-patient detoxification	8,7%	10,5%	19,2%
Day-time centre/day-time stationary	2,8%	0,9%	3,7%
Therapeutic community	-	6,5%	6,5%
Substitution therapy	11,3%	10,1%	21,4%
Treatment with medicinal preparations (Naltrexon)	4,4%	8,2%	12,6%
Other	0,1%	0,2%	0,3%

This astonishing difference highlights one of the main problems of treating drug dependencies in Bulgaria: the focus is predominantly on the handling of the medical aspects of the problem, while at the same time, a lack of rehabilitation and re-socialization programmes can be observed. Drug dependencies, being different from other illnesses, are just as much damaging, but not only in terms of health, but also in terms of social consequences for the individual. Rehabilitation programmes are the bridges, which would allow the users, after having handled the medical aspects of their problem, to successfully reintegrate into society as fully valued individuals. The very users share that it is not abstinence and dependency that obstruct them from giving up using drugs. On the contrary, the socio-psychological aspects of the condition are much harder to overcome – already formed habits, interrupted social relations with parents, relatives, and friends, as well as the lack of working skill, etc.

The positive trend is that during the last two years the share of PDU who have received treatment is raising. In the survey of Initiative for Health Foundation conducted in 2005, 47% of the respondent said they have received some kind of treatment for the last five years, whereas in the 2007 survey result this per cent is 56.2%. This can be explained with the increase of the number of options connected with the infusion of private alternatives – private methadone therapies, wide-spread application of substitution therapies with Substitol and therapy with Naltrexon.
The ranking of the most requested types of treatment in general corresponds to the options offered presently in Bulgaria. In other words those who use drugs seek for what they know they can find – i.e. the structure of the offering implies the structure of the search (see Table 7). Most frequently this is detoxification in hospitals or substitution therapy. With small exceptions the share of those who sought treatment coincides with the share of those who received treatment. But this fact should not be construed to mean that the demand for drug dependency treatment is met in full by the services offered. Most of the drug users are unmotivated to seek treatment and rely on self-administered treatment or alternatives outside Bulgaria.

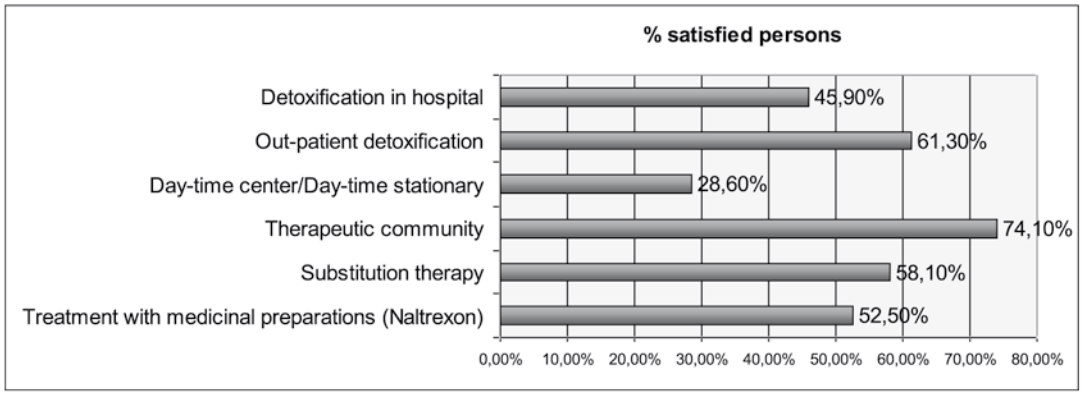
Table 7. Users who sought and received treatment during the last 12 months

Type of treatment	Sought by	Received by
Detoxification in hospital	18,8%	17,9%
Out-patient detoxification	8,4%	8,2%
Day-time centre/day-time stationary	1,2%	0,8%
Therapeutic community	3,7%	2,9%
Substitution therapy	18,3	14,8%
Treatment with medicinal preparations (Naltrexon)	5%	4,5%
Other	0,3%	0,2%

Comparing the numbers of those who sought and those who received treatment in the last 12 months, we can see that as most difficult to access three separate type of services can be outlined: day-time centres, therapeutic communities and substitution therapies. First comes the daytime centres option, where one fifth of those who requested such service did not receive it. Among the reasons behind that are the lack of enough finances, or the lack of vacant places available. Second comes the therapeutic communities option, where little under 1/5 of those who searched for this type service did not receive it. Most of the time the reasons are the fore-mentioned; lack of money and places.
The thirst hard to access service is the substitution therapy. Although several new methadone programmes opened for candidates – some 17% of the candidates did not receive this type of treatment. Reasons vary from long waiting lists to join the programme, to financial reasons, lack of free places in the programme, lack of such programme in the particular place of residence of the person in need. With the rest of the types of treatment available – the percentage of those who did not receive the treatment they sought for is between 3% to 9%, where the main reasons here are: lack of health insurance, lack of identification documents, lack of such programme in the particular place of residence of the person in need, lack of places available, adverse behaviour on the part of the personnel. Along with the efficiency of the already existing programmes, one of the most frequently discussed accompanying problems is the quality of the drug dependencies treatment options. In regard of this a key indicator is the satisfaction of the very PDU with the services offered. Data show that the respondents are most satisfied with three of the types of treatment offered – therapeutic communities, out-patient detoxification and substitution therapy (see Fig.11). The common thing between these three is that in Bulgaria they are available mainly

as private programmes. The existent state financed programmes experience shortages of free places, and consequently, access to them is hindered by a long waiting list. On the other hand, it is understandable why satisfaction with the private programmes is greater: because the service there is paid, it is usually of a higher quality. Very indicative in this regard is the fact that the detoxification in hospitals, which is first of all a state financed service, as a preferred treatment option ranks last but one in terms of satisfaction.

Fig. 11. Total satisfaction with the different types of treatment



When reviewing the insight of the types of treatments offered, it becomes clear, which the most frequent sources of dissatisfaction for the drug users are. As first factor they point out the lack of information for the various types of treatment available (see Table 8). Irrespective of the active presence of the issue in the media and irrespective of the works of many civil organizations to solve this problem, the reality is that much of the information never actually gets to those who need it – the drug users. In that respect there is a necessity to develop effectively working centres and programmes for consultation and directing of drug user, as well as a necessity to strengthen and further develop the capacity of the already existing ones.

Table 8. Hierarchy of problems causing aspects with drug dependencies treatment

Aspects of the treatment	Level of satisfaction
Information available	46,3%
Financial affordability	39%
Efficiency	34,1%
Location of the treatment	28,4%
Material base	23,8%
Attitude of the personnel	17,3%

The second source of dissatisfaction is the affordability. It is true that although options for treatment increase in number, it is mainly due to private practices and programmes. In general, the state has withdrawn from this healthcare sector, and the private alternatives available very often are too expensive for people using drugs. This is even more valid bearing in mind the abovementioned fact that over 50% of PDU are unemployed, and 60% have no health insurances. In this regard, ever more extreme is the need to initiate new drug dependencies treatment programmes, which are to be state and municipality financed.

The third most often quoted dissatisfaction factor with drug users is the efficiency of the treatment (see Table 8). This problem to a great extent is connected with the disproportion of the types of

treatment available. The lack of enough rehabilitation programmes in most cases deprives the user from the possibility to efficiently deal with the problem, and the user subsequently turns back to the practice of using drugs. This ultimately is an experience of inefficient treatment. Thus, apart from initiating new rehabilitation programmes, there is a need in Bulgaria for an even more complex service, which would not conclude with a short detoxification course, but would rather give the possibility to treat the person along the entire way towards a successful handling of the problem.

Of course, different types of treatment have different aspect, which may be assessed as most dissatisfactory (see Table 9). For example, in the case of detoxification in a hospital, the discontent results from the material base available. In the case of treatment with Naltrexon, substitution therapy and outpatient detoxification, the factor of discontent is the financial affordability. Regarding day-time centres and therapeutic communities, the lack of information available for such options and services may cause dissatisfaction.

Table 9. Levels of dissatisfaction with different aspects of the treatment

Type of treatment	Friendliness	Location	Efficiency	Financial affordability	Material base	Information available
Detoxification in hospital	35,5%	29,9%	47,1%	14%	52,9%	32,5%
Out-patient detoxification	10,1%	18,8%	39,1%	62,3%	11,6%	37,7%
Day-time centre	16,7%	33,3%	33,3%	16,7%	50%	83,3%
Therapeutic community	6,5%	32,3%	16,1%	19,4%	3,2%	45,2%
Substitution therapy	22,6%	29,3%	23,3%	48,9%	15,8%	39,8%
Treatment with medicinal preparation	12,1%	27,3%	45,5%	72,7%	9,1%	39,4%

Attitude towards treatment demand and barriers obstructing access to treatment

Considering the imbalances outlines and the problems connected with the search and the offering of the drug dependencies treatment programmes, is it not surprising, that only 41% of the respondents declared they intend to seek treatment in the near future. The attitudes towards treatment demand to a great extent follow the pattern of offering. The only significant difference is observed with the attitudes toward search for substitute therapy, where the search is greater than the search for hospitalised detoxification (see Table 10). In this context, although four new methadone programmes were initiated throughout the country during the last three years, the demand is still not met for this type of treatment. Furthermore, two of these new programmes opened in Sofia, and the other two elsewhere in Bulgaria.

Table 10. Attitudes towards treatment demand

I intend to seek the following services/ treatment	Number of individuals	Percentage of the answers given	Percentage of the treatment seeking
Substitution therapy (methadone, Substitol)	168	25.9%	46.0%
Detoxification in hospital	143	22.1%	39.2%

Out-patient detoxification	87	13.4%	23.8%
Therapeutic community	70	10.8%	19.2%
Treatment with Naltrexon or other preparations	68	10.5%	18.6%
Day-time centre / Day-time stationary	36	5.6%	9.9%
Other	76	11.7%	20.8%

Data indicate that those who have undergone some type of treatment are likely to search once more in the near future, in comparison with those who have never been treated: 47% of those treated vs. 31% of those untreated intend to seek treatment. This discrepancy is normal, considering the fact that those who have been treated at least once have already experienced the need to stop using drugs, whereas this experience is unknown to those untreated.
Bearing in mind the high share of PDU who do not intend to seek treatment in the near future, there is a question to be posed: which are barriers limiting the access of the group to drug dependencies treatment? The data of this present survey draw out several basic types of barriers: the conviction that "Treatment doesn't help", "Treatment is expensive", "The personnel is unfriendly", "There is no treatment in my place of residence", "There is a long list of people waiting", etc (see Table 11).

Table 11. Most often quoted barriers obstructing the search for drug dependencies treatment

Reasons likely to prevent the users from seeking or receiving dependency related treatment	Number of answers	Per cent of the answers
Treatment doesn't help	1310	24,8%
Treatment is expensive	738	14,0%
Personnel is unfriendly	579	11,0%
There is no treatment available where I live	529	10,0%
Lack of motivation for treatment	439	8,3%
Lack of information where and how to find treatment	361	6,8%
Bad previous experience with other type of treatment	348	6,6%
Required documents missing	261	4,9%
Long list of people waiting to join	187	3,5%
Too remote	156	3,0%
Embarrassed to be registered	152	2,9%

In general, the answer "Treatment doesn't help" is difficult to interpret, because it is a subjective conviction of the very person. To some extent, the PDU are not motivated enough to seek treatment and to stop using drugs, and this attitude of theirs serves as an excuse not to seek help. On the other hand, the popularity of this answer among the group members undoubtedly reflects the assessment of those users who have undergone a programme, without handling their problem. In this regard, the level of satisfaction with the efficiency of the different types of treatment (1/3 of drug users say they are dissatisfied with the efficiency of the treatment they have undergone) also supports the above-mentioned thesis. One more argument to support this thesis is the comparison between the said barriers with treated and untreated users (see Table 12). It is clearly seen that this conviction is the most frequently quoted reason the lack of interest towards treatment with both treated and untreated users.

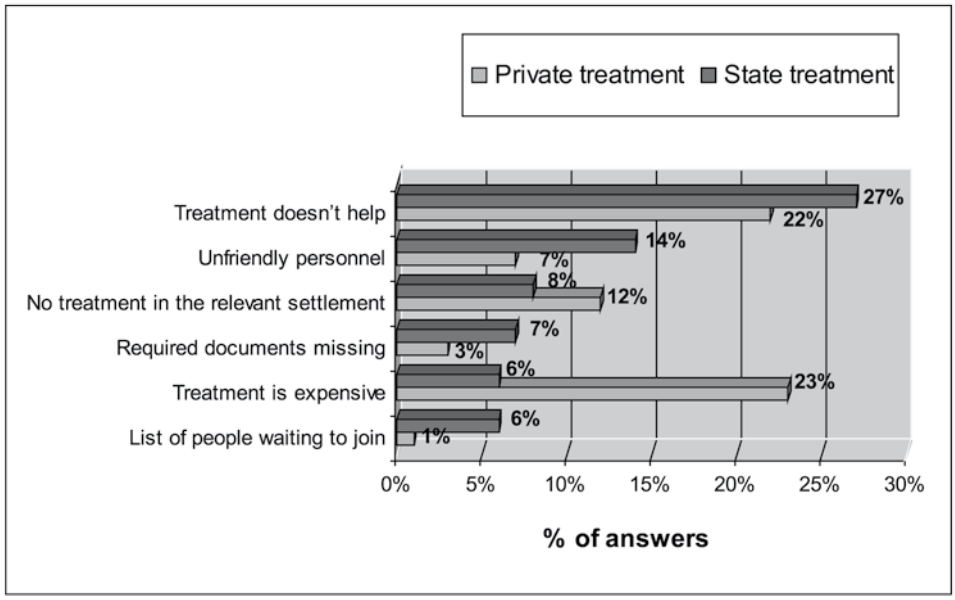
Table 12. Comparative data about barriers with treated/untreated users

Reasons stated	Treated	Untreated
Treatment doesn't help	20,3%	33,4%
Treatment is expensive	15,2%	11,7%
Personnel is unfriendly	12,8%	7,5%
Bad previous experience	8,1%	3,7%
Lack of motivation for treatment	7,2%	10,5%

This comparison shows the main mechanism serving as disincentive for the groups to stop seeking treatment in general. The experience of those who have undergone some treatment under the existent healthcare system does not stay unshared; on the contrary, it is shared by, and serves as a blocking mechanism for the entire group. Furthermore, the negative experience, when shared has a bigger influence on those members of the group who have never undergone any treatment.

The second most frequently quoted reason is the financial one (see Table 11). In some sense it relates mostly to the existent private alternative, because presently there is a deficiency of state-financed programmes. Additional evidence is the comparison of the barriers for access to state and private programmes – with concerning state programmes only 6% of the respondents answered "Treatment is expensive", where as with the private one this percentage is 23 (see Fig12). This fact once again highlights the necessity to provide more state and municipality financed drug dependencies treatment programmes, because only a small number of the PDU can afford to pay the treatment alone. Nevertheless, there is a search also for private programmes, as much as 12% of barriers quoted in relation to private programmes are "There are no such in my place of residence".

Fig. 12. Main differences between barriers obstructing access to state and private treatment



The mirror image with state programmes is the poor quality of service. Unfriendly attitude of the personnel is the third, most frequently mentioned barrier obstructing the access of users to

relevant treatment (see Table 11). Moreover, it is twice as often stated as a problem with state programmes, than with private ones. This problem in the case of state programmes is many times put in parallel with the paper difficulties, i.e. bureaucratic hurdles connected with the entry into such programmes.

Table 13. Lack of treatment programmes in the relevant settlement as a barrier obstruction access

Type of treatment	% of people who quoted this barrier
Detoxification in hospital	2,2%
Out-patient detoxification – state financed	3,1%
Out-patient detoxification - private	4,7%
Day-time centre – state finances	8,7%
Day-time centre – private	8,8%
Therapeutic community	8,1%
Substitution therapy – state finances	7,3%
Substitution therapy – private	7,5%
Treatment with Naltrexon – state finances	3,6%
Treatment with Naltrexon - private	5,2%

In most cities in Bulgaria, another very significant problem remains the lack of treatment programmes in different residential areas where people in need live – both state financed programmes, and private ones (see Table 13). This problem is particularly acute regarding three types of treatment: substitution therapy, therapeutic communities and daytime centres. Even if such programmes exist in neighbouring places, additional costs connected with transport make such treatment unaffordable for PDU. In this context there is definitely a need for decentralization of treatment programmes and the initiation of new ones in towns, other than Sofia, Plovdiv and Varna.

5.4 Conclusions

The present situation in Bulgaria indicates a decrease of heroin use and an increase of the mean age of the problem drug users. At the same time, the group of PDU is ever more marginalized. The share of people with no health insurances increases; half of the group members are unemployed and have left school before completing secondary education.

At the same time, this group remains under severe health threatening risks: over half of the PDU indicate they had risk injection behaviour at least once in their life. It is not by accident that the data compiled under the Programme for Prevention and Control of HIV/AIDS of the Ministry of Health show that during the last three years the number of HIV positive PDU has tripled. Apart from that, the data from the NFPDDA for the 2001 to 2005 period indicate that the drug related mortality rate tripled.

To the background of these worrying tendencies, one of the most important policies to limit the drug use practices – drug dependencies treatment – is still not accessible and not efficient

enough. Most of the PDU have undergone 3 or 4 courses of treatment, without stopping to use drugs. The analysis of the data within the framework of this survey identifies several problems and barriers, which give explanation to why such findings are observed:

- Drug users assess the major part of the programmes available as inefficient, which does not motivate them to seek further treatment. To a great extent this is due to the fact that detoxification or substitution therapy are not implemented together with subsequent rehabilitation and re-socialization programmes, which would help the patient go along the entire path until fully stabilized and successfully reintegrated into society. Therefore, lacking the above, the patient, at the end of the treatment often turns back to using drugs.
- There are not enough rehabilitation and re-socialization programmes: the majority of treatment programmes offered presently in Bulgaria are detoxification and substitution therapy.
- Regardless of the presence of certain treatment programmes (e.g. substation therapy, therapeutic communities, Naltrexon treatment), most of them are private and therefore cost-prohibiting for most of the drug users.
- Great parts of the treatment programmes offered are concentrated in Sofia, and to some extent in Varna and Plovdiv. In the rest of the towns in Bulgaria, such programmes are not available and this is the main barrier for PDU in those towns to receive treatment.
- The state financed programmes are often repulsive to drug user, because of the poor quality of the service offered there: personnel with unfriendly attitude, in combination with long list of bureaucratic hindrances, piles of documentation, etc.

In this regard, several recommendations can be formulated, connected to the most urgent measures to be undertaken to improve the current situation. First, adequate financing should be provided to financially secure the National Anti-Drug Strategy, in particular measures aimed towards the opening of new treatment and rehabilitation programmes. If possible, when such new programmes are initiated, the principle of decentralization should be followed, i.e. programmes are needed not only in few selected cities (such as Sofia, Plovdiv, Varna), but also in most of the rest of the bigger towns in Bulgaria. Additional investments are needed for further training and remuneration of doctors, so as to allow the improvement of quality. The challenge here remains the already rooted model of multi-use of PAS, which puts to the test and creates a lot of hardships for the traditional drug dependency treatment methods. Further efforts are needed to elaborate a complex network of services connected to drug dependencies treatment. Thus, entering the treatment system, the PDU is to a great extent likely not to drop out of the programme immediately after its first stage (e.g. detoxification), but, rather, the PDU will go through rehabilitation and re-socialization programmes to be stabilized and reintegrated into society.

5.5. Policy debate

The debate was carried out on June 25-26, dedicated to the International day against drugs and drug trafficking. It was titled "The Treatment of Addictions in Bulgaria – Opportunities and Problems", took place in "Matti" Hall of the National Palace of Culture and was co-organized by IFH and the National Centre for Addictions (the institution hosting the National Focal Point). The debate was attended by 67 participants, representatives of the treatment system and policy makers in the area of drugs and drug addictions: harm reduction programmes (NGOs), treatment programmes (hospitals, methadone programmes, outpatient clinics – both state-run and private), rehabilitation programmes (therapeutic communities), representatives of the National Drugs Committee, Ministry of Health, The Parliament, Sofia Municipality and others.

