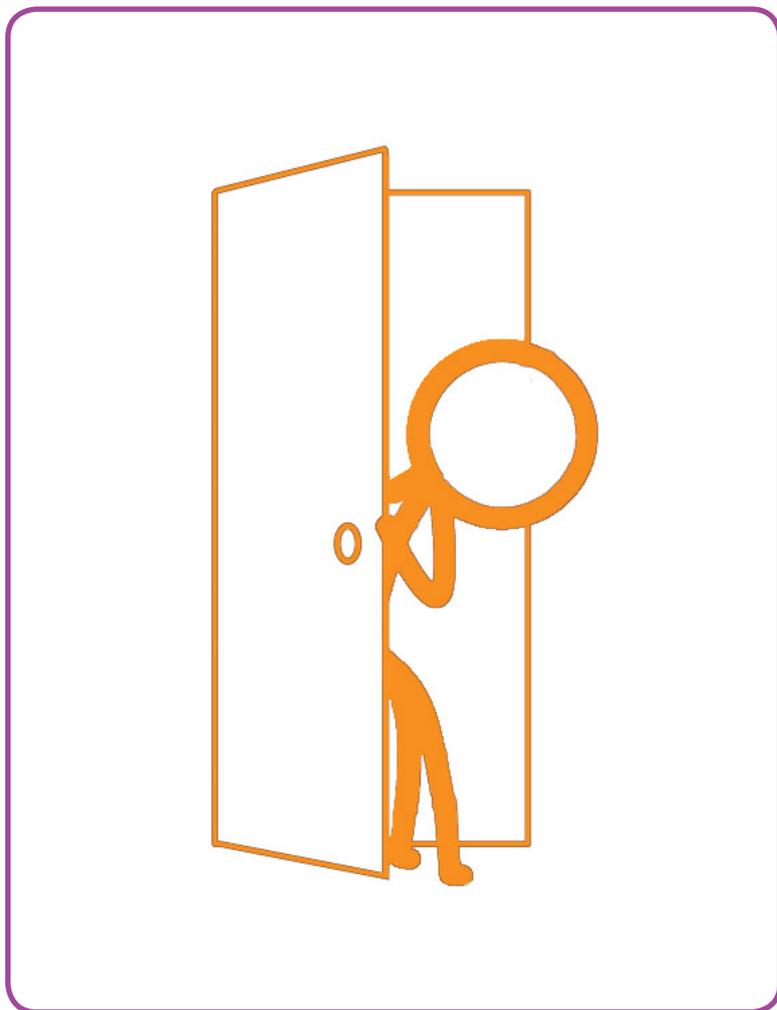
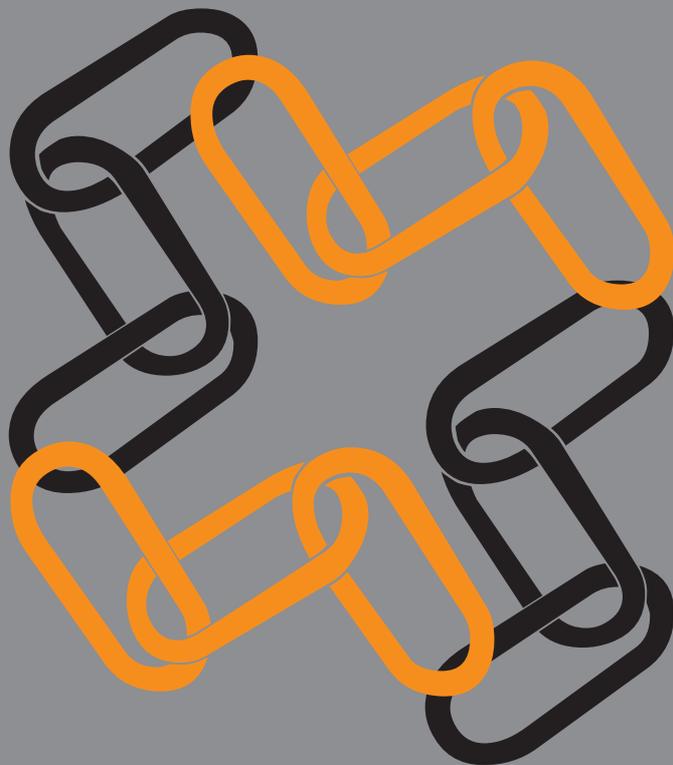


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COMING OUT OF THE CLOSET?

Assessment and evaluation of advocacy efforts for the improvement of quality of drug dependence treatment programs in Skopje