The aims of the event were:

- To draw society's attention to the problems related to the treatment of drug addictions;
- To outline the existing treatment possibilities for drug addicted people in Bulgaria, through the viewpoint of patients, experts, practitioners and policy makers;
- To deepen the dialogue between practitioners and decision makers.

During the meeting, the results from the above-mentioned study were presented, outlining the experience with treatment facilities among drug users, their perceptions, needs and expectations. An overview was presented of the existing care system for drug users in the country and remaining gaps. The discussion among professionals highlighted problematic areas and possibilities to tackle these.

A summary of the results of the policy debate was presented at a meeting of the National Drug Council and was sent to the Health Commission at the Parliament. The event and the study results were reflected in four newspaper publications and six interviews in electronic media.

6

Obstacles in availability and accessibility of assistance programs: Perspectives of illegal drug users in Slovenia

Dušan Nolimal, Evita Leskovšek, Tatjana Pokrajac[17]

6.1. Introduction

Problematic use of illegal drugs in Slovenia

Problematic drug use is defined as drug use with injections or long-term, frequent use of heroine other opium based drugs, cocaine and /or amphetamine. In Slovenia, heroine users still represent the largest share of problematic drug use. However, there is no reliable time evaluation on problematic drug use. Media writes that in Slovenia there are between 7,000 to 10,000 problematic drug users. On the basis of the statistic information on treatment of illegal drug users, which is available to the Institute of Public Health we conclude that in Slovenian, the most common user is one who uses heroin, often combined with other drugs (psychoactive medicine, cannabis and cocaine). This information must be interpreted within the context in which it was collected and, due to their incompleteness, inaccuracy and changeable collection methodology are an approximate evaluation as support to an exact picture on treatment of problematic illegal drug users. Empirical research of user's needs that rests only on epidemiological information is incomplete tool for planning measures and assistance programmes. Considering the information accessible, it can be concluded that a threat to and a vulnerability of the health of a drug using population group, especially those who inject drugs, is provided from four sources: Lack of familiarity to living conditions and lower resistance; taking (injecting) drugs; a strong exposure to typical illnesses (HIV/Aids, hepatitis B and C) or overdosing; unfavourable influences from general living environment. Economical, political and other social factors have an important influence on obtaining these (differentiation) characteristics or on the commencement and/or the course of consequential health illnesses and social situations. Pursuant to the information from the Records on Treating Drug Users, it is possible to prepare an approximate profile of typical characteristics of a Slovene problematic illegal drug user who is in a treatment at the Centre for Prevention and Treatment of Addiction to Illegal Drugs:

- Male;
- Younger than 30 years (most commonly from 20 - 24 years) M;
- The main drug and the reason for seeking an assistance is heroin;
- Every day and a number of times per day use;
- Frequent injection;
- Takes a number of drugs at the same time;
- Enrolled in an educational programme but at a lower level education;

17 The authors wish to thank Bojan Kuljanc, Tadej Keblj, Olga Perhavec, Vida Vozli and all - in this research for understanding reasons anonymous - illegal drug users who were prepared to participate in this research. Special thanks to five representatives of the target group - Azra, Miha, Bojan and Boštjan - who joined as lay research assistants.

- The first illegal drug taken was marihuana (cannabis);
- Before the first treatment, he was taking the main drug for more than 2 and a half years;

Female problematic illegal drug users, when compared to males, are generally:

- Younger when the illegal drug was taken for the first time;
- Younger when an illegal drug was injected for the first time;
- Younger when entering a medical treatment.

In 2005, the Institute for Public Health, in cooperation with 12 non-governmental organisations, has carried out a pilot research on collecting data on illegal drug users that are seeking help in a non-governmental sector. Upon analysing the data collected, it is possible to prepare the following profile of an illegal drug user that is seeking help in a non-governmental sector:

- Male;
- Already had a different treatment for drug use;
- Uses heroin;
- Using two drugs at the same time;
- Had injected drugs;
- Uses drugs every day;
- Is seeking help on own initiative;
- Lives with parents or alone;
- Has one child;
- Is unemployed.

Planning expert help for problematic drug users in Slovenia

Parallel to an increase in problematic use of illegal drugs at the beginning of 1990's and relatively poor readiness of services to give assistance to illegal drug users, different programmes were developed throughout 1990's on assisting drug addicts in the Republic of Slovenia. The key breakpoint in the development of assistance programmes for drug users in the public health was in 1994 when the Doctrine on Treating Drug Addicts and Doctor's Recommendations on Treating Drug Addicts were accepted. By setting up in the Slovenian cities Centres for Prevention and Treatment of Drug Addicts in 1990's (today there are 18 such centres), the accessibility and geographical coverage of assistance programmes for drug users was significantly increased. In these centres, various measures for treating addiction to heroin and other opium based drugs were carried out such as the Methadone Maintenance Programme, a gradual clinic-based detoxification with methadone, a short-term clinic-based detoxification with methadone, a clinic-based detoxification with the use of other medicine and psychotherapeutic treatment. Different treatments are also available for patients who have difficulties with abusing other non-opium based drugs. Special attention is given to measures on maintaining abstinence. Patients can have a psychosocial support, an individual psychological treatment, a group psychological treatment, a family treatment, a psychiatric treatment, a blood testing for possible infection with HIV and hepatitis with expert counselling, in cases of an infection a referral to a specialist treatment and vaccination against hepatitis B. Some centres also run counselling for parents, other relatives and partners, they introduce patients and their relatives to treatment opportunities and a treatment of addiction in other programmes, as well as prepare patients for entering high threshold treatment and rehabilitation programme. Telephone counselling is also carried out as well as various preventative activities directed to educating young people, their parents, educators and a general

population. Parallel to health care network, other forms of assistance were developed within the framework of social security, prison and non-governmental sector. Most information we have is on the work of health care public services that are included in the information system reporting on treatments of drug users, which does not mean that the accessibility to other forms of assistance is less developed. Typically, there is a lack of research to evaluate the users' needs and their satisfaction with the existing services. For these reasons we have no information to evaluate if the assistance programmes were successful in attracting as many users as possible that are in need of assistance the most, or who are capable of accepting the assistance offered or, who can participate in the assistance programmes for a sufficient period of time. We need information on suitability and adjustability of various services and programmes towards users' needs. We need to answer a question whether drug users have more opportunities in programmes accessible for a suitable medical treatment when compared to the past. Better data on the satisfaction and the needs of drug users would assist us in planning measures and in improving quality assistance to this population. Disclosing deficiencies in the suitability of health care, social and non-governmental sector is urgent in order to optimally distribute limited assets for various programmes and for an easier and more sensitive setting of priorities. Studying the needs and the satisfaction with the assistance programmes by drug users is, aside from respecting ethical principals, expert and economic efficiency, a condition for a suitability of health care and social security of drug users. A system of assistance programmes for illegal drug users is suitable when different services and individuals optimally satisfy current, past and potential needs of illegal drug users. Studying the needs on health and the satisfaction with existing services, together with active inclusion of drug users in a research, was one of the key tasks of the present research.

How drug users were included in the research

One of the research objectives was to develop an appropriate methodology on seeking contacts and communicating with illegal drug users, with the intention to study their experiences with the existing programmes and to evaluate actual needs for various assistance programmes. To this end, in the field research, we engaged illegal drug users as experts of street life who were the joining links between the researchers and the field. They played a role of research assistants. Many experts are of the opinion that people who use drugs for cognitive, psychosocial and other disturbances are not reliable and therefore they were excluded from the partnership relationship of expert - drug user. In most instances, there were excluded due to protection measures. Sometimes, it was possible to sense in the background various forms of paternalism, neglect, humiliation, annoyance and discrimination. This brings additional injustice, limitations or even elimination of various rights to health. This includes a right to decide on personal health and all procedures on restoring, protecting and strengthening health, including an active participation in research processes.

A field research success is largely dependant on the quality of participating researchers. Selecting appropriate field researchers affects the results in reaching hidden groups of drug users and assures their participation in the research. Aside from staff of non-governmental organisation, prisons and high threshold organisations, for an easier access to illegal drug users we asked for a cooperation of and trained four representatives from the target group. Research assistants were selected from drug users mainly due to their »insider« status and on the basis of their readiness for a partnership participation in the research, motivation on improving organisation of health care and social services for drug users. Namely, they had access to drug users and their meeting points. Their educational level and an ability to understand research questions were also taken consideration. We evaluated their ability to work under risky and difficulty conditions during

daytime and night time, in pubs and homes. Initially, we selected and trained four field workers. Intensive training included informal training and regular supervisory meetings. Two field workers ceased to participate sometime during the research. The remaining two field workers stayed until the end of data collection and were assisting data interpretation as well. It is important for field workers and representatives of the target group to participate in all research phases, from the conception through procedure and until presentation of results to expert and wider public and the evaluation. Such continued maintenance of contacts with representative of the target population would certain resources that were not provided for within the research framework. Regardless, we as researches learned tremendously from the users' active participation. We learned the advantages of including in the research work collaborators that are current or former drug users. They show great understanding of distress of others who had difficulties due to drug use. With the target group they had a common interest in improving accessibility and quality of existing assistance programmes for illegal drug users. As research assistants they helped us to uncover various and sometimes very subtle form of obstacles on accessing assistance programmes as well as violence between drug users. Some of our assistants were members of the target group as a result of which the users trusted and believed them more. They understood the terminology and sub-culture of own peers very well. Especially, they had access to certain more hidden groups of drug users, the existence of which we did not know. For these features, they were indispensable members of the research process. We also learned some weaknesses due to their participation in the research: firstly, there is a risk of mixing research work with socialising with peers or former acquaintances and friends. There was a risk they will return to the sub-culture of drug use.

The research assistants – the representatives of the target group also gave indispensable help in developing contacts at only to them known locations as well as developing and maintaining confidentiality. Participation in the research was volunteered and was based on a discussion on the research purpose. The researchers occasionally awarded the subjects with a coffee, a drink or a meal. Not all drug users were prepared to participate in the research. A number of them declined to participate due to non-payment. Another reason for a lack of participation was a fear the information would be passed on, that the information would be disclosed to others (parents, employers, doctors, police). Some had bad experiences in the past. For these reasons, all the subjects were provided with an identity protection. We ensured that all collected qualitative and quantitative data remained anonymous. In order to prevent identification of the subjects, we occasionally changed the qualitative statements but retained the message value. The confidentiality gained was observed as an obligation not do disclose acquired, especially personal information in an inappropriate way or at inappropriate places or to inappropriate people as was asked by one of the subjects of the target group: *»please do not tell this to my doctor«.* By disregarding the principal of confidentiality the users would have covered information that could cause them trouble or would avoided to participate in the research from the beginning. In field research it is difficult to limit only to collecting data.
Conversations carried a disclosure of sensitive information that was not connected with patients' health needs. We found ourselves in a situation when we had to decide whether publishing data for the protection of others' interests would overcome the obligation to confidentiality of the questioners. We carried out additional discussions on values of open communication and truthfulness in relationships with people. For example, we explained why it does not make sense to lie to a doctor on »*dealing with therapeutic methadone*« or »*why it is necessary to tell a partner when infected with hepatitis C«. At such times we also offered assistance and counselling*
One of research assistants from the target groups was of great help. The researchers must

provide vulnerable people with all the necessary assistance in understanding the complexity of matters associated with confidentiality. We also have to help them in expressing their needs. With such communication we gained confidence of drug users. A number of participants joined the research because, at the same time, they wished to solve their own problems that they could not solve alone. They requested our assistance in getting health insurance and other documents and for an intervention for priority assistance in a detoxification programme (»*to be seen quicker*«) and for an intervention with a doctor (»*so that the doctor would reduce the methadone dose«)*. They also asked for our help in finding employment, in solving troubles with the police and so forth, which is, at the same time, a unique indicator that certain needs are not met. One female and one male user took us to their home where we had conversations with his/her parents/ partner. When we visited the primary and the secondary family of the drug users, the research work was actually complemented with therapeutic (counselling) work with the family. This also gave us a better knowledge of the living environment of the users, strengthened mutual trust and allowed for additional data collection for the research. Field researchers had difficulty not to offer such assistance especially when drug users voluntarily participate in the research. Offering such help and favours was an actual reward for participation, which at the same time created greater trust and enabled collecting more reliable data. We can conclude that research projects, which include members of target groups, current or former drug users, have to have a suitable organisational structure and must anticipate certain possible specific complications.

6.2. Methodology

Research approach

The research is an active and developmental field research with the following characteristics: guidance towards social fairness and collective development; defence of rights of illegal drug users; influencing people through involvement, empowerment and information; achieving changes in the community and including actual users in identifying problems with a research process. Field research was carried out by people of various education: two research specialists and one public health specialists, two expert workers experienced in field work, and four illegal drug users as research assistants. Field data collection was mostly collected in pairs consisting of a researcher and his research assistant or a member of the target group. We applied a combination of qualitative and quantitative methods.

Objectives and research questions

Key research questions were whether assistance programmes are sufficiently assessable to drug users; Do they have access to information, preventative materials, health care and social security and other support? We studied how and what the users experience as a barrier to obtaining general and specialised help offered by the health care, social and non-governmental sector. We were especially interested with the ability for a more involved participation of the actual drug users in different research phases and their participation in the final political discussion, together with the representatives of key experts (implementers of assistance programmes) and political decision-makers (mostly employed by the Ministries) For the purposes of research, the following (sub-)objectives were important:

- Together with illegal drug users develop a methodology for studying their needs, satisfactions and barriers in accessibility and attainability of the assistance programmes;
- Study the effects of assistance in various environments– health care service, social

security and non-governmental high threshold and low threshold organisations - on user's satisfaction;
- Identify and study factors that prevent (or strengthen) user's satisfaction with assistance in various environments;
- Obtain information on actual experiences with various health care and social assistance programmes on illegal drugs with an intent to obtain an »official picture« of their quality;
- Obtain information on possible breaches of a right to health (accessibility, availability, attainability, appropriateness, quality, user participation);
- Identify and study factors that prevent illegal drug users to seek and/or accept an appropriate expert or other assistance;
- Use data and information collected for expert and political dialogue with other researchers, programme implementers, political decision-makers and actual drug users, with an intent to affect national and local policies and practices;
- Use data and information collected for preparing further research and amending the doctrine of assistance to problematic illegal drug users.

Definition of the target group

The selected target group consisted of problematic illegal drug users who had previous experiences with assistance programmers on health care and social security as well as in seeking assistance from non-governmental high threshold and/or low threshold organisations. These are heroin users who had used drugs regularly for at least one year. Those who have already been treated in the health care system for drug addiction are referred to as patients; those who sought assistance in other organisations are called clients. In fact, drug users use different services offered by various organisations and move from between various institutions - therefore we use the term »user«. Throughout the research, there were approximately 100 informative contacts with users of various drugs. Among these, 59 users satisfied the criteria for research participation. From these, 53 users were prepared to answer a questionnaire or to participate in focused groups. Further enquiries showed that 4 subjects did not fulfil the criteria of being problematic drug users. Considering research finding, various experts who were subject of discussions and evaluations would be included into the indirect, target group. Present research includes the following experts: doctors, other health care workers, social workers, psychologists and other experts who were employed or volunteered in centres for preventing and treating addiction to illegal drugs, in a centre for treating illegal drug addition at the psychiatric hospital in Ljubljana, Slovene psychiatric hospitals, prisons, centres for social work and non-governmental organisations active in a drug field.

Questionnaire

The questionnaire » A survey on experiences (satisfaction) of drug users with assistance programmes» was developed by the Slovene working group for promoting social inclusion and health, together with partners from Hungary (coordinators of the international research Correlation) and illegal drug users in Ljubljana. Our questionnaire is only partially comparable to the Hungarian questionnaire, as it was significantly modified after the pilot phase on the basis of discussions with focus groups. In accordance with common views we added questions, which express characteristics of Slovene environment. The survey constitutes 131 questions, mostly of close-ended type. Each thematic section had at least one additional open-ended question. The questions were arranged into the following 10 thematic sections:

- Social-demographical characteristics;

- History on assistance/medical treatment/treatment and purchase/exchange of needles;
- Satisfaction with the assistance/attitudes of experts towards drug users (doctors and other medical workers, social workers, low threshold non-governmental organisations, high threshold (abstentious) non-governmental organisations);
- Presumed reasons why drug users do not seek assistance which they need;
- Additional questions on methadone or other treatment maintenance.
- Estimated number of heroin users in Ljubljana;
- My experience in a prison;
- Injecting and other risks;
- Consequences due to a temporary closure of low threshold programme Aids Foundation Roperts / Stigme / Cars on Wolfova street;
- My requirements for assistance.

Focus groups

Focus groups showed to be a suitable method for qualitative research work. With the assistance of group and expertly managed interaction we stimulated joint speakers – drug users towards deeper thinking about their beliefs, habits and opinions on appropriate assistance programmes in connection with their drug use. Thereby, we significantly modified the initial pilot questionnaire that was given to us by colleagues from Hungary. We carried out four focus groups, selected qualitative data from 32 problematic drug users including conversations with two 17 years girl prisoners. The majority of subject subsequently replied to an anonymous quantitative questionnaire. All female prisoners who had difficulties with drugs and were held in prison Ig volunteered and participated. The subjects of three focus groups were selected on the basis of their personal acquaintance with our research assistants who were drug users. The selection criteria were willingness to talk in a group, as well as past or current experiences with treatment system and other forms of assistance. The criteria included a recommendation for the subjects to come from various areas of Slovenia (not only from Ljubljana) and to represent various social-demographical groups especially regarding and not necessarily the gender; Great majority (more than three quarters were male aged between 18 to 52) As a desired criteria we recorded their addiction history (less than a quarter were former heroin users, a quarter were experimenting, some were habitual users, others were more or less everyday users). Regarding less demanding research criteria, on the request of the users (their primary criteria was willingness to participate) we respected their requests for confidentiality. This is the reason for not collecting exact demographic data. The information obtained was written down each time and most often, it was written down from memory immediately after a group meeting. Group discussions lasted approximately half hour. After the group dispersed, we talked some more with certain individuals.

Methods of data collection and sampling

For sampling we applied a non-probability approach, including the elements of the »snowball« method. Known users of drugs and certain coincidences served us as a starting point in developing contacts with the target population. Some of them were prepared to bring us to actual meeting points (street, pub, parks, homes…). This approach may also be the subject of prejudice problem as is the fact that the research assistants personally knew the majority of drug users. Using the snowball-approach allowed for the risk of prejudice to be lower. The data was collected with the help of a questionnaire in a form of an interview held at three locations from the beginning of January to the middle of September 2007. In prison Ig, a focus group was set

up and the data was collected with a questionnaire from 21 female prisoners. In Celje, eight drug users that casually answered the questionnaire were clients, participating in a high threshold programme on treating addiction at the institute VIR and they answered the questionnaire at the institute's premises. In Ljubljana, we applied the occasional model with elements of the snowball method and therefore obtained users that answered the questionnaire or participated in the focus groups. The data was collected at various locations in streets, parks, bars and homes. The information obtained was constantly written down and we were writing field journals with deeper insights. The fact that we collected the data from three different sources – prisons, high threshold and low threshold represents specific stratification of the whole sample and reduced errors in making conclusions on the whole population. However, this does not completely eliminate limitations due to a relatively small and non-representative sample.