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Title

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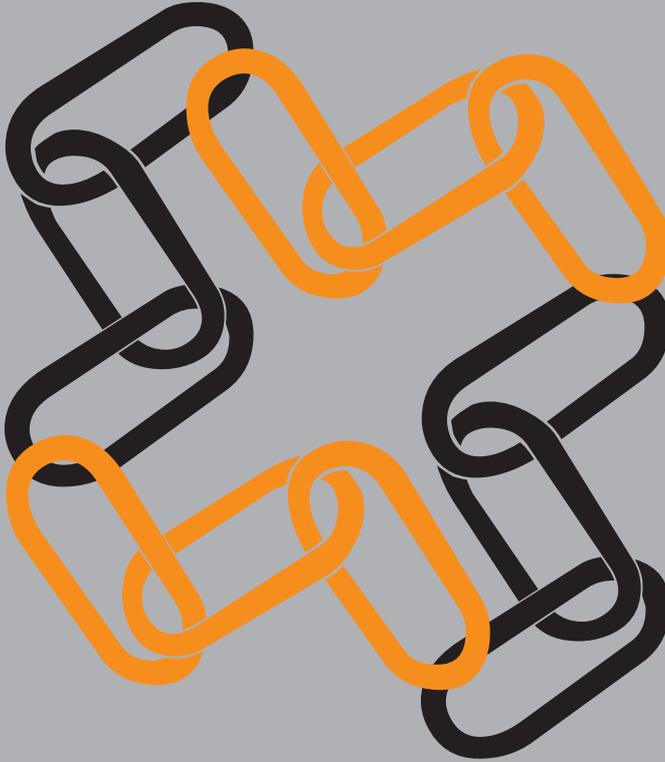
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My own experience of trying to make very large and monolithic public systems like the health system work is not easy. On the one hand these are huge and labyrinthine bureaucratic structures enjoying political patronage, while on the other hand communities often prefer a path of least resistance and seek the essential services elsewhere. Thus, to bring the two together in a relationship where the traditionally powerless community becomes enabled enough to "monitor and discipline" the public authorities and service providers is a most challenging but not an impossible task.

Abhijit Das (Das 2013: 7)

ABBREVIATIONS AND ACRONIMES

<i>A HOPS</i>	Archives of HOPS – Healthy Options Project Skopje
<i>AIDS</i>	Acquired Immune-Deficiency Syndrome
<i>HIV</i>	Human Immunodeficiency Virus
<i>IDSC</i>	Institute for Democracy Societas Civilis – Skopje
<i>LGBT</i>	Lesbian, gay, bisexual, transgender
<i>MADU</i>	Macedonian Association of Drug Users
<i>PHI</i>	Public health institution
<i>YEF</i>	Youth Educational Forum

Abstract

This document contains the assessment of community-based monitoring and advocacy activities for the improvement of the quality of state supported programs for the treatment of drug dependencies in Skopje. The assessment covers the period from the beginning of the monitoring and advocacy in December 2011 until June 2014. The active involvement of the person who carried out the evaluation in the monitoring and advocacy activities was of utmost advantage, because it provided an insight into the assessment from the prism of the wider socio-political context which makes the understanding of the weaknesses and appreciation of successes easier.

Having in mind the existing socio-political context, advocacy activities may be assessed as successful. According to plan, an advocacy team was founded, from which several motivated individuals stood out, prepared to continue advocacy for the rights and interests of people treated at the drug treatment programs in Skopje. With a varying dynamics and frequent drops in motivation, this team carried out several advocacy activities, directed simultaneously towards improving the quality of drug treatment programs and towards animating the community for more active advocacy.

Although there is no supporting environment in Macedonia for the developed of grass root activism among people treated for drug dependencies, monitoring and advocacy have created fertile grounds for the development of civil awareness in this community and their encouragement to activism. This starting point may and should be used for further development of this spirit of activism and for the creation of a critical mass which may cause some larger movements towards the improvement of the quality of drug dependence treatment programs in Macedonia.

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1. Introduction

The project "Improvement of the quality of drug dependence treatment programs in Skopje financed by the budget of the Republic of Macedonia" began implementation in November 2011 and based on the contract with the current donor, the Open Society Foundation – Macedonia, it formally ends on 31 May, 2014. The initial idea was to encourage and support people treated for drug dependence in Skopje, to be able to advocate themselves for improvement of the quality of treatment in dependence treatment programs, financed by the state budget, and to that end, the community monitoring and advocacy methodology was applied. Still, at the very beginning of the project, it was discernible that the community of people treated for drug dependence needs support in advocacy, and that community representatives had the need to improve personal skills needed for the advocacy and leadership. This is why both associations the Healthy Options Project Skopje (HOPS) and the Coalition "Sexual and Health Rights of Marginalized Communities", have undertaken the responsibility to manage the project and have enabled a continuous support to the community and its representatives.

Community monitoring, in its widest sense, means the active inclusion of a specific community in the monitoring of the work of public services and in the provision of certain public services which are of concern to that community. At the same time, monitoring should encourage a process of social change in the monitored services and/or institutions for the benefit of the concerned community (Das 2013: 6-7; 11). In this project, people treated for drug dependence were performing monitoring of the quality of drug dependence treatment programs in Skopje, and negotiated for possibility for improvement of treatment conditions.

The community monitoring, in this project, was carried out in three project cycles:

- I. Cycle: from December 2011 until December 2012,
- II. Cycle: from December 2012 until December 2013,
- III. Cycle: from December 2013 conclusive with May 2014.

In line with the applied methodology, monitoring and advocacy were carried out in all three cycles as interconnected and mutually supporting processes, all in the interest of improving the quality of drug dependence treatment programs in Skopje.

Although at the very start of the advocacy efforts, attempts were made to avoid pompous public appearances and pressure on dependence treatment centres and it was instead on maintaining a relationship of partnership with them, it was soon established that there isn't always openness and readiness for mutual cooperation. On the other hand, the weak support, and in some cases, the obstructions by the wider community, additionally de-motivated the team and made advocacy efforts harder. Still, despite all these barriers, the advocacy team persevered in the established objectives and priorities and showed it was possible and necessary to improve the quality of dependence treatment programs and to create conditions for the successful re-socialization of drug dependent people.

The team's external obstructions and internal weaknesses raised a range of issues regarding the effects of socio-political context in which advocacy is performed, its value system and the motivation for active inclusion of the specific community in advocacy for issues that directly concern it. All this brought out the need for a wider contextualization in finding solutions for effective advocacy.

The described context in which advocacy was performed, has changed, i.e. it has amended the concept of this document. According to the initial plan, this document was to contain the assess-

ment of the effectiveness of advocacy actions towards improving the quality and treatment of drug dependence treatment programs in Skopje, but it was established that it was not possible to explain these assessments without taking into consideration the influence of the wider socio-political context in Macedonia (Das 2013: 13), manifested by the motivation for active engagement of the community in question. The first seven chapters are dedicated to advocacy for improvement of the quality of drug dependence treatment programs, and especially the assessment of advocacy effectiveness, while the eighth chapter is dedicated to the analysis of motivation and preparedness of the concerned community for active engagement. This text structure should enable easier insight into the obstacles and weaknesses in the advocacy for achieving the basic needs in treating drug dependence, especially in circumstances already regulated by policies adopted by the Republic of Macedonia.

2. Subject Headings

In the text below, as well as above, several notions may be encountered, with various long phrases which might make sentences too complex and hard to comprehend. In order to overcome this, phrases have been differently formulated in this text, and, in order to avoid possible obscurities and misunderstandings, below is an explanation of several key terms used in the document

Community monitoring and advocacy. This is a key notion because it is the basis for the whole process described here. In the text, the phrases **community monitoring** and **community advocacy**, or simply **monitoring** or simply **advocacy** may be met, each of which should be taken to mean the specific type of activity described – monitoring or advocacy, although in reality these activities are mutually interconnected. To make it clearer, community monitoring and advocacy means initiatives in which members of a certain community monitor certain aspects of the dedication and serviceability of public offices and advocate for the improvement of the quality of services and alignment of public services with the needs of that specific community (Das 2013: 6-7).

People treated for drug dependence. In this text, this phrase may be found in contexts such as **people treated in drug dependence treatment programs**, **patients in drug dependence treatment programs**, **community of people in treatment for drug dependence** or similar lexical units.

Drug dependence treatment programs. In the text below, this phrase can also be found as **dependence treatment programs** or as **dependence treatment programs**, each of which may refer to the centres in Skopje used for treatment of opioid dependencies, financed by the state budget. Additionally, the term **dependence treatment program** also signifies an entity that provides such health services.

Drug dependence treatment program staff. Similar to the above phrases, this one can be found in the text in several collocations: **dependence treatment program employees/staff**, or **simply treatment program employees/staff**, **medical personnel in dependence treatment programs**, **social workers in dependence treatment programs**, **psychologists in dependence treatment programs**

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3. Community monitoring and advocacy: idea, concept and social context

The community monitoring and advocacy, in its widest meaning, is an active inclusion of a certain community in the monitoring of the work of public offices or specific public services concerning that specific community. At the same time, it is expected that monitoring results should be used to encourage the process of social changes within the monitored services and/or offices which are of benefit to the concerned community. In doing so, community monitoring is much more than just a research data collection. Its primary purpose is to serve in the representation of social changes, as a key strategy for strengthening democracy, serving as an argument for citizens' needs when demanding rights before the state bureaucracy (Das 2013: 6-7; 11; Shukla et al 2013: 5-6).

3.1. The idea and concept of community monitoring and advocacy for improvement of the quality of treatment in dependence treatment programs in Skopje

The purpose of community monitoring and advocacy, described herein, was the improvement of the quality of treatment programs in Skopje, financed by the state budget, i.e. the following described programs:

- PHI Psychiatric hospital "Skopje", Centre for Prevention and Treatment of Drug Abuse, known as Kisela Voda, according to the name of the neighbourhood in which it is located. This is the oldest Centre for treatment of drug dependences in Macedonia, working from the beginning of the 1990s and until 2005 it was the only Centre for drug dependence treatment which treated patients from the whole of Macedonia. Within this Centre, there are three treatment programs offering methadone substitution therapy.
 - Out-patient clinic for prevention and treatment of drug abuse. This is a high threshold treatment program, also known as "Goren Shalter". This is a first methadone program opened within the Centre, which practically started to introduce methadone substitution therapy in treating drug dependence in Macedonia.
 - Out-patient clinic for extended treatment from drug misuse. This program is low threshold treatment program, and is also known as "Dolen Shalter". It started operations in 2002.
 - Centre for prevention and treatment of abuse of drugs and other psychoactive substances, located in the facilities of the PHI University Clinical Centre – Skopje. Also known as "Drzavna bolnica" or "Klinicki Centar" after its location. It started work in 2007.
- City General Hospital "8. Septemvri", Department for Psychiatry, Centre for prevention and treatment of dependence illnesses. The centre started operating in March 2012, and is known under the term "Voena Bolnica" (Military Hospital) after the object it is located in, which during socialism was full time military hospital for the needs of the Yugoslav People's Army. It provides treatment for drug dependence by methadone substitution therapy.
- PHI University Toxicology Clinic – Skopje. Since 2010, it has provided combined in-patient and out-patient treatment, by applying buprenorphine substitution therapy.