Data analysis

We interpreted the material collected from various sources (records on conversations held with focus groups, field records, observation records with participation, other sources). The collected qualitative information was first copied, many times reviewed and organised with categorisation procedures into uniform procedures which were then linked with each other, resulting in models or explanations being created. By analysing, comparing and classifying we organised only those parts of texts, which related to the research purpose. In italic, we cited literal statements of the participants, or even more commonly, we shortened or summarised and arranged them into a readable form. Aside from relevancy to the research framework, the most important element was selecting and connecting the contents for data protection and for ensuring anonymity. We therefore changed or withheld personal names, names of (smaller) places, certain institutions and other data through which it would be possible to identify individuals. We generally gave a priority to information given by individuals about themselves or their peers. Rarely we added personal observations and sometimes we included the views of other experts. As coding units we selected various concept terms. A text to which we assigned the same concept, we selected and separated from the text, which referred to another concept and organised data accordingly. Therefore, we obtained a number of concepts, studied their characteristics and importance. From a large number of such selected concepts we selected those, which appeared to us as relevant to the research purpose. We therefore collected the data required which helped us in modifying the initial quantitative questionnaire. We developed the following sections on research questions:

- What is the general attitude of experts towards drug users?
- Who do I evaluate expert treatment received (»my satisfaction with attitudes of doctors, social workers, low threshold and high threshold non-governmental organisations«)?
- What are my experiences with methadone programme, detoxification, assistance from non-governmental organisations, pharmacies, health care and social rehabilitation, assistance in prisons and other type of assistance?
- Were my questions answered in a way that I understood them?
- Did I participate with the expert in making a decision on my treatment?
- Did the expert treat me with dignity and respect?
- Did the experts provide privacy during conversations and treatment procedures as well as data protection?
- Did the expert notify me of rights and obligations I have as a patient?
- How did the closure of the programme on exchanging needles/syringes on Wolfova Street affect me?

Answers to quantitative questions which were included in the above sections were processed with the statistical programme SPSS. We calculated a frequency of all variables and, in the results, expressed them in absolute numbers and percents. The medium value of variables, coded from 1-5 (1 = the lowest; 5 = highest or 1 = least important and 5 = most important), was calculated and the situation evaluated.

Ethics

Researches and researchers on »obstacles and dissatisfaction« with assistance programmes may negligently expose groups as well as individuals to certain damage like economical loss, stigmatisation, guilt and so forth. Researchers must be very discrete in disclosing and explaining the findings, especially because we were studying a relationship between an expert and a drug user. In experiencing a relationship with an expert, drug users are affected by their expectations, current experiences with assistance programmers, their value systems, education and numerous environmental influences. Experiencing a relationship must therefore never be generalised. Experiencing rights is subjective and typical for an individual and a group in a specific moment in expert treatment. Similarly, an expert also participates in a relationship. For these reasons we appropriately amended the statements made during the course of the research in order to avoid recognition. Only when the circumstances were important in understanding the results did we keep them but ensured confidentiality and used language that would not implicate moral criticism of discovered behaviours and occurrences. Possible damage by disclosing general findings on (expert) treatment of drug users was, in interpreting results and especially during the discussions, alleviated by interpreting data in a way that optimally protects interests of all concerned and at the same time is consistent with scientific integrity. The research enlightens until now a very dark unknown side of illegal drug users, as they understand it. When it was possible to anticipate we avoided wrongful interpretation that would cause damage to others.

6.3. Results

Socio-demographic characteristics of drug users

Socio-demographic characteristics for three data sources – low threshold (»street«) population, high threshold population and drug users in prisons - were summarised in table 1 and table 2. Socio-economic characteristics of the subjects interviewed show a very high unemployment. Only 25 % of people in high threshold sample listed employment whereas not one was in a regular employment in low threshold sample. It is understandable that during interviewing all female drug users in a prison or people who had drug difficulties were without regular employment. For a more complete interpretation, data on the percentage of people in education at the time of interviewing is missing. Within further research, it is interesting that the highest percentage of people without a completed primary school fell on female prisoners, high percentage (100%) of problematic drug users from high threshold sample lived with parents when compared to low threshold sample of drug users that were homeless. Almost half of people interviewed (42%) in a low threshold sample did not have basic health insurance, one quarter were without basic and additional health insurance which was an important factor influencing their motivation for seeking assistance or prevented them from enforcing their right to treatment.

Table 1: Socio-demographic characteristics of interviewed drug users for three sources of data, Ljubljana, Celje and Ig 2007

	Low threshold n=24 (45.3 %)	High threshold n=8 (15,1%)	Prison n=21 (39.6 %)
M	83.30%	75%	14.30%
F	16.70%	25%	85.70%
Under 20 year of age	5.66%	5.66%	0
Average age	28.58	22.88	27.67
Without completed primary school	0	0	4.80%
Completed secondary school	58.31%	62.50%	57.1
In regular employment	0	25%	0
Living with parents	13%	100%	0
Living with a partner	21.70%	25%	0
Homeless	26.10%	0	0
Already convicted and in prison	21.7%	20%	100%
Basic health insurance	58.30%	100	33.30%
Basic and additional health insurance	25.00%	100%	66.70%

Table 2: Social-demographic characteristics of interviewed drug users, full sample, Ljubljana, Celje and Ig 2007

	No.	%
M	29	54.7
F	24	45.3
Under 20 years of age	6	11.4
Average age	27,36	
Without completed primary school	1	1.9
Completed secondary school	31	58.5
In regular employment	2	3.8
Living with parents	11	21.2
Living with a partner	7	13.5
Homeless	6	11.5
Already convicted and in prison	25	53.2
Basic health insurance	21	39.6
Basic and additional health insurance	28	52.8

Problematic drug use and risky behaviours

Throughout the research, there were approximately 100 informative contacts with users of various drugs. Among these, 59 users satisfied the criteria on research participation. From these, 53 users were prepared to answer a questionnaire or to participate in focused groups. Further enquiries showed that 4 participants did not fulfil the criteria of being a problematic drug user. From the total sample, there were 67% of those that injected heroin a number of times within the last year and 49% who used injected heroin almost every day within the last month.

The other participants fell in the group of former heroin users or took this drug by exclusively smoking it on a foil.

Table 3: Problematic drug use and risky behaviours

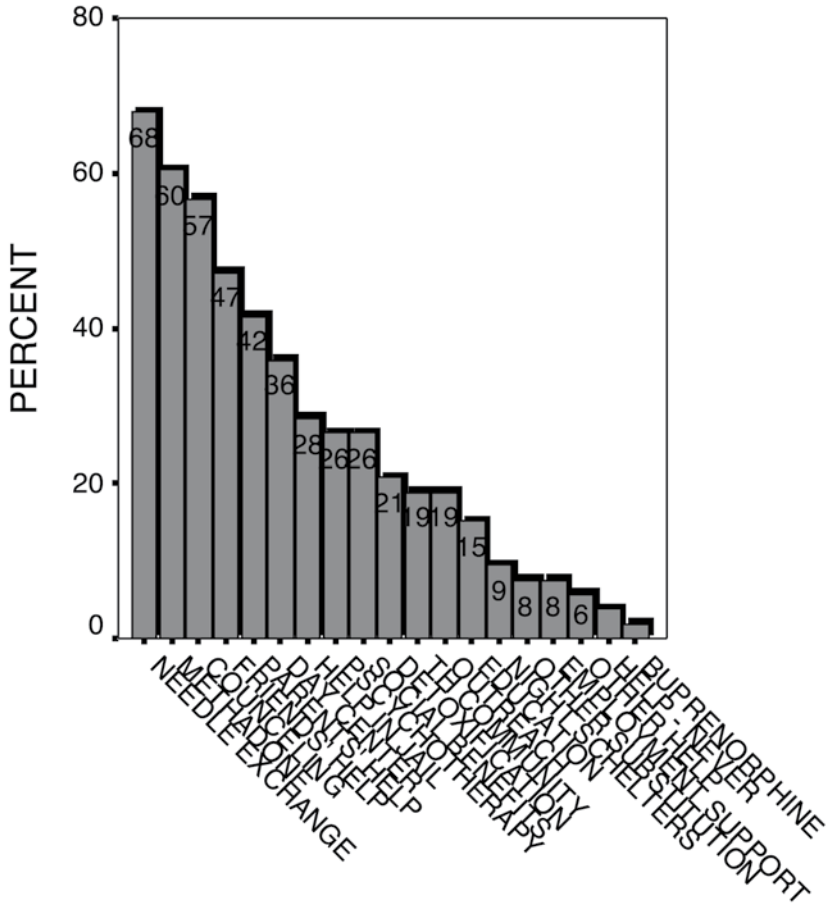
	No.	%
Heroin as the main drug	49	98
Injecting in the last year	34	66.7
Injecting in the last 30 days	23	48.9
Sharing syringes/needles (anytime)	35	68.6
Sharing syringes/needles (in the last year)	14	28
Sharing other accessories (in the last year)	23	45.1
Overdosing (anytime)	22	44
Testing for HIV (anytime)	36	70.6
Testing for HBV (anytime)	35	68.6
Testing for HCV (anytime)	36	70.6

Table 3 shows a high percentage of those who shared syringes/needles anytime (69%) or in the last year (28%). Worrisome is also the percentage on sharing other accessories in the last year (45%) and overdosing anytime (44%), which shows a great past threat of those interviewed. We collected information on testing done for possible infections with HIV, HBV and HCV but without consulting on the results of these tests.

History on seeking assistance

Considering the answers to the questionnaire, the majority of drug users had visited programmes for exchanging syringes and needles (68%), were treated with methadone (60%) and did receive various advice on drug problems (57%). One of key findings of the research was that more than two thirds of participants were of the opinion that now there are fewer barriers in accessibility and attainability of assistance programmes and that the attitude of experts and programme access has in many places improved.

Picture 1: Which form of assistance did you already receive?



Discussions in focus groups also gave a similar picture on the most attended assistance programmes. More than half of subjects were receiving methadone and attending the programme for exchanging syringes and needles at the same time. Before commencing a treatment with methadone, less than half tried to quit drugs without medical assistance. Only a small number, 3 out of 15, were already treated in psychiatric hospitals, 2 people were involved in therapeutic communities abroad as well as in high threshold programme of a therapeutic community.

Some psychosocial characteristics of problematic drug users

Almost all subjects of the focus groups were strongly burdened with various psychotic traumas and life failure. As suggested by research assistants, the first contacts were made on streets, then we moved to a bar or a home of one of the assistants were the conversations were held. With some users we were in contact for some time and meet with them alone, which allowed us to study some of their psychosocial characteristics. Even though it was interesting to listen to their life stories we could describe our contacts as slightly uncomfortable due to them being different. Being different was an expression of their deprivation in psychosocial development. Deprivation in psychosocial development as a rule originated from indecent, frequently poisonous environment at home, and later in school and among peers. As they did not have stimulating childhood and an opportunity for a versatile education and development, they sought solutions in drugs and

other forms of astray life style which reduced their ability for versatile functioning even further but increased them falling behind the peers. Many spoke of traumatic childhood experiences caused by their parents and/or other adults who were looking after them. We evaluated that these deprivations and traumatic experiences in some irrational way balance their behaviour and feelings, shape various psychosocial difficulties and consequently contribute to taking drugs. Use of drugs developed secondary circle of their problems, including further stigmatisation, falling behind peers and social exclusions: *»I changed, I did not care but I felt that I was falling behind my peers... I never finished school.... I left my job.... I spent all the money on drugs and alcohol… I was becoming more and more addicted… I was in a wrong job…. I could not stop until I ran out of money«.*

Evaluating expert treatment by sectors

Drug users were questioned on barriers preventing accessibility and attainability and were asked for their opinion on the quality of accessible assistance programmes. We did bear in mind the old saying »everyone sees the world from his or her perspective« and the facts that many drug users are different as if sick which must be taken into consideration when interpreting their evaluations. One of key findings of the research was that more than two thirds of the subjects were of the opinion that »these days there are fewer barriers« and that the attitude of experts and programme access has improved. Evaluations showed mixed satisfaction of drug users with various assistance programmes. Higher quality for assistance in non-governmental, when compared to public (governmental) organisations was typical. We marked many praises on the friendliness of individual experts who despite poor working conditions make efforts in various high threshold and low threshold organisations:

»Assistance is sufficiently assessable when I need it.«
»I was treat with dignity and respect.«
» I participated in making a decision on my treatment.«
»I was provided with privacy during conversations, treatment procedures and on data protection.«
»I evaluate the assistance given as good.«
»Before commencing, the procedure of treatment and risks were explained in a comprehensible way.«
»I was notified of rights and obligations I have as a patient.«

However, warnings on barriers preventing accessibility and attainability of assistance programmes for drug users from the viewpoint of a right to health were predominate and are alarming. Illegal drug users from one larger city in Ljubljana complained that they were given methadone, due to relocation of the programme upon complains of the local community, *»in an underpass where there were rats and a lot of rubbish«.* One of few clinics that was offering assistance to people who cannot obtain health insurance was on the demands from neighbours »*not allowed to treat drug addicts.«* In one centre for prevention and treatment of addiction to illegal drugs, addicts patients were due to complaints from other patients recommended to »*come for checkups through the back door«.* As we were asking the drug users mainly on barriers preventing accessibility and attainability of programmes and reasons for dissatisfaction, the majority of information collected was critical towards existing expert services. The most complains concerned a lack of friendliness in public institutions, and »*paperwork with no further purpose*« and *»bureaucratic absurdity«.* The greatest dissatisfaction was with the work by the Centres for Social Work, less with health clinics and least with the operations of non-governmental organisations. During conversations we agreed that:

»We can meet anywhere experts who do not have the required human qualities to work with drug users«.
»They are not deeply engaged with your needs, are snobby as if they are gods and you are nothing.«
»Are being more bureaucratic then being experts.«
»Are not capable of understanding those that are different and with it connected effective communication«.
»They are unfriendly, do not know their job…«.
»They do not take enough time for certain people… are too busy.«

Some participants defended their therapists and tried to understand that they also have specific needs:
»There is a need for more expert workers who could give more attention to an individual«.
»Not all are the same… some do understand.«
»There are not many serious conflicts with the experts.«
»We need more therapists who could spend more time with an individual«.

With the aid of a questionnaire, the users evaluated treatments they received or their peers on four key areas of assistance offered: in health care and social centres, and low threshold and high threshold non-governmental assistance programmes. Evaluations were carried out on nine areas of communication between experts and users. The results, confirmed by findings for focus groups on the quality of expert treatment are summed up in Table 7.

Table 4: Evaluation of expert treatment by sectors (1- worst and 5 - best)

Sector	Good attitude :	Assistance assessable	Compre-hensible conver-sations	Appropriate[4] notification on procedures and risks	Partici-pation in decision making	Dignified and respectful treatment	Protected privacy	Notification of rights and duties	Quality treatment
Health care	3.32	2.92	3.6	3.47	3.14	3.18	3.37	3.5	3.16
Social	2.82	2.56	2.97	2.9	2.9	2.	3.1	3.26	2.78
low threshold NGO	4.27	4.19	4.52	4.22	4.38	4.67	4.21	4.23	4.38
high threshold NGO	3.8	3.32	3.48	3.58	3.25	3.76	3.74	3.71	3.54

Legend:
1 – I evaluate attitudes of experts towards drug users as good;
2 - Assistance is sufficiently assessable when I need it;
3 - My questions were answered in a way that I understood them;
4 - Before commencing a medical treatment, an expert explained to me in a comprehensible

way the procedure of a treatment and risks;
5 - I participate with an expert in making a decision on my medical treatment;
6 – Experts treated me with dignity and respect;
7 - Experts provided privacy during conversations and treatment procedures;
8 - Experts notified me of rights and obligations I have as a patient;
9 - I evaluate the assistance given as good;

On all evaluation areas the drug users gave the best mark to low threshold non-governmental organisations, followed by high threshold non-governmental organisations, health care institutions and at the very end the Centres for Social Work.

Experts should have the interests of patients or clients as the most important. The most important is the first contact between a user and an expert or an expert's office as well as general friendliness of all the staff. If this does not exist, a user averts from the office or does not seek assistance due to poor previous experiences. If a user comes across friendliness, professionalism and understanding then this can be the beginning of a process reverse from submitting into a doom of a »junkie«. The users responded the best to those expert workers who were prepared to »*listen«, »talk«* and tried to understand them and learn something about their lives. Unfriendly communication with experts were by the subjects often experienced as making a judgement on their life style and behaviour, as a lack of expert knowledge for working with (problematic) people as well as violence:
»Experts judge too much.«
»One big bureaucracy… they are unfriendly, do not know their job.«
»There is a lot of judgement calling of those who do not want to stop… I would like to be considered, listened to, be given an opportunity to take methadone home, not to be in environment that has a bad influence on me.«
»They judge me for not being quite normal, but I wish a normal treatment.«
»Undervaluing and lack of understanding… they said to me: all you drug addicts are villains, you will never change, you only abuse the help you receive.«
»A nurse was offensive when she had to take blood and could not find veins.«

The clear on unfriendly attitude of (some) experts towards illegal drug users was expressed by a subject who wrote on the questionnaire: »*They treat us like dogs.«*

(Dis)satisfaction of drug users with health care services
People that use illegal drugs have long-term difficulties with mental health. Drug users, with psychotic diagnosis, are in their environment labelled twice which leads to social isolation as both illnesses have a destroying effect on a family and environment. Family members and/or closer environment often do not recognise either illness. People with such »double diagnosis« need psychiatric help which does not seem to be readily available when considering the information gathered:
»I was constantly depressed but none cared.«
»I need a conversation with a psychiatrists but I do not get an appointment.«
»Psychiatrist is out.«

Often, they do not have good physical health, which is demonstrated through an increased risk for a premature death due to associated physical diseases. In comparison with the general population, they have more difficulties due to various infections, poor nutrition, frequent accidents,

poor teeth and various neglected medical conditions and disturbances which was confirmed and shown by the research subjects. Needs for general medical help and other specialised assistance (that does not treat addiction) are according to statements by drug users often deficiently treated or not treated at all;

»Look, this wound I have for few years.«
»I need a dentist«.
»I complained of a leg pain for few months and the doctor dismissed me by saying that the pain is due to whether or because I was no longer on methadone therapy...later it showed I have wrong bone alignment after treating broken thighbone and a surgery is urgent.«
»I have asthma and I am without medicine for two months.«
»I am waiting for gynaecological operation for two months and no one has informed me when I will be seen.«

For a doctor, patient's interests are the most important irrespective of patient's socio-economical status and life style. Even when patients are drug users, a doctor must prescribe medicine that is in accordance with patient's needs and must not allow for external factors to influence the help offered and responsibility to these patients. Unfortunately, in practice this is not always the case. Among subjects, there were those who had difficulties in obtaining assistance from a doctor because they did not have proper documents and health insurance. It is a fact that all citizens, including drug users, when seeking doctor's help must have a personal identification document and health insurance. Drug users often do not have these documents, especially those with the most chaotic life style. They might have lost them or do not know how to help themselves or do not know their rights or how to enforce them. In such cases, they do not know how to obtain the required documents and do not get treatment. *»Without personal identification document and health insurance it is not possible to sign up for methadone.«* The greatest problems have homeless drug users who are constantly moving, who have no permanent address, accessibility for basic hygiene and other need, as well as poor opportunities or none to access various health care or social assistance. It is shocking that the only Slovene health clinic with a surgery for people without health insurance, being the last available help for people at a social end *»does not treat drug addicts due to protests from the neighbours.«* We discovered serious needs of uninsured drug users like ethical dilemmas of doctors under pressure from external factors that affect their work and meeting their obligations to all patients. Generally, we can talk about dissatisfaction with staff requirements in health care (not sufficient number of doctors), which prevents medical experts to pay more attention to problems of drug users. One programme expert worker best described the needs of expert workers: *»Ministries are at fault with their management, which does not benefit people but only their comfortable jobs. People are prepared to work with drug addicts. But many loose interest when they have to fight dirty tricks and chaffting on daily basis. Financing is always a problem. Good quality programmes and professions that work well are not supported. They are left to linger on and fail. Then they manipulate people, drug addicts and their parents. They took half a person... and killed all enthusiasm in me. Take took all my energy. You are constantly under political, administrative and primitive pressures and, if you wish to retain expert stance, you encounter unnecessary obstacles at work, manipulations and schemes that mark our working hours. There is no interest to truly help these people. As if evilness should win. And more. Internally (within the system of dealing with drug problem) people who have only personal or political interests wish to get involved. However, while I am inside, I will defend the profession.«* From such working atmosphere inside health care institutions there are probably a lot of mutual dissatisfaction. Users of health care programmes wish to have more conversations,

more personalised form of assistance, more human friendliness, less moralising and bureaucratic stringencies. The most information gathered on (dis)satisfaction of users or their experiences with methadone maintenance (see separate chapter).