All above stated treatment programs are primarily concerned with treating opioid addiction, and crucial condition for their inclusion in this project was because they are financed by state budget, i.e. from public funds, which corresponds to the methodology of community monitoring and advocacy programs (Das 2013: 6-7).

Activities within the community monitoring and advocacy project started in December 2011 and were carried out in three cycles:

- I. Cycle: from December 2011 to December 2012,
- II. Cycle: from December 2012 to December 2013,
- III. Cycle: from December 2013 conclusive with May 2014.

Here we should point out that the treatment program within the City General Hospital "8 Septemvri" was not included in the first cycle because the monitoring and advocacy activities had already started when this Centre for prevention and treatment of dependence illnesses was formed.

The remaining part of this chapter contains a short description of the activities in all three cycles of community monitoring and advocacy, while in-depth data will be presented in the following chapters.

3.1.1. A brief overview of the dynamics of activities within the first cycle of community monitoring and advocacy

The first cycle started with an analysis of the legal framework and international recommendations based on which the treatment of drug dependent people is carried out, and based on this the community based parameters were established (Dimitrievski and Boškova 2012). The two analyses emphasized the differences between existing policies and practices and formed the ground for negotiating the quality of treatment in drug dependence treatment programs in Skopje. During the first cycle, we established initial contact with health institutions concerned with the problem of drug use and a Counselling body was formed, comprised of a representative from the Macedonian Health minister cabinet, the director of the State Bureau on Drugs and the president of the Inter-ministerial committee on drugs in the Republic of Macedonia, the coordinator of the drug dependence treatment programs in Macedonia, the director of the PHI Psychiatric Hospital "Skopje", the representative of people treated for drug dependencies and of the community monitoring and advocacy team leaders. This is part of the key positions affecting the policies for drug dependence treatment in Macedonia. The counselling body has supported efforts for improving the quality of treatment in dependence treatment programs and has helped in clarifying disputable monitoring findings. Meetings of the counselling body signify the start of advocacy.

3.1.2. Brief overview of the dynamics of activities in the second cycle of community monitoring and advocacy

Efforts from the second cycle were directed towards strengthening advocacy capacities and proactive inclusion of people treated for drug dependence. At the beginning of this cycle we identified individuals from the community who were motivated to take part in advocacy activities towards fulfilling the rights and needs of the whole community. In March 2013, advocacy training was held, at which 14 community representatives were representing the four described drug treatment programs (See Chapter 3.1.). At this training, among other things, advocacy priorities were set and five volunteers were selected from among the representatives, thereby formally constituting the advocacy team. The three advocacy priorities were:

-
1. Patients should be involved in the decision making processes and in the new patient admission committees;
 2. Saliva tests, instead of urine tests, should be used to determine possible relapses in patients; ¹
 3. Psycho-social support (therapeutic programs) should be introduced in dependence treatment programs.

By forming the advocacy team, advocacy efforts intensified towards improvement of the quality of drug dependence treatment programs in Skopje, but unfortunately, it did not always happen with the foreseen dynamics. Contrary to initial assumptions and expectations, certain resistance started to appear where it was least expected, while some problems we considered very difficult were resolved very easily. Worth noting is the fact that the advocacy dynamic regarding the same set of issues took a different pace at each different treatment program included in the project. The inconsistency of the advocacy team and the lack of motivation in the community for involvement in advocacy efforts additionally influenced the dynamics of planned activities. In the second cycle, in a period of nine months, the advocacy team saw two different representatives of people on treatment with buprenorphine therapy at the PHI University Toxicology Clinic – Skopje. From the people treated in Kisela Voda, we could not identify any other sufficiently motivated members to advocate for the benefits and needs of this community. The team at “Clinical centre” remained consistent with its two representatives, and only in “Voena Bolnica” several motivated persons were identified.

The dynamic of the second cycle soon transferred into the third cycle, but new advocacy issues arose.

3.1.3. Brief overview of the dynamics of activities in the third cycle of community monitoring and advocacy

The third cycle kept the second cycle’s dynamic with the only difference that in the advocacy team there was no longer a formal representative of the community treated with buprenorphine therapy at the PHI University Toxicology Clinic in Skopje. Still, the previously achieved cooperation with employees from this clinic made it possible to achieve part of the planned advocacy objectives.

The intensity of advocacy activities in the two treatment programs in “Kisela Voda” decreased mostly because of the changes in power relations within the community itself, which affected the representative in the advocacy team, but also due to her private reasons.

The community representatives in “Klinichki Centar” continued negotiations from the previous cycle, mostly regarding the right to get a room for meetings and socializing for the people in treatment at this program, but also about the competences regarding the practice of injecting methadone in the vicinity of the treatment program premises and its eradication. Up until the end of the evaluation, no issue has been resolved.

At the dependence treatment program “Voena Bolnica”, the main efforts of the advocacy team were focused on the strengthening of relations among the people treated in this program, for which they were greatly supported by their program staff.

The changes in the advocacy team became an additional burden to team members, but despite this, another key question was raised before the representatives of methadone substitution therapy treatment programs – considering the possibility for individual dosages of pharmacotherapy, i.e. cancelling dosage limitations.