Some criticised mixing the users of methadone (patients included on the methadone treatment programme) with other drug users who sough help. For example being included in a treatment programme where there is a majority of methadone patients pushed some other drug users (who had never injected) into negative social connections where they did learn to inject. *»Physically separating treatment of young beginners from old junkies.«*

These warnings show the importance of providing »healthy centre« within various assistance programmes. People seeking assistance must have more opportunities to mix with peers from whom they can learn life skills without drugs. It is possible that one of solutions is a more important role of a general doctor in a health care clinic that would treat drug users as other patients without psychiatric and other specialised programmes. A number of users expressed a desire to be treated with own doctor. Such treatment would also be less noticeable since drug users would mingle with other patients and therefore be less stigmatised.

Subjects exposed a problem on accessibility of programmes for special groups especially that there are no programmes dedicated to beginners, the existing programmes are less suitable or even unsuitable for beginners, especially for young population that is just becoming acquainted with drugs.

»There is a case when a doctor gave him methadone...my brother…he almost died when he took a speedball (a mixture of cocaine and heroine)… because he does not know, does not have proper information.«

Today, there are a lot of new, young or even children smoking heroine. These are called *»fakers«.* The biggest problem is how to access them as they are »hidden« and do not yet need assistance. The opinions of subjects were that educational system does not offer information that would be available to those who are trying drugs for protecting their own health. As expressed by one of the participants who is supposedly infected with hepatitis C: *We never learned about this in school… if I had information I would have protected myself and would not fall into this…«*

Methadone medical treatment maintenance

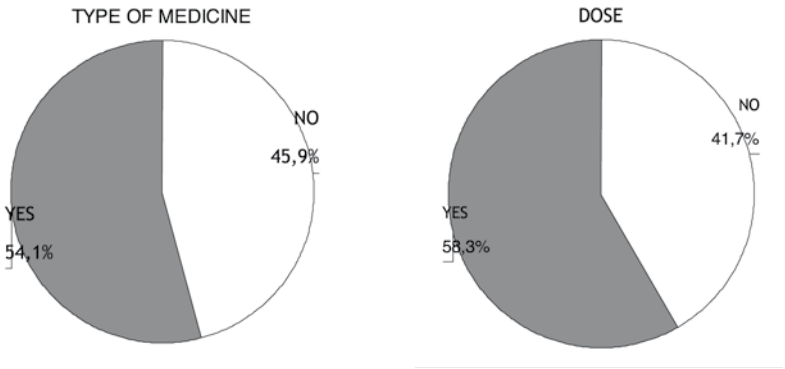
Attitude of drug users towards methadone treatment is still to charged with preconceptions due to lack of knowledge and understanding of a substitution treatment method. Almost half of subjects were afraid that methadone would addict them even more or even cause death:
»Methadone is even more addictive than a horse.«
»Methadone is only an abetment until you get drugs, abstinence is much worst after methadone.«

Participants were not educated sufficiently with the purpose and procedure of methadone substitution. This of course has a bad influence on treatment process. Some were of the opinion that prescribing methadone is controversial whereas others thought that only the practice in prescribing was controversial:
»Even those who are not addicted are prescribed methadone«.
»Doctors sometimes prescribe methadone too hastily, which is not good, as one can get addicted

to it«. However, for at least for half of the subjects, methadone maintenance was useful and even a successful medical approach. Some were even of the opinion that methadone is »at its best very helpful and at its worst cannot harm«. One of the subjects summarized fundamental doubt on the right to prescribe methadone: *»It is only exchanging one addiction with another.«*

For methadone programme, a special supervision is typical that should prevent flowing of methadone onto the black market as well as special and specific rules that are given to patients orally and in writing at the time of the first conversation with a doctor. The rules prescribe that a patient must not use other drugs, must not try to obtain additional methadone, must do routine urine tests and must participate in consulting process. Participants had no real problem with general rules set by a doctor. Only two subjects of the focus group commented that the general rules are »absurd and too stringent«. The majority thought that such rules were »fair«. One was of the opinion that »***doctors should set more rules (….) and together, will supervision for those who are in the programme for a longer period«.*** Daily visits to the Centre did nor represent a greater problem Such regime was recognised for its usefulness and protective measure to prevent over prescribing methadone to an individual, preventing selling of and overdosing on methadone. The majority was satisfied with daily visits to get methadone but some were nevertheless critical: ***»it cannot be the same for me when I have been on methadone for five years«.*** All wished to have more flexibility, discussions and conversations and less bureaucratic rules that make accessibility to these programmes difficult.

Picture 2: Inclusion of methadone patients in decision making on treatment. »Did you have an opportunity to influence the type of drugs and the quantity of a dose?



The majority of those treated obtained from special instructions on appropriate behaviour from a doctor. Some have said that ***»they had signed some contract on rules«.*** The majority of rules were given orally and with reference to behaviour while in a programme: ***»do not come high« or »do not get high in the centre or near the centre«.*** Some mentioned rules on punctuality when attending the visits at the centre, special warnings on prohibited hitting and violent behaviour: ***»the doctor walks around Metelkova and writes down who is there...«*** Many participants agreed that such rules are necessary but some thought that: ***»warnings were exaggerating, for example warning not to hangout and drink in the vicinity of the centre or Metelkova.«.***

Some were worried about attainability of methadone when going on a holiday or when injured or ill. Some participants started a problem on organising time: ***»if you are in school you cannot come«***. The regime of daily distribution of methadone is for most patients acceptable except for one who thought it was ***»unbearable«***. Majority of participants were unemployed or were not in

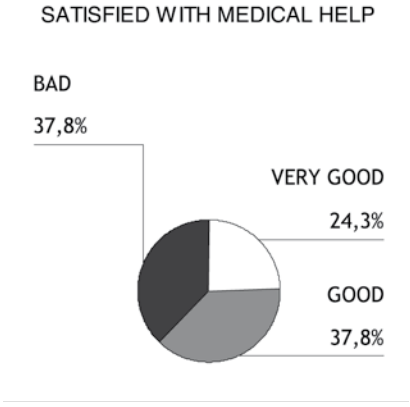
school and therefore the working time of the clinic did not bother them.

Some participants thought that different forms of supervision place methadone patients into unequal situation, which represents a breach of rights to health. *»My rights are breached.«* Some are worried about the supervision but at the same time embrace it as *»help in getting better«.* Rules that refer to supervision over drinking and/or giving urine sample by the participants caused a number of negative comments. Supervising the drinking of methadone and giving urine was by many experiences as discriminatory and stressful. For many, it represented a breach of privacy, disgrace and embarrassment. A smaller number of individuals reported that supervised taking of methadone and giving urine sample is good at the beginning when *»you are prone to abuse but not later as it diverts from the treatment.«* It is important to respect dignity of every patient event a drug addict. Supervision over taking methadone is a good reason for preventing dealing with methadone: *»On Metelkova it is possible to access larger quantities of methadone, as dealing with methadone and other drugs is wide spread.«* Some patients receive methadone exclusively for dealing with it. With this respect, some have warned of harmful procedures when no responsibility is accepted from them. *»Only coming to the clinic and drinking methadone syrup, without further assistance was not good…«* A lot of participants agreed that it was supervision that enabled them to be disciplined and follow the programme, which also protected them from overdosing.

Among reasons stated by the users for their dissatisfaction with daily visits to obtain methadone were continued contacts with the drug scene, which makes it harder for them to break contacts with the old company and the environment that is full of risks to revert:
»Here you are seen by a lot of people.«
»You are additionally stigmatised.«
»There are a lot of dealers around the Centre.«

Some find it unbearable the »forcing» into additional forms of assistance they do not want. Methadone is sufficient for some and therefore do not need further assistance which is sometimes a condition by the experts for being prescribing the medicine. For this reason *»some prefer to buy methadone on the illegal market.«* Others wished to receive more psychosocial support, an individual psychological treatment, a treatment of other illnesses and referrals to other specialised treatments but instead they were only receiving methadone.

Picture 3. Aside from methadone, did you receive any other medical, psychological or social assistance?

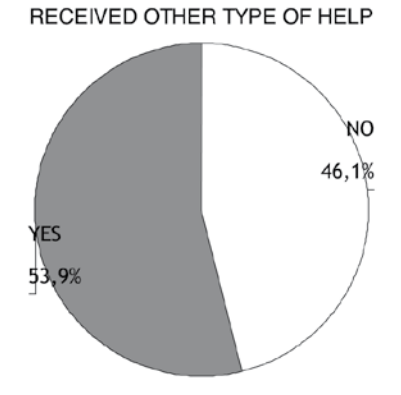


A lot of subjects thought urine testing was »absurd« for this not being a real method to prevent abuse with other drugs. Some thought that they should be carried out more frequently. Some thought that »*the test was unreliable«, »too protective and repressive*« and »*generally was of no use.* Urine testing sample is frequently abused: *»Using urine of a friend instead of one's own.«*

One of participants of the focus group was of the opinion that »*restrictions with no medical foundations can be harmful«.* Some doctors tended to force »*unnecessary rules, regulations and tests.«* Concerning this, the subjects in one focus group concluded: *»Instead of doing urine test for drugs, they should simply ask the patients if they had taken or are taking any other drugs.«* The conclusion was made upon the presumption that the condition for treatment to be »*clean from drugs*« is a breach of patient's rights to health and treatment irrespective of their life style. Only one of the subjects reported that the doctor demanded participation for urine test as a condition for participating in the treatment.

When we asked the participants if they could evaluate supervision in general terms and in comparison with other patients, their frequent answers were:
»Supervision is useful only occasionally«.
»It is useless and even harmful.«
»Supervision is bad due to shame.«
»It is not necessary that all who are supervised would abuse.«
»Interrogations are humiliating.«
»Those who want to abuse will always find another way«.
»Supervision is unsuitable as we are patients.«
»Urine test is most controversial as it is abused.«
Almost 40% of the subject marked the relationship with their doctor as poor.

Picture 4: How do you evaluate relationship with your doctor regarding methadone treatment maintenance?



Relatively high dissatisfaction with personal doctors by drug users on methadone programme maybe partially explained with the following statements:
»When I ask for a doctor they always say he is on a holiday. For treatments with methadone it would be necessary to make Rules that would apply equally to all. Because there are no such rules or are not published, employees at the centres have free rein to treat an individual

as they like. This problem is very widespread. There are sum duties written in the agreement that is signed at the beginning of the treatment but they are not sufficiently defined. Therefore, they treat addicts as they wish.«
»They give unjust punishments to those they do not like. I think this area is open and it is necessary to do something about it. I speak in the name of all methadone addicts.«
»It seems this is money and not medical institution. Employees do not care for us. They are offensive to drug addicts. It appears that we, as methadone addicts, are part of an experiment since they give as methadone very readily and withdrawing from it is, thanks to them also very long. There is a problem with doses. Many drug addicts do not see if they are really getting the dose for him or her. It has happened that they did not pour your dose but you got methadone in a bottle with no writing on it. I think that workers have free rein and deal with us as they please. Nobody knows this nor wants to believe it. There is a need for a number of improvements. First, it would be necessary to introduce psychotherapeutic treatment with institutes like the methadone centre. Youngsters taking drugs mainly need support and expert assistance. There is one psychologist (not compulsory) in the methadone centre but a conversation with him lasts half an hour at most per month. He prescribes numerous tables, which is generally the most common reason for seeing him. There is another problem: in centres that deal with only psycho treatments there is a problem because they follow only one method of treatment which may not be suitable for everyone. Therefore, many addicts are not satisfied and leave the treatment. They return to their old ways.«
Irrespective of doubts expressed and relatively negative thinking of research participating drug addicts, we can conclude the report on the satisfaction by drug addicts with methadone treatment with the following statement: »*majority of junkies would never receive treatment was it not for being on the methadone programme.«*

Detoxification programmes
The primary task of detoxification is to relieve withdrawal symptoms when a patient is getting used to being without drugs. Actual detoxification is not sufficient but it is a useful step on the path to a long-term treatment in a clinic, hospital or therapeutic communities. The subjects were united that the biggest problem for joining hospital detoxification programmes is the waiting period. Waiting for detoxification is within the health care framework one of most commonly unsatisfied needs of drug users: »*Detoxification must be immediate without unreasonable waiting periods.«*
»Detoxification programme must run in a number of centres in order to shorten the waiting times.« »I waited for detoxification so long that I landed in a prison instead.«
»I wanted to join the programme but the waiting periods are so long that it is necessary to wait 6-10 months to be seen.«

There is also a problem with »*inaccessibility*«, sometimes »*illogical*« criteria that are conditions for receive expert detoxification:
»Joining the detoxification programme includes illogical demands – not to test positive for illegal substances even before joining.«

Expert (physiatrist) demands and administrative restrictions are most often understood as an abuse over the patients:
»I did not go to detoxification because I do not like physiatrists since they cause terror.«
»I was treated in the detoxification programme but did not like the way they work, they demand to much and they coerce you, withdrawal is too fast and rules are too strict, you

go there because you need help and expect to receive it but upon a smallest violation they discharge you or increase the therapy to the previous level due to a fear of overdosing.«

(Dis)satisfaction of drug users with social services

Social work with drug users is placed into various systems and groups and in Slovenia. The most common system is in public sector, with social services in Centres for Social Work. Social work is also active in a voluntary and private sector, in public health, schools, legal organisations, police, administration and industry. It deals with a wide range of people who are taking drugs: children, youngsters, old people, poor people, homeless, unemployed and people experiencing various social, emotional, economical, medical or other distress. It deals with everyday circumstances and needs of people, especially those suffering distress due to social and other circumstances. Perceiving social justice and reducing harmful consequences of social changes is very important. It uses a lot of various methods: from providing services and giving information, counselling, training on social skills and team work, individual planning, evaluating risks, legal representation, field work and work in communities. It deals with everyday circumstances and needs of people, especially those suffer distress due to social and other circumstances as well as with global processes and structural changes. Information gathered in this research shows a significant inconsistency with above declared values, work methods and everyday practice as experienced by drug users when seeking assistance in Centres for Social Work.

The majority of the subjects warned of a great »*inhumane…bureaucratic assistance*« in Centres for Social Work. There were complaints about the »paperwork *which has no further purpose*«, as well as insufficient expertise of employees at Centres for Social Work, poor communication and long waiting periods. However, some users had very positive experiences with experts in the Centres for Social Work: *»In my experience, I had no problems with social workers.«*

Below we publish some typical user's opinions showing prevailing dissatisfaction with public services for social work:

»*These are not humane programme, you are nothing, only papers are important.«*

»*When they found out that I am an addict I received the lowest social financial assistance.«*

»Social workers do not sufficiently explain your rights… they are interested only in the information and not the person.«

»*They have no knowledge... no idea.«*

»They have no idea how damaging they are.«

»They do not take enough time, there is no interest in real problems, they are not interested.«

»For social workers help it is necessary to wait for a long time.«

»Requests for discussions last too long.«

»They do not approve of taking drugs and I appear to be standing by you when in truth, they are not interested in this problem and you are left on your own.«

(Dis)satisfaction of drug users with low threshold NGOs

Invaluable role of low threshold non-governmental organisations has also been shown in Slovenia where the country by its self cannot solve all the problems associated with drug abuse, especially its injections. These organisations are the first to recognise drug problems and consequential threat of infectious illnesses in the community. They are more flexible, friendly and attractive for active users who cannot or do not want to stop taking illegal drugs. They are less formal, more innovative and they complement the public sector. The method of outreach work is an important way to reach the problematic population in its territory. Many people do not attend

such programmes to get sterile needles and syringes but for a conversation and information for possible detoxification or treatment. These programmes recruit a lot of individuals to participate in state methadone programmes.

Great majority of the subjects evaluated these programmes as the ones that satisfy their needs the most. They were of opinions that these organisations can be trusted. They all thought that »*there aren't sufficient organisations like these in Slovenia«,* and that they are »*given insufficient funds«,* to use them »*as places for getting high*« or »*safe room«.*

Participants warned of problems on ensuring privacy of an individual who comes to this organisation to get needles. *»One problem is insufficient protection of privacy.«*

Work in non-governmental low threshold programmes may be improved as evidences by the following statements:
»I miss group discussions and I would also be happy to join a club (art's club, woodwork club).«
»There is only one centre in Ljubljana and even this is not a centre.«
»Working hours are too short.«
»Not enough experts and a lot of addicts.«

Effects of closing the programme for exchanging needles/syringes on the drug user's health and communities

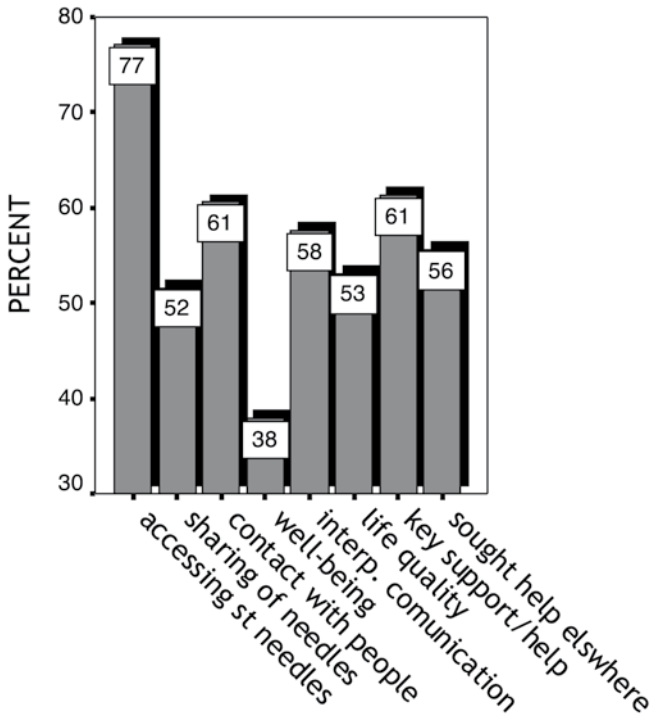
Increased accessibility of sterile syringes and needles through various programmes on exchanging needles and syringes as well as a possibility to purchase these in a pharmacy had an important positive effect on the health of problematic drug users and public health in general. This led to less exchange of needles and syringes between users and reduced transfers of infectious diseases. On these programmes, users that inject obtained information on possible treatment and other forms of assistance. However, in the opinion of the participants, the government paid little attention to the employees' needs in these organisations. Many participants agreed that *»in the future, attitude of the government towards drug users will be worst, repression will increase, addicts will be stigmatised even more... the government supports only abstinence.... with the new government all liberalisation was suspended, repression is greater and the attitude towards us worst and improvements are not expected.«* Despite this, one of the largest programmes for exchanging syringes and needles in Slovenia that was visited by more than 1300 individuals needing assistance per year, a programme within the framework of Aids Foundation Robers (ARF) had to be closed down due to constant obstacles in obtaining financial assistance.