Part of the key efforts in the third cycle was directed towards strengthening team members' capacities for independent advocating. In fact, exactly these activities emphasized the weaknesses of the advocacy team and opened new questions which can be directly related to the effect of drugs and sub-culture, but also indirectly, to the wider socio-political context in Macedonia and the region. Still, prior to any further elaboration of the assessment findings, it is desirable to provide a short overview of the methodology that was used in the assessment.

3.2. The social context

The experiences from the monitoring and advocacy activities have shown that for the precise evaluation of activities performed, a realistic approach should be applied (Das 2013: 13), i.e. when assessing described activities it is desirable to take into consideration the socio-political context in Macedonia.

Still coping with the consequences of the transition from socialism to democracy ², Macedonia is a polarized state, both on the grounds of ethnicity and by political parties. It is obvious that this polarization is reflected in almost all social relations, including public institutions susceptible to corruption, nepotism ³ and cronyism ⁴. Judiciary is under governmental control, and freedom of media is extremely limited (Grozdanovska Dimishkovska 2014; Dimitrievski 2014: 18-19; Kirbiš 2013; Kržalovski 2013; Marković et al 2012; Institute for Democracy Societas Civilis (IDSC) 2012; Broughton-Micova 2006: 129-130). A similar polarization is visible in the civil sector. Political parties in their power struggles have destroyed almost all models of civil activism (Dekov and all, 2013: 3). Citizen associations and informal groups that are trying to point to the need for fundamental institutional changes and the implementation of humane policies for socially marginalized groups/communities are labelled "treacherous", "serving the enemy", "money laundries", "supporting the opposition". During public protests, it is frequently the case that at the exact same location, a counter-protest happens to be organized by another organization or informal group with diametrically opposing positions and attitudes very similar to the current governmental policies. As a result of this, a very large number of civil initiatives have ended without an epilogue: the protests against police brutality, the civil initiative against the increase in electrical power cost "Aman", The YEF initiative regarding external academic testing. The end result of all these – as well as many other – civil initiatives is an apathetic citizen (FOSM 2013: 72-74). All this only further encourages citizen's scepticism towards associations of citizens and contributes to an increased passivisation (Grozdanovska Dimishkovska 2014: 179-181; Nuredinoska and Ognenovska 2014: 44-65). A research carried out by the association "Reactor" in 2013, has shown that only 1/5 of Macedonian citizens have participated in some form of civil initiative in the 12 months prior to the research. Most research confirms this apathy and the lack of participation of the Macedonian citizen in civil society and in other social and political activities in general, all in the interest of the community (FOSM 2013, Klekovski, Kržalovski and Stojanova 2011).

Mass electronic media permeated by commercial content (Maširević 2005: 301-310; Veselinović 2005: 273-288) diminishes the significance of political activism and overflows the public sphere with an "infective" conformism. (Trajanoski et al. 2013: 13-14, 61-62, 66; CSHRMC 2012: 12-14; CSHRMC 2011: 13-16, 41-42, 44; Klekovski et al 2011: 20-21)

According to current estimates, there are around 10.900 people dependent on opioids in Macedonia, of which around 3.150 live in Skopje (Mikić et al. 2012: 36). Of the total estimated number of drug dependent people in Skopje, only 800 are treated in the treatment programs covered by the community monitoring and advocacy, which points to the fact that most drug dependent people in Skopje avoid treatment in public drug dependence treatment programs. On the other hand, users of services in the monitored programs are not fully satisfied with the quality of treatment. The phar-

macotherapy dependence leaves them in a dependent position in relation to staff in treatment programs, but also in relation to certain more powerful individuals from the community itself, and their marginalized social status makes them dependent on their family or on other sources of existence.

Faced with limitations on all sides, it would be easy to assume that people treated for drug dependence would demonstrate bigger initiative and motivation advocating for their own rights and interests. However, reality proves the opposite. There is no group solidarity. Most individuals from the community take the line of least resistance and seek one-off, self-benefiting only solutions. Just a selected few show the motivation and readiness to represent the rights and interests of the community, but they also have a problem with persistence in their intentions.

Similar cases of passivization of communities most in need of public services are found in other countries. However, the massive and monolithic public system is not considered an insurmountable obstacle and flexible solutions are found to support a community's capacities for independent advocacy for their own rights and benefits. (Das 2013: 7)

Having in mind the described socio-political conditions, what follows is an overview of the effectiveness, obstacles and possibilities for improving the monitoring and advocacy efforts towards improving the quality of dependence treatment programs in Skopje.

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4. Methodology for community monitoring and advocacy evaluation

The main objective of the assessment of activities within the community monitoring and advocacy was to assess advocacy effectiveness. In addition to this, the evaluation was expected to provide:

- An assessment of the reasons hindering people treated for dependence to actively represent their own rights and their motivation for active engagement, and based on this, to find possible solutions for improvement of community monitoring and advocacy efforts;
- To improve existing knowledge and experiences for wider promotion of monitoring and advocacy methodology in the community of people treated for drug dependence.

These objectives made it possible to use the realistic assessment approach, which in turn, gives understanding to the planned mechanisms in correlation with desired results and the context in which advocacy is carried out (Das 2013: 13).