The programme included daytime refuge and stimulated self-protection activities and mutual help. At the same time, it offered health care, referrals to health care clinics, giving needles and syringes, telephone counselling field medical education. Distribution of sterile syringes and needles, triage, referrals to treating addiction were only a part of a complete non-governmental approach to lowering damage caused by injecting drugs. As well as assistance in solving social distress, field social work and assistance on employment. For preventing sexual transmission of HIV virus, expert programme workers stimulated more responsible and safer sexual behaviour. In other Slovene cities such complete assistance have not even developed or are very limited due to various circumstances. Ljubljana programme had through its existence from 1992 to 2007 offered good quality assistance to threatened drug users from the whole of Slovenia and even abroad.
Many participants had already visited the programme by the non-governmental organisation AFR

in the centre of the town and were very hurt due to its closure: »I know a lot of people who got hurt due to the closure of Wolfova. This location is accessible because it is in the city centre.« With the closure of AFR/CARS the users lost to daytime centres for getting together. For some, socialising at these premises was the only connection with other people: »I lost an opportunity to talk with friends.« These individuals may be in greatest distress due to the closure. At the same time they are more prone to suicidal acts, which are proportionally higher among drug users when compared to the rest of the population. We can expect more loitering by the bars, more begging for buying heroin and more criminal acts in the capital. Due to the closure, former visitors had to move to less permanent locations where there is more opportunities to start again sharing the same injection equipment in chaotic contacts with other users: »It bothers me there is no day centre and no place to obtain needles in the city centre as needle dispensing machines do not work and there aren't sufficient number of them.« Some have moved to other programmes: »I was looking for help else where.«

Answers to the questionnaire confirmed the presumptions on problems in purchasing sterile syringes and needles (77%). Worrisome is the information that almost 52% of users thought that sharing needles and syringes has increased. 61% thought that drug users lost key expert and social support in the city centre. 58% thought that the users lost an opportunity to have a conversation. 56% of participants thought drug users sought assistance elsewhere due to the closure of the low threshold programme (picture 5).

Picture 5: Opinions on negative effects caused by the closure of the non-governmental programme on exchanging syringes and needles, Ljubljana 2007



Considering the data obtained it can be concluded that the closure of the biggest programme on exchanging syringes and needles in Slovenia has created conditions for an easier transfer

of infections through (infected) injection accessories. Maintaining safer behaviour between problematic illegal drug users and stable epidemiological situations in the community is only possible if drug users are in regular contact with appropriate expert services and the accessibility of already established programmes continues.

(Dis)satisfaction of drug users with high threshold NGOs

Objectives and work in high threshold non-governmental programmes are differentiated by the work objectives in such programmes. These are mainly creating and maintaining stable abstinence without a substitute medicine. Users are helped to get involved with creative and qualitative life. There is assistance to enrol into or continue with educational programmes and assistance in seeking employment. A drug user is supported in establishing qualitative relationships with the family, peers and new groups. Frequently, the aim is to get the whole family involved with the programme, with an objective to learn to change those family patterns that have not been successful. It is important for a user to live in a home environment while in psychosocial rehabilitation as this type of environment provides an advantage in setting up relationships within a new social network. Therapeutic communities or communes are more suitable for an individual who has sufficient motivation to change but is psychologically to weak to abstain in a home environment.

As it is true with studying satisfaction with other assistance programmes for drug users equally, various participants experienced available programmes on social rehabilitation differently; some more positively, others less and the rest somewhere in between.

Some praised a lot the work of experts in these programmes: »*they were very friendly and persistent*.« On the research questionnaire we mainly wrote barriers on seeking assistance in high threshold programmes on social rehabilitation:

»They are snobby.«
»They are extremely strict.«
»They meddle with the whole family.«
»I was there only once and they were arrogant and unfriendly.«
»There was not enough staff to deal with addicts.«
»There is a problem with the flexibility of programmes, if you are not clean you cannot join a commune.«
»I waited so long that I returned to drugs due to which I was again placed at the end of the waiting list.«

Some participants criticised »*imposition of religion*« in some communes during the rehabilitation.

»To me, the biggest problem seems to be the imposition of religion.«
»You must introduce religion into your life… they resent you and then refuse to help at all.«

If we wish to change the risky behaviour of drug users in order for the greatest number of users to stop taking drugs, it is important to make high threshold programmes more accessible. This does not mean that it is sufficient for them to be physically accessible. It is important to think who can afford them. Social rehabilitation in quality programmes is not for free, especially expensive are the programmes abroad lasting for few years. Individual subjects mentioned the price as a very important factor in making a decision to get involved with such programmes. Conversations showed that the programmes are more accessible to those individuals in higher social classes.

Accessibility of various treatment programmes and social rehabilitation that must be paid by members of a lower social class is significantly weaker:
»I did not go to commune because it is payable.«
»I wish free commune in Ljubljana or Slovenia.«

Prisons
Slovenia is a country with relatively well-established assistance for drug users in prisons. We are one of few countries in the world where methadone is used to treat heroin and other opiates addiction even in prisons. »Clean« (drug free) sections were set up in some prisons and a re-education for those users who would like to completely abstain. We made one focus group in a prison and learned again that within presumed success in offering assistance to drug users, which is often descried by experts, there are »hidden« barriers in accessibility as well as unsatisfied needs of drug users:

»Experts in a prison are not prepared to help drug addicts, they do not motivated, treatment is general and does not allow for many opportunities.«
»In a prison there is no treatment for addiction, physiatrists do not have the time nor the psychologists or social workers... at the same time there is not enough staff, experts and resources.«
»They do not stimulate creativity and positivism but individually treat only difficult convicts… the only treatment requirement is to prove the abstinence with a urine test.«
»There is no personal data protection.... urine test results are known to all in the section… they are showing across the hall they you are positive.«

Participants warned of discrimination and inappropriate treatment: »*only because you are drug users.«*
»In comparison with other female convicts we are in a worst situation, as addicts we have a much stricter regime and are more often punished. «
»For working in the kitchen they test us for viruses, which is not done to other convicts.«
»We had a fashion show, we make jewellery but no one praised us for wanting to do something… only if there is a problem, if you test positive to drugs then they treat us individually... this is not stimulating, even when we try hard there is no praise, abstaining is all that matters.«
»Drug addicts are not believed if they are not feeling well and cannot be on duty they say they are pretending... they do not like to prescribe medicine.«
»I am waiting for a gynaecological operation for two months and no one has informed me when I will be seen.«
»Is an addiction an illness... is it right to put sick people in prisons?«

To imprisoned drug users the most important question was how to integrate into life after leaving the prison. We did not get a satisfactory answer. Usually, the most threatened are individuals without support from the primary family. After leaving the prison, people need initial financial assistance, help to find employment and a place to live. During the whole period of prison sentence, especially prior to discharge, for a reintegration a specific contact by the convict with the external world is important:
»The problem is the last month in a prison when I would want to arrange my life in a community but this option is not available. When you leave the prison you are basically on the streets.«
»When I leave prison, I am on the street…. In prison, at least there is someone to help you find a job, a place to live...«

Pharmacies

Even at the beginning of 1990's, Slovene pharmacies were not allowed to sell syringes and needles to drug users. Drug users were therefore forced to buy or borrowed used injection accessorised found on streets. This way they exposed themselves to possible infections and many did get infected, especially with hepatitis C. These issues have gradually become better and today, sale of needles and syringes in pharmacies should be available to drug users injecting as they are available to diabetics.« Pharmacies on call should be open 24hour a day and should have a developed network across the whole country, in cities and county-side where there is often no programme on exchanging syringes and needles. Throughout Slovenia it is supposing possible to obtain needles through dispensing machines but these do not work due to shortage of resources. But subjects disclosed other sides: *There are no needles available when I need them.«*

Some further information on accessibility or attainability of needles and syringes in pharmacies:

«Needles should be given free but the insulin needles were charged at night according to the night tariff of 500 tolars per one need.

»Selling needles for drug users was sometimes simply stopped.«

»Needle dispensing machine are broken.«

Needs of drug users

Aside from the need to take drugs, drug users have the same need as other people: for social contact, respect and security, appropriate place of living, education and employment. Majority of people addicted to drugs may need medical and other forms of assistance, and with such help they are capable of living independently. Satisfying their needs is connected with organisation and accessibility of assistance programmes. Cooperation between various implementers in medical, social and non-governmental sector is important.

Unsatisfied needs

Even though that general accessibility of programmes has improved, there are still a lot of unsatisfied or insufficiently satisfied needs for assistance. Some results (the first thirteen for drug users important needs) are demonstrated in table 5. From those asked, the most important need is a financial assistance for unemployed, a day centre in the centre of town, a dentist's assistance and assistance for searching for home/room/apartment. On the fifth place was the need for a safe room to inject. Those who were in favour of opening a safe room for injecting in the capital justified it on the grounds that it would provide more safety and hygiene in injecting, accessibility to appropriate accessories for injecting, medical help, and feelings of normalcy and self-supervision.

Table 5. Unsatisfied needs on assistance

Needs	Middle value (1- least important to 5 - most important)
Need for a financial assistance for unemployed	4.12
Need for a day centre in the city centre	4.1
Need for a dentist	4.02
Need for finding home/room/apartment	3.67
Need for a safe room for injecting	3.65
Need for finding an employment/job	3.59
Need for actual participation in a programme for treating addiction	3.54
Need for treating other illnesses	3.52
Need for dealing with matters in court	3.42
Consulting on problems with parents and relatives	3.29
Consulting on problems with partners and friends	3.27
Assistance in getting health insurance	3.2
Need for information on assistance programmes	3.12

On the basis of answers to questionnaires and conversations held, it is possible to conclude that drug users are relatively well aware of accessibility of various assistance programmes. Therefore, the need for information on assistance programmes falls only on 13th place in the scale on evaluating the importance in satisfying the needs.

Why drug users do not seek help

When we talked with drug users why they come for treatment only after two, three or more years of being addicted to drugs we confirmed known findings that they seek help only when they are mature to receive treatment. Due to pleasure for taking drugs, addiction, personality change and other reasons, they have poor motivation for a treatment. They come for a treatment only when due to consequences for drug taking they find themselves in a dead end distress. They seek help mainly due to social pressures and severe medical complications. They put off visiting experts who would require abstinence and active personal growth. Much earlier, they seek assistance from low threshold programmes on lessening damage that satisfies their needs for taking psychoactive substances and that are more tolerant to their different life style. There are a number of other reasons why drug users do not seek assistance they need. Most often because they feel discriminated. They are discouraged by long waiting lists and a lack of understanding of their needs. Among important reasons, they have listed expensive assistance and poor past experiences (table 6).

Table 6. Why drug users do not seek help

Reasons	Medium value (1- least important to 5 - most important)
Users are discriminated	4.2
Waiting lists are too long	4.1
Users are not understood	3.92
Needs of users are not satisfied	3.87
Assistance is too expensive	3.82
Poor experiences in the past	3.78
Over emphasised abstinence	3.71
Experts judge too much and have negative attitude	3.69
Experts are unfriendly and disrespectful	3.63
Time for a conversation is limited	3.52
Users do not have the required documents	3.51
Official hours are inappropriate	3.4
Programme cannot help	3.39
Privacy is often breached	3.38
Problems with geographical accessibility	3.22
Problems with travelling	3.18
Experts do not have sufficient knowledge/expertise	3.13
Users are insufficiently acquainted with accessibility of programmes	3.06
Atmosphere in programmes is too chaotic	2.91
Other reasons	1.6

If we really wish to help a drug user it is necessary to motivate him as soon as possible and direct him to a suitable assistance programme. We must know the most frequent reasons that discourage users from expert treatment. Some are shown at the end of this chapter on why illegal drug users do not seek help:

»I do not have health insurance.«
»I do not have money for a treatment in commune.«
»I do not wish to be registered.«
»I am afraid they will call the police.«

Rejecting proposes treatment procedures

Reasons why drug users do not seek help that they need and the reasons for rejecting proposed treatment procedures are intertwine. Recognising the reasons for rejecting proposed treatment is a key to further relationships between drug users and an expert. An expert who does not recognise these reasons contributed towards dissatisfaction of the user with the relationship and assistance. Very important is informative consent to a treatment, which must be the key in the decision process on treatment procedures. This concerns appropriate information and explanation on procedures, benefits and risks of the treatment. The primary reasons for informed consent is not only of a legal nature but is based on ethical principals of human autonomy and care for one's own wellbeing. Data collected in table 4 shows a presence of significant levels of

dissatisfaction on informing users of their rights and duties and on explanations on treatment procedures. Greater deficiencies in explaining procedures and in acquainting drug users with rights and obligations were felt with respect to treatment in public social and health care centres as well as in non-governmental sector. Such deficiencies may affect trust between users and experts, and contribute to reasons for refusing a treatment or a specific procedure. Frequent depression, other psychiatric problems, fear, and denial of addiction illness and psychoactive affects of drugs at the time of making the decision affect the capability of accepting treatment procedures and the quality of decision-making. Experts some time do not understand why a drug users who is capable of informed consent, who was given all the required information on drug user problem and its treatment, and who has understanding nevertheless declines for him the most appropriate treatment:

»I do not need a detoxification programme because I can deal with abstinence alone.«

»I will not take drugs because I decided for sober life.«

The fact is that many drug users do not trust health care and social system:

»Even though they are experts, their expertise is not so authentic… they know very little about drugs.«

»There is too much condemnation, lack of respect, often you get the feeling they do not consider you as a human.«

Some drug users reject a proposed treatment because they have had bad experiences with experts, procedures or medicine: »*they send you from one door to another…in between you are on a needle again.«*

Many subjects were insufficiently aware of the purpose and procedure of methadone substitution, which has been described in the chapter on methadone treatment maintenance. They were not sufficiently aware of all the consequences of their decision to be treated. Incorrect information on methadone and presumptions regarding treatment maintenance affect their rational thinking. Therefore, doctors must especially ensure whether such patients – users sufficiently understands the important of proposed measures – benefits to be brought by proposed way of life and possible consequences for disrespecting proposed treatment procedures. Unsuitable communication and a lack of two-way information flow are the most frequent reasons for refusing a suitable treatment. An important reasons for communication problem which was noticed by users themselves is a lack of expert staff and the time for talking and making joint decisions on a treatment:

»I never get to see my doctor, they never have the time.«

»In a prison there is no treatment for addiction, physiatrists do not have the time nor the psychologists, social workers... at the same time there is not enough staff, experts and resources.«

Irrespective of personnel or time restraints which are present everywhere, especially in Slovene medical care, informed consent to a treatment is of key importance in the decision making process on treatment procedures. When there is no informed consent there is no trust between a drug user and an expert and quality treatment is generally not possible. Instead of independent decisions by presumably ignorant drug users (quite a number of users thought »they know more about drugs than doctors«), it would be better to suggest to a user to select another treatment programme or another expert. In such instances it is better to refer a user to another assistance programme, which may be more suited to his/her needs.

Needs of some special groups

Understanding the needs of people who (do not) seek help due to problems associated with drug use is of prime importance in developing effective responses. Analysing the needs for a treatment and other assistance shows that drug users, when they are referred or seek assistance

as users, generally represent a varied population with significantly different needs. This means that various answers are needed in order to accommodate the needs of individual drug users. The needs are intertwined and dependant especially on the length of user's history, namely how long has it been from the time a drug was taken for the first time until the first attempt to seek expert assistance or our interviews. This allows for separating the needs of individual subgroups of drug users. Help with employment would be needed more or less by all users. Beginners, experimenters and occasional users wish to have more day centres and options for night centres, more information on risks, a representation for their rights, an easily accessible and attainable assistance programmes (low threshold detoxification, a safe room for injecting), a financial help and help with employment. Regular users have a number of varied medical and social needs. On the basis of information gathered on specific needs, we can make a list of some special groups:

- People after a discharge from a prison;
- People after a discharge from a commune;
- Female drug users, mothers with children;
- People with double or triple diagnoses (psychiatric patients, infected with viruses, disabled people);
- Homeless;
- Unemployed;
- Students;
- Hidden drug users.

Hidden population of drug users are generally regarded as a group of beginners or occasional users when assessed by considering the length of their history or the intensity in drug use. Among them there are a few stabilised chronic addicts who do not wish to be registered. Therefore they reject assistance from (traditional) expert institutions.

We noted needs for the following programmes, which are, in opinions of the users, insufficiently or not developed at all:

- A crisis centre or low threshold detoxification programmes;
- Programmes on helping to find employment;
- Programmes for accommodation and various forms for living, including various types of apartment groups (for people who are still on drugs; for those who abstain, for people who return from a commune, for people who are discharged from a prison, for families or single mothers);
- Programmes for giving information on the field and assistance programme that are more accommodated to various target groups (for users-beginners who are not yet seeking assistance; for those who are rejecting assistance and for those who do not know to help themselves);
- Additional assistance and programmes for people with problems in mental health and with combined additions (double diagnoses, gambling, eating disorders, alcohol or other additions);
- Programmes on life inclusion after a discharge from a prison;
- Separate programmes (counselling and informing) for beginners from the programmes (treatment, rehabilitation and re-socialisation) for chronic addicts;
- a safe room for injecting (for heroin addicts who cannot or do not want to stop taking drugs).

Cases of human rights breaches

Equal access to health care and social services and their quality should be one of the foundational objectives of health care and social security organisation and of other assistance for drug users. It must include frequently neglected social reintegration and equal access to high threshold and low threshold programmes. Cooperation by actual users, their representatives, especially non-governmental organisations is necessary in planning, setting priorities and deciding that will realise their rights to health through various ways. Rights of communities and of those who have participated in implementing expert services are also important. As already mentioned, in treating drug users, the gravest problem are not experts' errors but rather, the attitudes of some experts, organisations and communities who frequently appear or are actually unfriendly and do not benefit in creating confidence between a drug user and an expert. Users do not even know where to turn for certain explanations or information and where can they complain if they are not satisfied: *»to whom shall I complain?« »*

Right to health and other rights

It is known that many doctors (and other experts) think as stated by one doctor during a discussion on the Act on Patients Rights: *»If we are to be treating as requested by patients we would not need a medical degree at all«.* Then he explained: *»Freedom to accept or reject a medical procedure does not mean that a doctor must treat as requested by a patient even if this wish is not in accordance with a medical doctrine.«* In medicine, independence (autonomous) is one of the four principals of medical ethics and is a right of a patient to decide on his own on suggested medical procedures. However, in medicine and other professions with less developed ethics on treating patients, problems with the principle of independence are often encountered that are linked to over paternalistic relationship between experts and drug users. The degree of paternalistic attitude affects the degree to which a user's right to independently decide on his/her health is affected. A distinct paternalistic attitude leads to a decision being made by an expert and not a user, which may be harmful in certain circumstances; when it is shown that a drug user is not capable of making a decision alone then such an attitude is nevertheless justified.

Drug users are social groups that are due to threat, vulnerability and legal sanctions associated with drug use limited in enforcing their rights. This does not only concern a right to an independent decision making on personal health and social and economical rights but also a full spectre of human and citizen right, including wider rights to health, health care and social security. Under the Constitution they should have, as other citizens do, a right to respect a personal human dignity, to own determination and cooperation in making decisions that concern them. In Slovenia, taking drugs is not expressly illegal, illegal are the acts associated with it (for example buying, trading, possessing, giving to others). Of course, it is difficult to imagine being able to take drugs without possessing them. More or less all drug users suffer from consequences of negative discrimination, which affects their self-image and health. Our research has shown that drug users, especially those with no permanent residence and no health insurance are often human rights breach victims. On the testimonies of subject we can derive the following type of breaches:

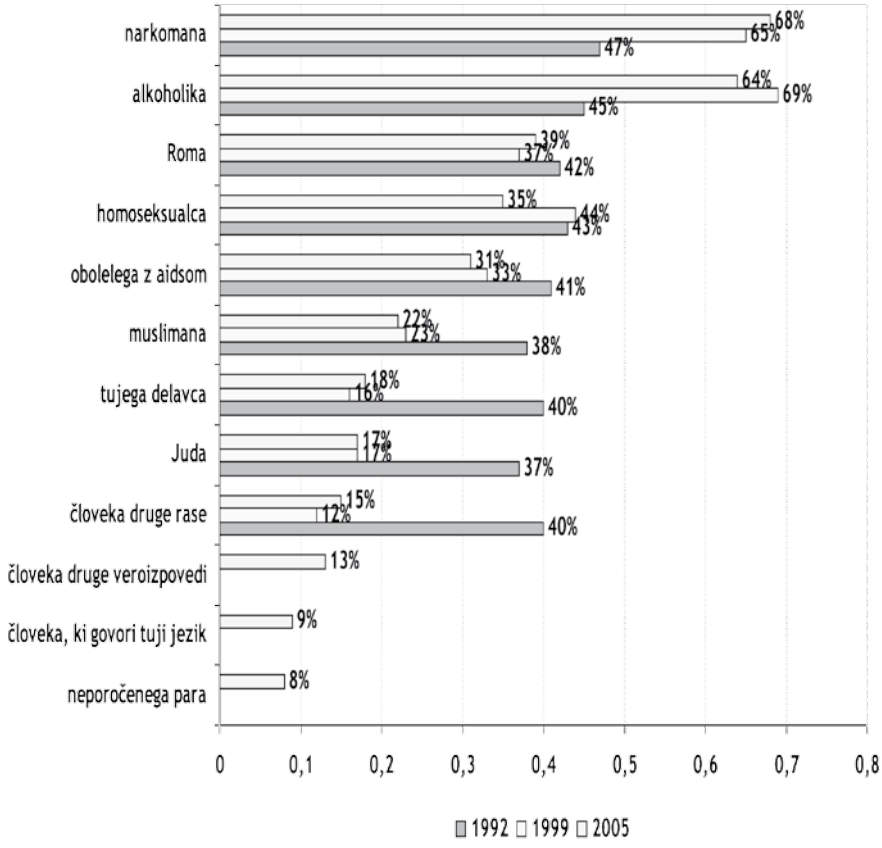
- A number of discrimination cases due to a different life style;
- A right to basic health care;
- A right to dignified human standards (food, accommodation);
- Instances of humiliating behaviour and punishment;
- Rights of disabled to special care;
- A right of parents to contacts with children;
- Freedom of movement and assembly;

- A right to information on rights;
- A right to independence and privacy;
- A right to judicial protection;
- Individual instances of cancelling permanent residence and all rights associated with permanent residence as is a right to work, basic health care, social security – so called deletion.

Stigmatisation and discrimination

Research on Slovenian public opinion shows that Slovenia is a country in which a level of tolerance is not problematic when compared to the EU average. Indifferential level of a lack of tolerance to various »different« groups was typical in 1992. In later years, there is a significantly lower tolerance to groups who acquired their differential characteristics »through own acts« There is a high level of intolerance to alcoholics, drug users and male homosexuals. (Picture: »Does not want as a neighbour.«) There is intolerance to those who are »at own fault« for being different and for having rejecting characterises

Picture 6: Does not want as a neighbour



Text from top to bottom: a drug user, an alcoholic, a Roma, a homosexual, an aids patient, a Muslim, a foreign worker, a Jew, a person of another race, a person of different religion, a person speaking a foreign language, an unmarried couple
Source: FDV CJMMK, Slovene public opinion, 1992, 1999, 2005

The majority of subjects agreed that the »attitude of the profession has somewhat improved in last years but the attitude of the society has not.« General labelling, rejection and social exclusion of people who use illegal drugs increases their personal suffering and contributed to their deficient ability to enforce their rights and interests. These are another barriers in accessibility and attainability of health care and social security. Due to fears of discrimination and consequences brought by it, users often do not seek assistance even though they need it. To the question why he does not seek expert assistance for addiction and poor physical health, a participant replied: »I do not want them to find out am an addict because I would loose my *job.«*

In focus groups we talked about »people with drug phobia« and »drug phobia«: *»As soon as it comes out that you are an addict or a former addict, you are stigmatised forever«*. The label, which can rest through life on a recognised drug user, is one of key obstacles in effective treatment, rehabilitation and reintegration. In this regard, already poor self-image of a user is diminishing even further:
»If you are a junky you are rubbish«.

»Due to complaints by the local community, the methadone centre had to be relocated to unhygienic place where methadone was given in an underpass full of rats and rubbish.« «

Drug users may be expelled from school or work even if they do not violate any school rules or rules at work. It is sufficient to be stamped as a »drug addict«. With the label »drug addict« it is practically impossible to get a job. People who do seek help for addiction are fired. A drug addict met her boss by chance when she went to get methadone at the clinic: »Methadone treatment was used against me and I was fired from my job.«

There are a lot of similar testimonies with regard to unequal treatment in connection with drug use:
»*I was looking for a job and got an answer… we do not take people like you… you drug addicts are the biggest blight.*
»A dentist did not want to give me an injection when pooling out a tooth when I told her I am on methadone treatment.«
»I was punished because I was loitering in front of Metelkova due to methadone….loitering of junkies is prohibited.«
»Social assistance was reduced when they found out I take drugs.«
»They want me to go to the clinic through different doors than other patients.«
»I have problems with social services because they do not allow contacts with my child and my wife.«
»There is still discrimination in pharmacies when purchasing sterile needles… they look at *you as rubbish…and if you have a diabetes then they pity you and there is no problem.«*
»For your type, we do not have.«

Health insurance
All people in Slovenia who meet the conditions under the Health Care and Health Insurance Act must arrange a compulsory health insurance. They need certain documents that must be submitted upon the registration for the compulsory health insurance, which some drug users for various reasons do not have, consequently prohibiting these people an access to health care. If one has no citizenship, a permanent residency or a postal address, he/she cannot arrange a health insurance. With higher unemployment and employment uncertainty as well as other accommodation uncertainties there are more and more such people, increasing the barriers to accessing and attaining health care services for socially excluded people. As a response to this deficiency, a clinic with a surgery was opened in Ljubljana and Maribor that is offering care to people without health insurance. But due to pressures from neighbours, the Ljubljana clinic does not offer assistance to illegal drug users. Users who have basic but not additional health insurance also have difficulties in receiving care from public health. Public health network does offer assistance but without additional health insurance they cannot pay for medical services or buy prescription medicine due to poverty. A special problem is social rehabilitation and inclusion of users into various forms of payable programmes, which run medical treatments not covered by health insurance resources.

Drug users also encounter problems with a right to a salary compensation when absent due to long-term treatment or rehabilitation in communes, especially abroad. Further separate problems include prison discharge, communes, hospitals for various treatments; medically intensive treatments, for example drug detoxification when special assistance, care and security is needed but some do not have even a suitable accommodation. Even in instances when people

have accommodation in a shelter, of which there is not enough of them, their care is often unsuitable since shelters do not have trained staff for post-hospital care. Special problems are prematurely aged or disabled drug users. A suitable solution in such instances would be to accept an individual in an old age home or in another suitable programme. However, there are not enough such programmes, or joining an old age home due to waiting list and lack of finances is not accessible to drug users.

Protection of personal data and privacy

Information on illegal drug use is certainty especially sensitive personal information, which must be protected with legal, organisational and appropriate logistic-technical procedures and measures. All expert who directly and indirectly offer assistance to drug users are under obligation to protect individual's personal data in accordance with expert ethics and legislation. Users have warned us that despite this, breaches do occur or fears of a breach are present which is the reason why certain users refuse to seek help and join a programme. We state some typical breaches of personal data protection which were written and disclosed by the subjects:

»Because the area is not large everyone listens to our conversation.«

»I miss privacy during urine tests.«

»I did not join a programme… everything would become known.«

»More anonymity is urgent.«

»Anonymity and discreteness is urgent.«

»Everybody in the section finds out the results of urine tests, social workers shouts across the hall that a result is positive and everybody then treats the addicts according to the urine test result.«

»It bothers me that they do not respect privacy… they collect a lot of information for which I could be pursued by the police… where does this information go to?«

»They send information to the police.«

Social reintegration

Illegal drug users cannot and do not know how to enforce the majority of their rights which has a significant effect on limiting their living opportunities, often pushing them into grave stress and reversion. The level of their social integration into daily life is a good indicator of enforcing in practice the principle of protection of human rights of all citizens, namely it provides for true equality. Approaches of social integration of drug users are to us not a new concept. They are defined as intervention with intention to include former or current problematic drug users into community. We differentiate at least three pillars of social integration: help with accommodation, help with education and help with seeking employment (including vocational training). Other measures can also be applied like counselling and activities in free time. When comparing to medical treatments, social integration is significantly less recognised response to problematic drug use. »The problem is that you are left to your self and do not know how to look for a job.«

Separate problems are discharges from prisons and/or various therapeutic communities and communes when people would need special assistance but do not even have an appropriate accommodation.

»The problem is the last month in a prison when I wanted to organise my life in a community but this option was not available. When you leave the prison you are basically on the streets.«

»It is necessary to include us in the society, not only to support abstinence, training, work. When you leave a prison, start-up money is necessary...where shall I go.... back to streets?

Homelessness

Homelessness between drug users is serious and growing problem that is becoming more noticeable. 26% of drug users from low threshold (street) sample described themselves as homeless (table 1). Homelessness represents utmost pilling of social exclusion in a number of areas. The most frequent is exclusion from a family, then from education, employment, medical care, information system, accommodation opportunities, and especially a lack of medical-social networks that could compensate insufficient access to social resources. Homelessness exists in different forms. The most common form of homelessness among the subjects was rotating between various accommodations. These individuals are not included in an educational system and neither are they employed. Their social networks are connected exclusively with drug users and are useless in terms of social mobility. Their daily activities are similar to activities of »real« homeless people. Certain periods were spent with friends and acquaintances where they were getting »high« together. Many occasionally returned to parents who have not fully cut off ties with them. Some had rented an apartment during certain periods when they were dealing drugs and earned enough money. Therefore, they had an accommodation but were excluded from productive life. Majority did not want to use services of organisations for homeless since they did not consider themselves are »real homeless« and especially, they would have been presented as »unwanted« drug users which they did not want. They preferred to move daily from acquaintance to acquaintance, from one accommodation to another, and sometimes even slept in basements, stairs, trailers, or under a bridge. They felt that this type of homelessness was only an intermediate phase into »full« or »real« homelessness. Prior to doing into prison, one of important factors associated with real homelessness was: »where shall I go after the prison?« Living in a prison often meant completely cutting off ties with parents or other relatives. Even returning from a treatment in communes for some meant returning to streets if parents or relatives did not let them in: *»After returning from a commune I was on the streets again.«* There is a shelter for homeless illegal drug users since 2002 but it has only 15 beds, which is not sufficient when considering the gravity of the problem.

»There are no shelters or they are full.«
»Help in finding a room when you find yourself on the streets.«
»Place for personal hygiene.«
»Need for a shelter... parents threw me on the streets.«
»To bathe, dress, talk and sleep, like a human.«

Unemployment

Only 4% of drug users from the whole sample was in regular employment (table 2). With reference to improving the quality of treatment programmes, 53% of drug users wished to have specific assistance in seeking employment (table 5). The need for assistance in seeking employment was expressed even more than a need for a treatment. This is understandable since this population has great difficulties in searching and/or maintaining a job due to labelling and social exclusion.

Drug users marked solving individual's employment problem as the most urgent problem that would positively influence taking less drugs: *»If I was employed I would not take drugs.«*

Understandably, this is a complex problem, which must be solved in an expert way. Administrative procedures alone are not sufficient. Users wish for an introduction of individual counselling approaches in the process of assisting unemployed people seeking employment. Such assistance the users would need in a number of other areas: *»help to find a job… a financial assistance for unemployed… looking for accommodation… dealing with matters in court… help in organising health insurance… this is for us the most difficult.*

6.4. Discussion

The key research question was whether assistance programmes are sufficiently accessible to drug users. Do users have access to information, preventative materials, health care and social security and other support? What are their (subjective and objective) needs and how satisfied are they with expert assistance. We studied how and what the users experience as a barrier to obtaining general and specialised help offered by the health care, and the social and non-governmental sector. Our presumption was that accessibility of specific and general assistance programmes is an important precondition for users to participate in a programme. But as our research has shown, this is not sufficient. Accessibility of assistance programmes is not the same as their attainability and quality. Therefore, aside from the findings of the epidemiology research, knowing illegal drug users' needs for assistance is necessary to be included in evaluating the suitability of programmes. We must collect information on wider social-economical situation as well as narrower and wider breaking and stimulating factors of threat, vulnerability and participation in treatment and social rehabilitation programmes. Poorly planned interventions, unsupported with scientific findings and other information are not only financially ineffective, they are also ethically problematic. There are a number of examples of unsuitable conversations on drug problems that show long term negative effects. Therefore, the research shows the effects of closing the largest programme for exchanging syringes and needles in Slovenia on the wellbeing and health of drug users in community.

By publishing research results in this publication, we wish to bring attention to such and other similar rejections that arise despite the statements on backing up the principle of fairness and thereby contribute to improving suitability of treatments for illegal drug users across the country and elsewhere. The concept of cooperation between citizens and patients in making decision on personal health is showing to be more and more important with the objective that health care and social services would suite the needs of users better and would be more democratic. The view, promoting a right for especially threatened individuals and groups to participate in health care and social processes, places new challenges onto the health care and the social policy as well as on educational and research system. Our research findings also warrant a change in health care and social practice work with illegal drug users. In accordance with developmental approach based on scientific findings, a concept of drug addiction as an illness is carrying more weight. In many instances, drug use develops into addiction and secondary illnesses that require expert (medical) treatment on the basis of scientific findings and not ideology. In this regard, drug addicted patients must have equal opportunities for a medical treatment irrespective of their life style. Medical treatment and other assistance for illegal drug users must be more integrated with the general health care and social services.

One of the key findings of the research was that more than two thirds of the subjects were of the opinion that in the present time there are fewer barriers in accessibility and attainability of assistance programmes and that the attitude of experts and programme access has in many places improved. But the research nevertheless showed that a lot of improvements are necessary for implementing principals on protecting human rights and participation of drug users in active care for their health. Even though a lot was done in the past ten years in the area of making assistance programmes more accessible to illegal drug users, there is still a lot to be done on attainability, acceptability and quality of assistance. These areas may be improved by stimulating better information exchange and dialogue with various partners on implementing rights of illegal drug users while giving warnings of their specific obligations. It holds no doubt that unfriendliness,

discrimination, unnecessary administrative barriers in seeking assistance occur in a relationship between expert – user. Failure to be included in the decision making process on personal health may be an uncomfortable experience for a user which must be eliminated whenever possible. Much more fateful may be deviances from a good expert practice since they provide illegal drug users with timely and correct diagnosis of an illness and an expert treatment method or other assistance.

Relationship between experts and drug users is complex and mutual experience of rights is varied. In the research we found many instances with poor organisation on seeing patients or clients recognised by users to which they rarely complained for other reasons as well like »existential« dependency on the expert or their organisation. Waiting for a medical treatment is common in other areas of health care and social security, but are not self evident and could be removed through an appropriate organisation of eliminating waiting lists. Frequently, the profession did not defend the (subjective and objective) expectations held by drug users. In many instances, treating addiction was not successful and other expectations on recovering were not met. In many instances, our research noted feelings of guilt which developed from actual discrimination for which there is no justification. Taking into the considering the research findings and other observations leads to a conclusion that illegal drug users are the most discriminated population group. In 2005, 68% of residents would not have an illegal drug user as a neighbour. Therefore, they are often inhibited in seeking health care and social assistance. Barriers exist in setting up new programmes for health care and social rehabilitation. Suitable jobs and programmes for social integration are almost non-existent. Barriers in accessibility and attainability of programmes are an important reason for their dissatisfaction towards existing expert services. It is difficult to distinguish whether dissatisfaction of users is a result of a general discrimination, expert's work or a lack of financial resources for assistance programmes. It is important to emphasise cases of breaching the most important patient's rights - a right to a suitable expert treatment. Information on not satisfying the needs of drug taking patients' and client's cannot replace the actual profession in evaluating the expert assistance. By carrying out such a research we obtained specific perceptions on ethical, communicational and medical-organisation problems that arise in a relationship between experts and drug users.

In group-interviews, the importance was stressed on human qualities of an expert, a quality in understanding being different and ability for effective communication. The users responded best to those expert workers who were prepared to listen; who did not mix punishment with medical treatment; who tried to understand them and learn something about their lives. There were a lot of complaints about »*inhumane experts – bureaucrats*« in certain programmes who hold exceptionally distant and negative attitude towards his/her clients for whom he/she should be caring. These are most common in the Centres for Social Work and less in health care organisations. They were more satisfied with work by employees in high threshold non-governmental organisations and the most with low threshold. This is understandable from the view of the selected target group, members of which were problematic drug users with significant number of them in need for low-threshold assistance. Interpreting dissatisfaction of drug users on certain experts and assistance programmes requires broader consideration on suitability of assistance programmes for illegal drug users. A concept of suitability of assistance programmes is much wider than just the experiences of drug users. It is necessary to pay regard to epidemiological and other research data, ethical aspects, expertness and economical effectiveness of programmes. Even just articulating the barriers in accessibility, attainability and specific needs as they are understood by actual drug users, may have an important contribution to making changes for the better and to bringing about adjustments and innovations on improving attitudes on illegal drugs. Justification of criticism must be interpreted in a context of a complex

relationship of the whole community towards a threatened and vulnerable population. Different attitudes of a community to drug users would also bring about more changes in operations of expert services. Nevertheless, assistance programmes must be improved even further by taking into consideration the needs of drug users.

The fact is that different systems on assistance to people in need, especially health care, are presently in crisis in many European countries. Many of them have financial and organisational challenges. Economical and political reasons force the governments to reduce costs on assistance to threatened and vulnerable groups, including health care and social security of illegal drug users. Parallel to this, »smart« governments aim to change and improve the effectiveness of existing health care and social assistance programmes. In some countries, they have started with a reorganisation, with an objective to improve quality, cost effectiveness and quality of services that meet the needs of drug users or different needs of modern societies. Financial crisis is on the rise everywhere as there are greater number of people who try drugs and become addicted. At the same time, expenses for health care and social system offering assistance are rising. Aside from financial crisis, we also have »knowledge crises«. As high threshold programmes are more challenging and more expensive, and also protect rights of drug addicts better, the experts and the government support the programmes on minimising damage. Even people who fall ill due to drug use most often are not motivated for a treatment that requires changing unhealthy life styles. They have certain expectations on assistance offered mainly by programmes on minimising damage. This is most likely the greatest satisfaction with the low threshold assistance programmes in the present research. On the other hand, it is known that the assistance system carries no key influence on the health of the population. More important are general economical and political influences, especially social inclusion in a community and a possibility to participate in making decisions on protecting personal health. The suitability of health care and other assistance available to drug users is now frequently evaluated in term of the measures meeting the needs of the users. Their satisfaction with assistance programme available is assessed this way. Many experts are of the opinion that users cannot satisfactory decide on personal medical treatment and evaluate the suitability of services in areas that requiring expert knowledge. All drug users, especially in beginning stages of treatment are not interested or capable for active participation as they are not capable to confront present situation. They are not motivated, are inactive and have difficulties in recognising their interests and life objectives. They are not aware of all the consequences of decisions on selecting a treatment offered by the society. In such cases, a representative is required, most often a close family member or other close person or a field expert who puts social pressure towards motivating and guiding before important decisions are made regarding a treatment. It is also necessary to evaluate what are actual needs of drug users who presumably need assistance and what type of treatment would fit their wishes best. If an evaluation is not possible, treatment offered is the one regarding which it is believed that it suits personal interests of an illegal drug user best. Irrespective of divided opinions on the capability of illegal drug users to decide on personal health and treatment, there is an increase in appeals for nurturing and maintaining good communication and relationship between drug users and experts. This includes avoiding over paternalistic attitude of experts. Over exaggerated paternalism, this being supervising drug users whose needs have been taken care off through understanding of these needs by experts was condemned by majority of participants. Excessive paternalistic attitude means that the experts and not the drug user makes a decision in all treatment phases which can frequently be bad due to prohibited influences on the principle of independence. It may represent an elimination of certain rights to health, treatment and autonomous decision-making, and may lead to various forms of discrimination, which is shown as discrimination, mocking, humiliating and an abuse of these people. There is also a crisis on perception of suitability of

various high-threshold and low-threshold assistance programmes for various drug users. High-threshold programmes are more challenging and more paternalistic. Low-threshold programmes are less demanding and give more autonomy to drug users. The strictness of high-threshold programmes often reduces their attainability. Strategically, there is no consensus on actual needs of drug users, which is shown through priorities on various approaches or assurances on uniform accessibility of high threshold and low threshold programmes. It appears that not even one programme alone can provide suitable assistance but rather, it is necessary for them to work together. In order for the government to exceed the above exposed critical situations it must develop policies and strategies, which will ensure uniform accessibility to various programmes and will also strengthen the rights of people, using illegal drugs. This requires cooperation by the representatives that are drug users even when making political, health care and social securities decisions. Even the problematic drug users are very heterogeneous group. Many are very threatened and vulnerable and incapable of making health care decisions. There are also those who are better informed, with high rehabilitation or a substitute therapy enabling them to participate in educational, employment and other processes. Nevertheless, due to stigmatization and social exclusion they have problems with equal opportunities. Currently, drug users, their representatives and organisations in many countries act as a new partner with an ability to equal selection and decision making even in political and other social processes. Such cooperation must be an integral part of health care and social security systems, involving a sufficient influence of all interested groups including drug users and civil organisations that are active in solving drug problems. New perceptions represent new political challenges in drug area and health care, social, educational and research system, which must appropriately reply to expectations and demands of drug-taking citizens.