Primary target groups for the evaluation were:

- Members of the advocacy team;
- People treated for drug dependence within the treatment programs in Skopje;
- Employees in dependence treatment programs in Skopje.

A secondary target group in the evaluation was a group of activists from the LGBT community ⁵, who helped make a comparison between the two communities, people treated for drug dependences and the LGBT community, regarding the conditions, motivation and readiness to actively engage in advocacy for one's own rights and interests. The comparative research for the motivation for active engagement in advocacy of their own rights and benefits in these two socially marginalized groups helped in understanding the weaknesses, and strengths of activism in marginalized communities.

In accordance to the recommendations for evaluation of the activities within the community monitoring and advocacy (Das 2013), the evaluation of community advocacy was performed by applying ethnographic methods (Hammersley and Atkinson 2009). As recommended by Abhijit Das (Das 2013: 24-26), one of the world's leading experts on community monitoring and advocacy, evaluator was selected to be one of the team member involved in the planning and performing the monitoring and advocacy and who is fully familiarized with all undertaken activities. A great part of the evaluation's success was the methodology we implemented in the second cycle of the community monitoring which was also used to assess the efficacy advocacy. The application of ethnographic methods for representational (developmental) purposes is known as: qualitative research, interpretative method, case study, participatory action research (Hammersely and Atkinson 2009: 1; McKechnie 2008: 598-999; Jordan 2008: 601-603; Somekh 2008: 4-6).

A leading research method used during monitoring was the participatory action observation (McKechnie 2008: 598-999). The evaluator was a direct witness to almost all activities since the beginning of the monitoring and advocacy activities in 2011 until the formal completion of the advocacy activities in May 2014. Data from the observation were kept in the form of field notes containing key details from observed events.

Data gathered with the observations have been amended with information from interviews, focus group discussions, informal conversations, formal meetings (meetings, seminars and symposia). Just as for observations, most of these data have been saved in the form of field notes, and a lesser number exist in audio form.

From formal methods, which are easier to record quantitatively, the following were carried specifically for the needs of the evaluation:

Research method	Target group	Number of interviewed
Focus group discussion	People treated for drug dependence	3 focus group discussion (A total of 23 interviewees, of which 5 female)
	LGBT	1 focus group discussion (5 interviewees, of which 1 female)
Interview	People treated for drug dependence	5 (all male)
	LGBT activists	4 (all male)
	Staff from dependence treatment programs	2
Group interview	people working in community support	1 (A total of 2 male interviewees)

The interviewees all had extensive experience and deep insights into the problem at hand. Through the informal conversations and formal meetings, information was collected of interest for the evaluation, especially because in informal conversations, interviewees are more open, while in formal meetings, contradictory attitudes are better confronted. These data are taken as valid, corresponding to the research methodology. (Hammersley and Atkinson 2009)

Data from the evaluation carried out in the third cycle has been amended with information from the monitoring from the previous two cycles of monitoring and advocacy. Among these data, in addition to qualitative, there are also quantitative information (Dimitrievski 2014; Dimitrievski and Boškova 2012). The evaluation was made easier by research data from the monitoring carried out in the second cycle with which we partially evaluated the success of advocacy in the first two cycles. The well planned process ensured clearer insight into the weaknesses and advantages of the advocacy team, but also into the circumstances affecting advocacy's success.

4.1. Ethics

All people included in the monitoring or in any other way involved in the process were guaranteed complete anonymity and discretion. Parts of descriptions and attitudes presented here are purposefully left out thus providing a seemingly superficial analysis, but the reason behind was the necessary measure to prevent the possibility of identity disclosure. That same measure is applied in institutions, organizations and other entities, whenever possible and necessary, because the purpose of this document is not judge or stigmatize, but rather to point to the existing conditions and recommend measures for improvement of the quality of drug dependence treatment programs in Skopje.

This study does not intend to seek for guilty parties and judge, but rather to encourage dialogue for the improvement of the quality of dependence treatment in Macedonia, and to urge an initiative for finding quality solutions acceptable for end users.

5. Key activities and results from the community advocacy for improvement of the quality of drug dependence treatment programs in Skopje

5.1. Overview of key activities from the community monitoring and advocacy

Activity: *Community monitoring, I. Cycle.*

a) **Realization period:** December 2011 – June 2012.

b) **Activity description:** This activity included two components: 1. Analysis of existing legally binding documents for treating dependence adopted by the Republic of Macedonia and 2. Monitoring of three treatment programs in Skopje by applying quantitative and qualitative research methods. Monitoring was carried out by a team comprised of people from the stakeholder community, and a Counselling body was formed, created by representatives of competent institutions and organs (Dimitrievski and Boškova 2012).

c) **Result:** The cross analysis of the two components pointed out the deviations between existing policies and practices for the treatment of drug dependences. Employees in dependence treatment programs saw that their job can be found under scrutiny and monitoring and accepted, at least, declaratively, the cooperation with community representatives. Members of the community got the opportunity, anonymously and confidentially, to express their attitudes for quality of treatment of dependence treatment programs and supported the initiative.

d) **Obstacles:** In this part no major obstacles were encountered. One of the more significant barriers in the first component was the collection of part of the needed data, mostly because of bureaucratic procedures and the bad archive system of public institutions. A more significant barrier in the second component was the change of field monitoring researchers. The two barriers were easily overcome. Some serious obstacles started appearing after the end of monitoring when treatment program staff started reacting to certain parts of the Report, which they considered disputable. Part of the mentioned reactions had a negative effect on the future of advocacy. Similar to employees, some community members expressed dissatisfaction from certain parts of the Report, but it was established that their reactions were based on their personal interests, possibly because of the systemic weaknesses in treatment programs (Dimitrievski 2014: 13-14).

e) **Advantages:** The participation of experts in the area and the experience of the community representatives made the carrying out of the monitoring easier and enabled clearer overview of existing circumstances in dependence treatment programs.

Activity: *Community monitoring, II. Cycle.*

a) **Period of realization:** December 2012 – November 2013.

b) **Activity description:** Unlike the first cycle, in the second cycle, advocacy activities were monitored. Monitoring was primarily performed by applying ethnographic methods – participatory action observation and interviews, and at the end of the second cycle, a survey was performed assessing the visibility of efforts from community advocacy (Dimitrievski 2014: 9-11).

c) **Result:** Through the participatory action observation and the application of combined research methods, we formed a clearer image about the actual, as opposed to the declaratory preparation of employees in dependence treatment programs for cooperation with the community and for imple-

menting changes. At the same time, through the constant monitoring of the process, we could assess the capacity of advocacy team members representing for independent advocacy. Based on all the received data, the aims and objectives for the third cycle of the research were easier to identify.

d) **Obstacles:** Thanks to the applied methodology, the second cycle of the community monitoring was carried out without any obstacles. The only problem we encountered was that one team member left during the quantitative phase, but he was soon replaced, and the monitoring was completed according to the original plan.

e) **Advantages:** The person who led the monitoring activities and participated in the ethnographic research has extensive experience and knowledge in the topic at hand. The trust he enjoys among people in treatment and programs employees made information access easier for us.

Activity: *Counselling body for the community monitoring in 2012.*

a) **Period of realization:** January – October 2012.

b) **Activity description:** For the needs of the community monitoring, during the first cycle of activities, a Counselling body was formed comprised of the representative of the Macedonian Health Minister's Cabinet, the director of the State Bureau of Drugs, and the president of the Inter-ministerial committee for drugs of the Republic of Macedonia, the coordinator of drug dependence programs Macedonia, the director of the PHI Psychiatric hospital "Skopje", a representative of the community of people in treatment of drug dependence and the community monitoring and advocacy team leaders (Dimitrievski 2014: 13).

c) **Result:** the Counselling body supported the monitoring and with its constructive comments helped better understand the way in which the institutional system in the area of health operates.

d) **Obstacles:** Certain members of the Counselling body did not show any major interest in the topics discussed and passively monitored the process, while some members didn't participate regularly at meetings.

e) **Advantages:** The inclusion of representatives from competent and concerned institutions was a political decision of the advocacy team. Through the formal acquaintance of the Counselling body with the aims and objectives of the monitoring constitutional support was ensured and possible negative reactions and obstacles from institutions covered were avoided. Also, this was an opportunity for community representatives to participate in both, counselling and decision making processes, from their very beginning. At the same time, the foundation and activity of the Counselling body was the first objective of the advocacy.

Activity: *Better inclusion of the community in advocacy for their own rights and needs.*

a) **Period of realization:** March 2013 – ongoing.

b) **Activity description:** Based on the recommendations from the Report, from the first cycle monitoring (Dimitrievski and Boškova 2012: 72), at the beginning of the second cycle 15 community representatives were identified, who were more significantly motivated to represent the rights and needs of the community. In March 2013 advocacy training was organized, with a special emphasis on representing rights of people who use drugs by Mathew Southwell, a long term activist for human rights of people who use drugs. Of the group of fifteen, five members stood out volunteering to become actively involved in advocacy. In the period after the training, there was a period of consolidation and fulfilment of the criteria for advocacy determined in the training. The team's

activities were carried out with a varying dynamics, depending on the circumstances in separate dependence treatment programs. This gave rise to the need to apply separate approaches in advocacy and to advocate for different objectives in each separate treatment program separately, which started to happen in the third cycle of advocacy. These activities ended on 31.5.2014, with the end of the formal part of the project, but team members expressed readiness and initiative to continue existing and plan new activities. It was planned to organize a press conference, which was held on 26.6.2014. Through the media, the team actively took part in the global campaign "Support. Don't punish." (IDPC 2013). Through this approach, a public criticism was sent against the policy of criminal persecution of people who use drugs as well as a request for improving the quality of treatment programs.

c) **Result:** With the active inclusion of community representatives in the advocacy process, we animated most of the stakeholder community, and program employees started accepting patients as interlocutors and collaborators. From monitoring perspective, better understanding was gained of the circumstances in which treatment was carried out, but also of the relationships within the community itself that affected the quality of treatment.