The research analyses the influences caused by the closure of the programme on exchanging syringes and needles in the capital in the light of fears on spreading infections diseases. It also warns of other increased health risks and safety of affected drug users and communities. At the same time, the closure of the largest non-governmental organisations shows system confusion in financing and recognising the importance of non-governmental sectors working in solving drug problems. In Slovenia, we have 15 years of experience in giving non-governmental assistance to problematic drug users and we should not allow closing successful programmes due to a shortage of resources or appropriate political support. On the other hand, the system of public health care and social insurance requires more flexible organisations in which the experts seek drug users and in which the experts know how to listen to their needs and reverse.

6.5. Conclusion

The objective of the present research was to demonstrate a lack of equality in health of illegal drug users in attention centres, to contribute to a better social justice on supporting the protection and improvement of health of these especially threatened and vulnerable groups and making required changes in communities. The present report aims to provide data, based on evidence, on inequality in health of illegal drug users, which arises from their life style and wider social-political and economical factors. We also studied general and specific needs of drug users. The concept »need« is a feeling of lacking something and has an objective as well as subjective aspects. For these reasons, interpreting results on quantitative and qualitative needs is very complex. The purpose of the research was for drug users themselves to evaluate accessibility, attainability, acceptability, quality and fairness of expert programmes and services. The first

step was made through their active participation in identifying problems in the key phases of the research process. In general, their fundamental need is treating drug addiction. However, users evaluated this need as less important. Drug addiction, when compared to burning social problems and other medical problems, appeared to them as a lesser issue. Aside from subjective feelings of satisfaction, an important role was played by career characteristics of drug users that suit »subjective needs«.

Illegal drug users are a group that cannot be avoided in the framework of ethical dilemmas on expert treatment. Users are frequently excluded in making decisions on personal health due to preventative or protective measures. The drug users group has individuals with very different spectrum of problems. Many of them are capable of making independent decision on personal health. Experts have very different views on independency of drug users. In majority of instances it is important to adjust the quality of assistance reasonable defended by an expert and the desire for a quality life defended by a drug user. Awareness that an individual may affect their health with a suitable life style is very important but frequently not enough important. Even more important is the connection between political and social-economical factors like education, employment and accommodation with health. We concluded that drug users wish the same things as those who do not use drugs – respect, roof over head, respectful job and better living conditions. They wish to be healthy and happy, getting it through taking drugs that sooner or latter stop making them happy. On the basis of the findings in the present research we prepared some recommendations for activities on treating problematic drug users to be used by political decision makers and providers of health care and social assistance in public (governmental) and non-governmental sector.

- Reducing inequality in accessibility to health care and social services and other forms of assistance for illegal drug users and to ensure accessibility of high threshold and low threshold programmes in health care, social and non-governmental sector;
- Providing accessibility to health care services to drug users who are not included in compulsory/voluntary medial health insurance, due to financial and other inabilities;
- Supporting field work by non-governmental organisations and ensuring development and implementation of field work within the framework of public health care and social protection;
- Improving accessibility and attainability of measures and services on social integration and supporting processes on de-stigmatisation and social inclusion of illegal drug users;
- Supporting the opening of new shelters with programmes for a rehabilitation and reintegration of homeless drug users;
- Including drug users' representatives in decision making process on various levels, especially participation in various activity groups on protecting their health and supporting the establishment of self-help groups and other organisations of drug users;
- Develop on science based fundamental approaches and programmes for strengthening and protecting health, and for ensuring integrated help and respect of individual needs.
- Restoring and maintaining inter-sector cooperation (between medical and social organisations; between public and non-governmental services; between low threshold and high threshold non-governmental programmes);
- Setting up a single information system to monitor treatment of drug users in health care, social and non-governmental sector.

Researching problems of social exclusion and health, and evaluating suitability of approaches with special or less unequal health of illegal drug users and other especially threatened and vulnerable groups. For these reasons, the working group at the Institute for Public Health (IVZ),

working on strengthening social inclusion and health of especially threatened groups will continue in 2008 with the activities already started. In the context of efforts on greater accessibility, attainability and quality of programmes, and suitable assistance programmes for illegal drug users and other vulnerable groups, we will stimulate awareness on problems and will continue to especially support non-governmental organisations. The role of non-governmental organisations when dealing with drugs is invaluable – this was shown by the present research. Especially in carrying out activities when the government cannot satisfy the needs of the whole population. Non-governmental organisations see the problems with a community, they are more flexible, innovative and less formal, and are an urgent complement to the public sector. We will continue to offer expert assistance to the competent ministries and policies on lessening inequality in health, social exclusion, stigmatization and consequences of drug and alcohol use. We will also strive to join together the governmental and non-governmental sector. We will develop and implement new approaches and standards (methods on monitoring and researching, field work, lessening damage and promoting health of especially vulnerable groups). We will encourage connections between representatives of threatened groups with experts (implementers of preventative and treatment programmes) and political decision makers (with an objective for a more suitable recognition of the needs of threatened groups and better inter-sector cooperation). We will participate in training experts and volunteers on promoting social inclusion. We will continue to build an appropriate information system, which will include all illegal drug users in treatment in health care, social and non-governmental sector. We will strive for a universal accessibility to health care, including uninsured drug users and their sick family members. The most important shows to be our cooperation with the Sector for health care protection of threatened population groups at the Ministry of Health, other relevant governmental and non-governmental institutions working in public health and social security, as well as European network on social inclusion and health.

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7

General conclusions on the study results

Ferenc Márványkövi, Ancella Voets

From the results and conclusions of the four studies it is evident that in all of the four member states where the research took place, some gaps exist regarding the access to care and treatment for those who are in most urgent need of this kind of services. Without wanting to draw preliminary conclusions, we can state that this is probably the case in the whole European Union.

In Hungary, the results showed that methadone maintenance treatment and drug rehabilitation services are the most difficult to access regarding treatment programmes. In addition, methadone maintenance programmes do not always succeed in admitting all of those users who need this kind of treatment. The Hungarian users reached in the study rated methadone maintenance programmes as the hardest to access. Long waiting lists are typically defined as barriers to all services, while strict accession criteria were mentioned in connection with gaining access to methadone maintenance and drug rehabilitation programmes. Registration and administration procedures were also mentioned as barriers. What needs to be emphasized is that methadone maintenance programmes, that are basically harm reduction techniques, are actually difficult to reach.

The outcomes of the Dutch survey give an insight in the reasons why Moroccan drug users are under-represented in Dutch drug treatment clinics; the key message is that the Moroccan drug users of the sample do not expect to receive the help they need from drug treatment clinics. General practitioners and substitution treatment are described as being reasonably accessible; tuberculosis (TB) and hepatitis B (HBV) tests are easily accessible for drug users. The so-called 'low threshold' drug consumption rooms in Amsterdam only attract 43,5% of the respondents of the sample. Plausible reasons for this are that Moroccan drug users don't want to expose themselves as drug users, or that they don't want to be among other people who are using drugs. In addition social welfare services are hard to obtain, primarily due to the lack of proper documents.

The Bulgarian study has emphasised that problem drug users are in an ever more marginalised situation, with high figures of unemployment, low educational status and no social insurance. They are also characterised by high-risk behaviour. Despite this, drug dependencies treatment is either still not accessible or not efficient enough. The lack of rehabilitation programmes and re-socialisation programmes have also been mentioned as crucial factors. Moreover, certain types of treatment programmes are private and cannot be afforded by problem drug users. The ones that are state-funded are often repulsive for users due to the attitude of the medical staff. An important geographical aspect regarding barriers to treatment is that with the exception of few big Bulgarian cities, programmes are not available in the rest of the country.

The main conclusions of the Slovenian study were on the one hand that drug users wish the same things as those who do not use drugs; respect, a roof over their head, a respectful job and better living conditions. They wish to be healthy and happy, getting it through taking drugs that sooner or latter stop making them happy. On the other hand the Institute of Public Health concluded that cooperation with the Ministry of Health, other relevant governmental and non-governmental institutions working in public health and social security, as well as European network on social inclusion and health is very important. Researchers recommended, among other things, that health care, social services and other forms of assistance should reduce the

inequality in accessibility for drug users; that outreach work should be supported and that drug users should be involved in decision-making processes.

When it comes to the process of studying hard to reach or hidden target groups, one of the first conclusions is that research projects need both financial and human resources to be carried out. Mainline's example proves that manpower contributions can be satisfactory for a research project, if one accepts to work with a smaller scope: in Amsterdam, a smaller target group was reached and surveyed using the NGO's own resources.
The second conclusion is that the study project could be interpreted as a best practice in a sense that a common research tool was developed that was used in the same, or very similar context despite cultural differences. In the Correlation project, each partner chose target groups within the same context (marginalised people), focussing on the barriers to access to social and health services among marginalised people. A common structure and questions for the questionnaire were first developed, which were later tailored and modified in accordance with the target group and the cultural context of each country.

In Denmark, due to the fact that key persons failed to cooperate, the study could not be carried out yet. The Danish partner is applying to a research fund in Copenhagen for local social purposes in order to finance more manpower, students and professionals from the field in order to complete the survey.

8

Toolkit for making marginalised voices heard

József Rácz, Ancella Voets

A specific aim of the Correlation network was to make the voices of marginalised people heard. In this chapter we provide a toolkit for those organisations wanting to develop and implement research that supply grass roots data to service providers and policy makers, fuelling the debate to improve social policies for marginalised populations.

Making the voices of marginalised people heard means cooperating with these people as much as possible and during the whole process. Even though grass roots organisations are often close to their target groups and know these groups very well, the highest level of empowerment is reached by involving the groups. Too often we talk about certain target groups instead of talking with them. Grass roots organisations pretending to represent a target group cannot afford to make this mistake. So even if target group members have different ideas or viewpoints than we (think they) have, we cannot pretend to work from a bottom up-approach and 'forget' to include the most important participants.

The way of cooperating with your target group depends for a large part on the constitution of that group. But in all cases the most important thing is to really know your target group, to know their wishes, their problems, their ideas for solutions, but also how they are organised and the possible ways to work with them. If this is clear, you know whether your ideas and expectations are in line with those of the members of your target group. If your ideas of the goal to be reached or the methods to be used are different from the opinions of target group members, you have to find a way to streamline this. This implicates that you have to involve members of your target group from the very beginning. However, you may encounter many problems in doing so. Is your target group really a consistent group, with collective viewpoints? Or is it a mixed lot with diversity of meanings and without clearly defined leadership? This last option being more likely, you have to invest time to distil clear goals and select a representative team to work with. Do not underestimate the length of this process.

Once you have established a stable working relation with (representatives of) your target group and you have defined the goals you want to reach and the methods you want to use for this, time has come to design your research. Within the Correlation network partners co-operated with a research institute in developing their study. By doing this you have to be the intermediate between your research partner and your target group. This is a very delicate role. The first one probably wants to develop a scientifically based research and doesn't have the hand-on expertise to assess the extent to which this is possible. On the other hand, target group members are likely to focus on less relevant details and lack knowledge of the institutional environment you want to influence. In this process it is up to you to find the balance. Do not underestimate your own knowledge and experience and use these in negotiations with both parties. Remember that involving the target group does not mean blindly following their desires. You have the capability to translate the daily reality of this group to institutionally useful themes. Use this capability.

An important issue that should not be forgotten is that you have to make sure that preconditions are met for target group members to cooperate with you. Working with drug users like Correlation members did, means for example that target group members need to be able to fulfil their daily needs, like taking methadone. It may also mean paying drug users for their activities, in order to boost their motivation and to compensate for money they are missing because of not participating in paid day activities.

8.1 Organising a survey for and with service users

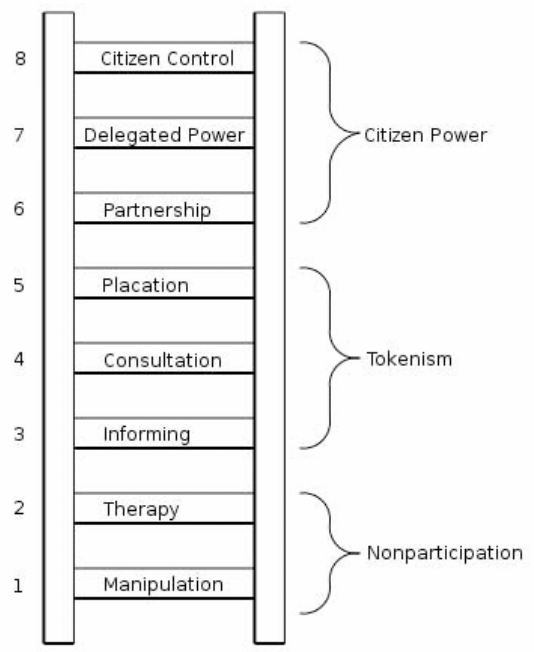
For methodological reasons, it is advisable to involve a research institute in study projects, which can give methodological guidance to organisations aiming to research their target group in connection with a particular problem. The Bulgarian research partner was supported by RIDS and the Bulgarian Reitox Centre, Enghaven in Denmark involved and will consult the Danish Social Research Centre, Mainline in the Netherlands was advised by RIDS, while the Slovenian study project was coordinated by the research department of the National Health Research Institute.

One of the main elements of the project was to involve service providers and service users in the project. This seems particularly important when the focus of a research project is marginalised people.
The reasons for this approach could be summarized as follows:

- Service providers have a practical view of the field they are working in. They know the current problems, which may become a subject matter of the research. In this sense, they are aware of the real problems and situations that must be researched to formulate research-based responses to problems. The service providers of the study partners acted as communicators of problems towards researchers.
- Service providers are also good methodological advisers in developing research tools and interpreting findings. What a researcher, who has no or little practical experience with service users believes a feasible question or a questionnaire may turn out to be less adequate. Service providers can provide very practical advice to improve methodological tools to be used in research. During the study project, service providers actively participated in the development of the common research tool as well as in the elaboration of the tailored questionnaires used in the local studies.
- Working with the service users, they also know how to reach certain subpopulations for research. This is rather inevitable for methodological reasons. In the Netherlands, service users of Mainline actively participated in approaching the target group of the study.
- Service users can be of great help in formulating policy recommendations based on research results. In Hungary, for instance, following the completion of the study, service providers working at low-threshold agencies were invited to formulate policy recommendations, which may help bring down barriers to access to social, and health services for problem drug users.
- Based on the study results, service providers can use the results to approach policy makers. This is what happened in Hungary, Bulgaria and the Netherlands.
- Service users, or former clients can be of great help in reaching target groups of the study using their social networks. In the Netherlands, Hungary and Bulgaria users were invited to participate in snowball sampling.
- Users can participate in pilot tests, where the research tool is put to a test. They may be able to judge which questions are feasible or less feasible in a questionnaire. The tools used in the studies were tested by target groups of the research.

Ladder of Participation

A model developed by Sherry Arnstein, the Ladder of Participation was developed in the late 1960s. Her eight rungs range from Manipulation to Citizen Control ("Empowerment").



The bottom rungs of the ladder are (1) Manipulation and (2) Therapy. These two rungs describe levels of "non-participation" that have been contrived by some to substitute for genuine participation. Their real objective is not to enable people to participate in planning or conducting programmes, but to enable power holders to 'educate' or 'cure' the participants. Rungs 3 and 4 progress to levels of 'tokenism' that allow the have-nots to hear and to have a voice: (3) Informing and (4) Consultation. When they are proffered by power holders as the total extent of participation, citizens may indeed hear and be heard. But under these conditions they lack the power to insure that their views will be heeded by the powerful. When participation is restricted to these levels, there is no follow-through, no 'muscle,' hence no assurance of changing the status quo. Rung (5) Placation is simply a higher level tokenism because the ground rules allow have-nots to advise, but retain for the power holders the continued right to decide.
Further up the ladder are levels of citizen power with increasing degrees of decision-making clout. Citizens can enter into a (6) Partnership that enables them to negotiate and engage in trade-offs with traditional power holders. At the topmost rungs, (7) Delegated Power and (8) Citizen Control, have-not citizens obtain the majority of decision-making seats, or full managerial power.
For our purpose the "citizen power" is understood as "empowerment" of the service users.

Conducting your research

Each research participant selects a research focus within the context of marginalisation and the barriers to access to services; the individual situation of the country or of the service provider will determine the specific goals. To define these goals a brainstorming is suggested. It is important that at this first point of the process, not only the workers of the service providers but the service users will be present as well as the research partner. The research partner's role will be to keep the goals in the reality and always keep in mind how to get and with whom to get the selected possible goals.

The research tool

We will show how a quantitative research tool can be developed. The main tool is the research questionnaire. The research questionnaire is to be developed in the following way:

- First a draft questionnaire is developed in cooperation with the research expert group and NGOs: brainstorming with the involved partners and later formalizing the questions (it is the research partner's role).
- Manual and glossary are to be provided with the questionnaire.
- Questionnaire for the tryout will be disseminated.
- Interviewers are selected: from the service provider's workers, from the service users, from other persons (e.g. students, volunteers).
- Interviewers for the pilot test are trained by the research partner.
- Pilot test takes place, monitored by the research partner.
- Feedback is collected from the participants.
- Results of the testing are analysed in cooperation with service providers and users participating in the testing.
- Research tool and manual are modified in accordance with the results of the pilot testing: the final version of the research questionnaire is ready!
- The questionnaire should contain a structure according to the goals defined:
    - Basic socio-demographic information
    - Treatment history
    - Substance use
    - Services (social and health) used by the target group
    - Satisfaction with the services (social and health) used by the target group
    - The additional service needs of the target group
    - Barriers of access to social and health services and remedies suggested
    - Level of participation and involvement in the services used
- Closed questions, open-ended questions as well as attitude statements are used in the questionnaire.

Research participants and data collection

The service provider can be requested to find possible respondents, as service workers have a considerable experience in finding their target groups. Sometimes, this target group is hidden, so that great efforts and peers are needed to reach these people.

In addition, members of the target group contribute to identify subjects for the questionnaire (snow-ball method). The research partner defines how many participants are necessary for a research (for the statistical analysis). In case of a research by a questionnaire, at least 50 participants are needed, but the number depends on the research questions, the population characteristics, etc.

Processing and analysing data

The data are to be gathered by local NGOs in Excel files. The research partner has to provide a simple code model and coding instructions. The research partners can then process the gathered and coded data. It is advisable that the whole data processing (including coding and statistical analysis) is one hand, i.e. it is the research partner who will carry out the whole process.

The analyses of the data can also be carried out by the research partners. In the interpretation of the data the research partner, the service providers, and the service users also participate. The interpretation defined here is a task that is "close" to the data. This is why it is important that the research partner is present. This partner can decide what kind of interpretation can be done or what kind of consequences can be drawn from the data. The policy recommendation is different from the interpretation, however, the interpretation and the recommendations basically do not differ.

Participants and distribution of tasks

The tables below summarize the workflow, including the distribution of tasks for each individual partner.

Table 1: Distribution of tasks among the partners

Task	**Responsible persons/organisations**
Development of the tool	
Proposing draft questionnaire	RESEARCH PARTNER
Discussing the content of the questionnaire	RESEARCH PARTNER Local partner: service provider + service users
Making modifications in the items according to the local needs	RESEARCH PARTNER Local partner: service provider + service users
Finalising the questionnaire	RESEARCH PARTNER Local partner: service provider + service users
Developing the interview guideline/technical manual	RESEARCH PARTNER
Pilot phase	
Select and train interviewers	RESEARCH PARTNER
Supervise pilot testing: - keeping contact with testing partners - monitoring data collection - providing help that is needed - clarify and respond to problems that may arise during testing - collect questionnaires used in the pilot	RESEARCH PARTNER Local partner: service provider + service users
Analyse the results of the pilot test, making modifications in the questionnaire and the interview guideline	RESEARCH PARTNER Local partner: service provider + service users
Data collection	
Supervise data collection: - keeping contact with partners - monitoring data collection - providing help that is needed - clarify and respond to problems that may arise during data collection - collect questionnaires	RESEARCH PARTNER Local partner: service provider + service users
Data procession	
Coding questionnaires into SPSS or Excel files	RESEARCH PARTNER Local partner: service provider + service users
Writing the research	

Compiling the research introduction description of research methods description of the results/findings discussion: interpreting data proposing implications for policy	Local partner: service provider + service users RESEARCH PARTNER
Policy debate	
Organisation of the policy debate where the results of the research will be discussed	Local partner: service provider + service users

Ethical aspects of the research

The optimal situation is when the service provider or the research partner has an ethical committee. This committee has give its consent for the research: they have to know the research's goals, the design, the target group, the potential benefit or the risks of the research for the participant and the written information form (for the research participants) and a written consent form (for the research participants).

As part of the later questioning process, the research participants signed an informed consent in all cases; this ensured that the anonymous data collection could be interrupted at any time, and that both the questionnaires and the database would be destroyed, once data procession would be complete. Before signing this form the research worker has to provide written information material about the research: about the goals, the potential benefit and the risks for the participants, the anonymity and the voluntary basis of participation. Sometimes, there is no direct benefit for the participant; in this case the research will help others with a similar life situation, but not the individual questioned.

8.2 Organising a national debate

Within the Correlation network, three national debates were organised by the organisations that finished their surveys among different groups of problem drug users. These debates took place in Hungary, the Netherlands and Bulgaria and were a logical step in the Correlation strategy of influencing local and national politics and policy.

What is a debate?

A debate is one possible format for a gathering. You could choose to organise a seminar, a presentation, a conference or a workshop depending on the goal you want to reach. Because of the controversy of the topics, Correlation members chose to organise a debate.

The typical format for a debate is a panel debate. This is a debate with three or four panel members and a chair. The panel members should represent different positions in the argument. The chair, preferable a well-known person who is used to these kinds of events, introduces the speakers briefly. Each speaker has four or five minutes to state his or her views. Ideally, these views are presented as controversially as possible. The chair initiates a panel discussion to get things started with some prepared questions. Then he or she opens the discussion to the audience, taking a whole series of comments before going back to the panel for their comments. Ten minutes before the end (allow a maximum 1 hour 30 minutes for the debate) the chair sums up the key points and asks each of the panel members for a final comment. Within this format, all opinions and all arguments are allowed. Humour and rhetoric are useful tools to make the debate livelier.

Desired outcomes

In organising a debate you have to take a number of steps. The first step is to think of the goal of the debate. What do you want to reach with the debate? What should be the outcome of it? Apart from aims with respect to content (present research findings), the three national debates in the Correlation project, all had specific aims concerning outcomes of the debate. In Bulgaria, organisers wanted to 'draw society's attention to the problems, related to the treatment of drug addictions' and to 'deepen the dialogue between practitioners and decision makers'. In Hungary, the goals of the debate were (among others) 'to point out the major problems of harm reduction in Hungary and make proposals for policy makers' and to 'contrast different views and opinions on how to improve harm reduction'. In the Netherlands, the major aim was to 'distribute findings from grassroots organisations to policy makers'. Moreover, organisers wanted to 'create a true debate' between marginalised Moroccan drug users and (local) policy makers. In Bulgaria, organisers also wanted to 'deepen the dialogue between practitioners and decision makers' and in the Netherlands organisers hoped to create a debate between drug users and policymakers. Shortly, the desired outcome(s) of the debate have to be formulated, before starting the actual organising of the debate.

Message

The second step to take is formulating the message you want to send out through the debate. In all three cases in the Correlation network, organisers of the debates wanted to draw attention to problems concerned with drug users and social exclusion. For many politicians and policy makers these are not popular subjects, for various reasons:

- Politicians and policy makers have little experience with drugs, marginalisation and social exclusion.
- The issue is complex: pharmacology, economy, neuroscience, public health, social work, and sociology all have something to say on the subject of drug policy. Moreover, the solutions are complex as well.
- Drug policy is dominated by ideology. The policy world has a moral 'opposition' towards drugs, which makes communication difficult.
- The political realities: drugs are a hot topic. It is dangerous ground and causes political dilemma. A lot of politicians understand the evidence, but they cannot afford to 'go soft on drugs'.

When organising a debate on a subject like this, it is important to be aware of these factors. Your message should be stirring without being too provocative.

Participants and attendants

Before having a clear picture of the goal and the message of the debate you might already have an idea of the people you want to invite. Make sure the desired outcome, the message and the participants you are going to invite are adjusted to each other. Like stated before, you should compose a panel of experts, or people who have an unambiguous opinion on the issue that is to be discussed. Invite a charismatic chair.

When it comes to the audience, attract people from both sides of the fence. This makes the debate more valuable and may change a few minds. Frame your message correctly for the various people you want to invite; people will not show if they are not interested in your message. This may mean making different types of invitations for different people. Within the Correlation debates organisers wanted to spread a message to policymakers in their respective countries. This meant policy makers should attend the debate. So their interest had to be raised and they had to be sure the debate would be useful for them.

Politicians and policy makers must be 'seduced' with a well-packed message in order for them to embrace your ideas. In case this is impossible, policymakers should at least be informed about the results of the debate. Naturally this will not have the same impact as policymakers attending the debate.
Service providers and other professionals from the field are probably easier to reach and willing to participate. But for these practitioners as well as for target group representatives – drug users in our cases – the same thing is true; they need reason to believe attending the debate will serve them for something. All 'target groups' have to be approached in a way that is suitable for them, in order for them to decide to attend the debate.

Media attention

Apart from a panel and an audience, it is essential to invite journalists and other people who will account on the debate for a larger public. Consider organising a press conference at the end of the debate. Another tool of informing journalists is providing them with the information you think essential in written form. Have a brochure or a press release ready for people who may put this to good use.
For a debate to be successful, it needs promotion beforehand. The event will not draw media attention on its own, however good the topic is. Therefore, you not only have to think of inviting journalists, you also have to have a plan on how to draw the attention to your debate beforehand. Apart from sending invitations, advertise in (professional) journals and on specific websites on the Internet.
After the debate, don't depend on the willingness of journalists to pay attention to your event. It is up to you to disseminate the results of the debate. Send a review to the people who attended the debate. This means collecting addresses of the attendants before or during the debate (through registration). Publish the same review in a professional magazine and, again, on the Internet. The most important action, however, is acting on the results of the debate; (continue to) lobby with the people who you think should take the results into account.

Resources

A last important message for grassroots organisations wanting to organise a successful debate is to cooperate with a (larger) organisation and to find proper funding. Correlation members in Hungary and Bulgaria cooperated with other parties in their country, which resulted in more finances and a broader scope. This has led to more participants, more attention and consequently more impact.

Annex 1:
Distribution of tasks among the study partners

Tasks	**Responsible organisations**
Development of the tool	
Proposing draft questionnaire in English	RIDS
Discussing the content of the questionnaire	RIDS & Local partners
Making slight modifications in the items according to the local needs	RIDS & Local partners
Finalising the questionnaire	RIDS & Local partners
Developing the interview guideline/technical manual	RIDS
Translation of the research tool that includes the questionnaires and the interview guideline	Local partners
Pilot phase	
Train interviewers	RIDS
Supervise pilot testing: - keeping contact with testing partners - monitoring data collection - providing help that is needed - clarify and respond to problems that may arise during testing - collect questionnaires used in the pilot	RIDS
Analyse the results of the pilot test, making modifications in the questionnaire and the interview guideline	RIDS & Local partners
Data collection	
Supervise data collection: - keeping contact with partners - monitoring data collection - providing help that is needed - clarify and respond to problems that may arise during data collection - collect questionnaires	RIDS & Local partners
Data procession	
Coding questionnaires into SPSS or Excel files	RIDS & Local partners
Writing the study	
Compiling the study - introduction - description of research methods - description of the results/findings - discussion: interpreting data - proposing implications for policy	Local partners & RIDS
Policy debate	
Organisation of the policy debate where the results of the study were discussed	Local partners

Annex 2:
Questionnaire used in the Dutch study

Interviewer's name	
Date of interview	
Beginning of the interview	
End time of the interview	
Where and how did you find your respondent?	

FILTER QUESTIONS

A. When were you born?

.....

If the answer is more than 1988, he or she is not suitable for the interview.

B. Which ethnic groups do you most identify with?.....

If the answer is not Moroccon to at least one of the questions, the respondent is not suitable for the interview.

C. Have you used any of the following in the past 3 years at least 3-4 times a week (longer period(s) of use perhaps interrupted by periods of abstinence)

	Yes	No
1. Cocaine		
2. Heroin		
3. Methadone		

If the answer is "No" to all of the items, the respondent is not suitable for the interview.

D. Which of the following is true for you?

	Detoxification	IMC	Rehabilitation Centre
1. I have never been to this kind of treatment, I have not completed such treatment.			
2. I have completed this treatment before but it was over a year ago.			
3. I have completed such a treatment in the past 12 months.			

If the respondent chooses item number 3 regardless of the type of treatment, he/she is not suitable for the interview.

E. If the respondent is a prisoner, please also ask the following question:

How long have you been in prison?

…….. months

If the number is '6' or more, he/she is not suitable for the interview.

Socio-demographic background

First I would like to ask you a few basic questions about your personal background.

1. Age	**2. Sex**
In which year were you born?	Male 1 Female 2 Transgender 3 Don't know 999
3. Since when have you lived in the Netherlands?	**4. Education level: highest level of education completed**
	Less than elementary school 1 Elementary school 2 Secondary school 3 MBO 4 College/university (BA/MA) 5 Other, please specify:……..... Don't know 999

5. Resources used in the past 30 days (more than one answer possible).	
Paid work 1 Unemployment benefit 2 Chronic illness benefit 3 (Early) retirement pay 4 Social welfare 5 Homeless benefit 6 Students' fee 7 Prison fee 8 Paid day activity 9 Informal (legal) job 10 Prostitution 11 Gifts from relatives / friends 12 Stealing 13 Selling stolen goods 14 Begging 15 Dealing drugs 16 Other:……17	
6. Documents held	
ID 1 Social security card 2 Passport 3 Residency permit 4 Nothing 5 (I don't hold any personal documents)	
7. Where did you spend your nights in the past 30 days?	**8.a. Do you consider yourself homeless?** **Yes 1 → go to 8.b.** **No 0 → go to 9.** **Don't know 999**
Own home 1 Social hostel 2 Relative's home 3 Friend's home 4 Squat 5 Night shelter 6 Prison 7 Street 8 Other:……...9	**8.b. For how long have you been homeless?** **……**

9. Who do you usually turn to when you face the following problems?

9.1. If you have no money, who do you turn to for help?

……
……

9.2. If you have no place to sleep, who do you turn to for help?

……
……

9.3. If you have nothing to eat, who do you turn to for help?

……..
……

9.4. If you have drug-related general health problems, who do you turn to for help?

……
……

9. 5. If you have general health problems, who do you turn to for help?

……

Treatment/service history

In this section, I would like to know what kind of social and health services and treatments you have been to in the past 3 years.

10. Have you received in the last 3 years any of the following services?			
Service type	**Yes**	**No**	**Don't know**
Day shelter			
Night shelter			
Social hostel			
Drug using room			
Organised day activities			
Meal distribution			
Methadone treatment			
Other substitution (Buprenorphine, heroin, palphium, etc.)			
Detoxification			
IMC			
Rehabilitation clinic			
General practitioner			
TBC screening			
Blood testing (HBV, HCV, HIV)			
Social work (counselling)			
Psychologist			
Psychiatrist			
Hospital			
Social security benefit			
Income assistance			
Housing assistance			
Juridical assistance			
Self help groups			

Perceived needs and barriers

In this section, I would like to ask you in more details about certain social and health services and treatments as well as the difficulties of getting into these services.

11. a Detoxification: past 12 months			
1	Treatment sought: **NO**	Why not?	
2	Treatment sought: **YES**	Treatment received: **NO**	Why not received? 1….. ..... 2….. ..... 3……. .....

11. b IMC: past 12 months			
1	Treatment sought: **NO**	Why not?	
2	Treatment sought: **YES**	Treatment received: **NO**	Why not received? 1….. ..... 2….. ..... 3……. .....

11. c Rehabilitation centre: past 12 months			
1	Treatment sought: **NO**	Why not?	
2	Treatment sought: **YES**	Treatment received: **NO**	Why not received? 1….. ..... 2….. ..... 3……. .....

11. d Substitution treatment (methadone, buprenorphine, heroin, palphium, etc): past 12 months				
1	Treatment sought: **NO**	Why not?		
2	Treatment sought: **YES**	Treatment received: **NO**	Why not received? 1……. …… 2……. …… 3……. ……	
3	Treatment sought: **YES**	Treatment received **YES**	How satisfied were you with the treatment? **1 2 3 4 5** *If 1,2,3 move to*	What was the problem? 1…… …… …… 2…… …… …… 3…… …… ……

11.e General practitioner: past 12 months			
1	Treatment sought: **NO**	Why not?	
2	Treatment sought: **YES**	Treatment received: **NO**	Why not received? 1……. …… 2……. …… 3……. ……

3	Treatment sought: **YES**	Treatment received: **YES**	How satisfied were you with the treatment? **1 2 3 4 5** *If 1,2,3 move to*	What was the problem? 1..... .... 2..... .... 3..... ....

11.f Any blood testing (HIV, HBV, HCV): past 12 months. Please specify				
1	Service sought: **NO**	Why not?		
2	Treatment sought: **YES**	Treatment received: **NO**	Why not received? 1..... ..... 2..... ..... 3.....	
3	Treatment sought: **YES**	Treatment received: **YES**	How satisfied were you with the service? **1 2 3 4 5** *If 1,2,3 move to*	What was the problem? 1..... .... 2..... .... 3..... ....

11.g Mental health treatment: past 12 months				
1	Treatment sought: **NO**	Why not?		
2	Treatment sought: **YES**	Treatment received: **NO**	Why not received? 1…… …… 2…… …… 3……. ……	
3	Treatment sought: **YES**	Treatment received: **YES**	How satisfied were you with the treatment? **1 2 3 4 5** *If 1,2,3 move to*	What was the problem? 1…… …… 2…… …… 3…… …… ……

11.h Social advice or counselling: past 12 months				
1	Treatment sought: **NO**	Why not?		
2	Treatment sought: **YES**	Treatment received: **NO**	Why not received? 1…… …… 2…… …… 3……. ……	
3	Treatment sought: **YES**	Treatment received: **YES**	How satisfied were you with the treatment? **1 2 3 4 5** *If 1,2,3 move to*	What was the problem? 1…… …… …… 2…… …… …… 3…… …… ……

12. How difficult do you think it is to get into the following treatment / service types?

1: very easy
2: somewhat easy
3: not easy and not difficult
4: somewhat difficult
5: very difficult
DK: don't know

	Rating (1….5)
Detoxification treatment	
IMC treatment	
Rehabilitation treatment	
Substitution treatment	
General practitioner	
Blood testing (HCV, HBV, HIV)	
Mental health treatment	
Social advice or counselling	

User involvement

Now I would like you to think about drop-in centres.

13. To what extent do you agree with the following statements? **Strongly disagree=1** **Strongly agree=5**	***Drop-in centre***
My needs are listened to by the service providers.	1 2 3 4 5 DK
I am told/informed about the rules of the service.	1 2 3 4 5 DK
Service providers ask me how satisfied I am with the service.	1 2 3 4 5 DK
I am involved in decision making concerning the service.	1 2 3 4 5 DK

Health status and knowledge on health issues

Now I am going to ask you a couple of questions about different infectious diseases.

14.a Can you tell me how TBC is transmitted?	14.b How can you protect yourself against TBC?	14.c How do you protect yourself against TBC?
- …… - …… - …… - …… **DK**	- …… - …… - …… - …… **DK**	- …… - …… - …… - …… **DK**

15.a Can you tell me how HBV is transmitted?	15.b How can you protect oneself against HBV?	15.c How do you protect yourself against HBV?
- …… - …… - …… - …… **DK**	- …… - …… - …… - …… **DK**	- …… - …… - …… - …… **DK**

16.a Can you tell me how HCV is transmitted?	16.b How can you protect oneself against HCV?	16.c How do you protect yourself against HCV?
- …… - …… - …… - …… **DK**	- …… - …… - …… - …… **DK**	- …… - …… - …… - …… **DK**

17. Testing	17.a How many times have you been tested in the past 5 years?	17.b When was your latest test?	17.c What was the result of the latest test?
TBC			positive / negative / don't know
HBV			positive / negative / don't know
HCV			positive / negative / don't know
HIV			positive / negative / don't know
Other STIs (please specify):……....			positive / negative / don't know

Drug use

18. Finally, I have some more questions about your drug use. Please remember that you do not necessarily have to answer these questions.

	cocaine	heroin	methadone	alcohol	tranquilizers
18.1. Age of first use					
18.2. For how long did you use it regularly?					
18.3. Do you currently use it regularly?					
18.4. How many days have you used it in the past 30 days?					
18.5. How many days have you injected it in the past 30 days?					
18.6. How many times have you used it in the past 48 hours?					

19. I would like to ask you a few questions in connection with your cocaine use.

Severity Dependence	Never / almost never	Some-times	Often	Always / nearly always	No answer
19.a Did you think your use of **cocaine** was out of control in the past year?					
19.b Did the prospect of missing a fix (or dose) or not chasing make you anxious or worried in the past year?					
19.c Did you worry about your use of **cocaine** in the past year?					
19.d Did you wish you could stop in the past year?					

	Not at all	Quite difficult	Very difficult	impossible	No answer
19.e How difficult did you find it to stop, or go without **cocaine** in the past year?					

Thank you for your help, this is the end of the interview.

This is for the interviewer to evaluate:

How much do you agree with the following statements?

1: strongly disagree
2: disagree
3: neither agree nor disagree
4: agree
5: strongly agree
DK: don't know

Statement	Rating
I think the responses were biased by the respondent deliberately (insincere answers).	
The respondent was unable to understand the questions in a lot of cases.	

Annex 3: Timetable for local study projects

	Mainline (Netherlands)	**Institute of Public Health Slovenia (Slovenia)**	**Enghaven (Denmark)**	**Initiative for Health Foundation (Bulgaria)**
September 2006				
October 2006				
November 2006				
December 2006				
January 2007				
February 2007				
March 2007				
April 2007				
May 2007				
June 2007				
July 2007				

One of the fields of activity of the Correlation network over the past few years has been to stimulate and support the development of comprehensive national policies on social inclusion and health promotion targeting marginalised populations. The ' policy group' of the network discussed effective approaches to contribute to that aim and stimulated the development of research in that area.

Partner organisations in four European member states implemented the study in their own country, adapted to the local situation and to their specific target group. They organised national debates for the distribution of results and for exchanging viewpoints with local and national policy makers.

From the results and conclusions of the four studies it is evident that in all of the four member states where the research took place, some gaps exist regarding the access to care and treatment for those who are in most urgent need of this kind of services. Without wanting to draw preliminary conclusions, we can state that this is probably the case in the whole European Union.

This booklet contains also a toolkit and recommendations for those organisations wanting to develop and implement research that supply grass roots data to service providers and policy makers, fuelling the debate to improve social policies for marginalised populations.

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