d) **Obstacles:** Change of membership, lack of seriousness, inconsistency and lack of advocacy skills among team members were some of the main obstacles. Thus, for example, representatives of the people in treatment at the PHI University Toxicology Clinic – Skopje twice changed, and after the second replacement left, we were unable, in the period defined, to find a representative motivated enough to take over advocacy actions. From an individual perspective, the nature of opioid dependence, as well as dependence on the substitution drugs, has proven to be a significant obstacle. The working capacities of community representatives may be made more difficult because of the lack of pharmacotherapy, but also because larger doses of it were used. To this we add the fact that despite the use of pharmacotherapy and the manner in which treatment was organized, community representatives as well as most community members depend on employees in dependence treatment programs and fear possible sanction if they confront them. The insufficient community support, personal conflicts and fear from possible confrontations with certain power centres within the community itself represents additional de-motivation for part of the advocacy team members. Described circumstances leave the impression that set challenges are irresolvable, which at times caused demoralization and de-motivation among advocacy team members.

e) **Advantages:** When all the obstacles described above are considered, one may get the impression that the whole initiative for community advocacy was unsuccessful. Fortunately, practical experiences are more hopeful. All members of the advocacy team had different skills, which simplified the distribution of tasks and their realization. Some team members demonstrated greater initiative and succeeded in organizing regular meetings with other community members on which they discussed their rights and needs. Despite their dependable status in relation to treatment program employees, community representatives started holding meetings with competent persons and talking about the needs of the community. Representatives of three out of the five treatment programs included in the project, demonstrated greater openness and within their competences enabled the use of premises for meetings and socializing of community members at set times. A large support in advocacy was the experience and contacts of the team leaders, who, although not community members, made the whole process easier.

Activity: *Including patients in the decision making process and in new patients admission processes.*

a) **Period of realization:** May 2013 – ongoing.

b) **Activity description:** This activity was one of the advocacy priorities set at the advocacy

training held in March 2013 (Dimitrievski 2014: 14-15). The intention was to make patients get the opportunity, through their representatives, to participate in the process of making decisions that directly or indirectly concern them. The negotiations with competent persons within programs started in May 2013 and everybody expressed a declarative consent to accept team members as community representatives. During negotiations, it was established that the second component in this objective, participation in the new patient admission committees, was impossible to accomplish because of the right to discretion and personal data protection of new patients, which was why it was removed from our advocacy priorities. Instead it was decided to have regular meetings with team members and program managers.

c) **Result:** The advocacy team members started holding regular meetings with employees in dependence treatment programs on which they represented the interests and needs of the community. One visible result from the negotiations may be the fact that representatives from three out of the five treatment programs included in the project, demonstrated greater openness and within their competences, enabled the use of premises for meetings and socializing of community members at set times, which strengthened the efforts in community animation.

d) **Obstacles:** The busyness of competent people from treatment programs as well as the annual holidays postponed the negotiation process, and made other activities slower. This in turn affected the personal motivation of team members. In two of the treatment programs there were no facilities to provide and in those programs our efforts towards community motivation took longer.

e) **Advantages:** Accepting team members as official representatives of the community by competent persons in treatment programs has partially strengthened their position in the community, which has started to accept them as their representatives. The meeting and socializing premises which were at disposal to the community in the three of the five programs proved to be a good basis for support of efforts towards animating the community. The good cooperation and the permanent communication with treatment programs helped in realizing the unrealistic assumptions of the advocacy team. One specific example for this was the pointing out of the person employed at one of the programs that participation of community representatives in new patients' admission committees violates the right to discretion and protection of personal data of new patients.

Activity: *Advocating for changes in the manner of taking relapse testing samples.*

a) **Period of realization:** May 2013.

b) **Activity description:** This activity was set as one of the priorities for advocacy defined at the advocacy training that took place in March 2013 (Dimitrievski 2014: 14-16). The initiative arose from the community itself, which considers the occasional urine testing for possible relapse carried out in treatment programs humiliating. Based on experiences from Great Britain, as described Mathew Southwell, training participants agreed that drug dependence treatment programs have the right to perform such tastings, but concluded that saliva testing is much simpler and more dignifying and decided to advocate for introducing this practice. The first action after constituting the advocacy team was to check community attitudes for introducing saliva testing. Although it was established that most of the community agrees with this, due to possible obstructions from the powerful minority which did not agree with the initiative, the advocacy team decided that carrying out this activity should be postponed until other conditions in treatment programs improve.

c) **Result:** Although not fully realized, this activity is the first example in which community representatives have performed independent monitoring of the needs of the community they represent. Also, the discussion inspired by the performance of objective has encouraged the process of reassessment and harmonization of different attitudes within the advocacy team.

d) **Obstacles:** The community needs assessment was carried out without any obstacles, with the

exception of several minor manifestations of lack of seriousness and inconsistency by certain team members which were easily overcome. The possibility of obstructions in advocacy by the powerful minority within the communication, which did not agree with the initiative for introduction of saliva testing, was the reason for postponing the advocacy efforts towards this objective, until other treatment conditions were approved.

e) **Advantages:** Proactive participation of community representatives in advocacy efforts made the communication with the community easier. Advocacy team members carried out this activity with great enthusiasm.

Activity: Introducing high quality psychosocial support in drug dependence treatment programs.

a) **Realization period:** May 2013 – May 2014.

b) **Activity description:** This activity was set as one of the advocacy priorities defined at the advocacy training in March 2013 (Dimitrievski 2014: 14-16). The need of patients for a comprehensive approach to dependency treatment initiated the efforts towards advocating for the introduction of high quality psychosocial support in dependence treatment programs. First cycle monitoring showed there were no employees/engaged psychologists and social workers in all monitored treatment programs, and in those programs where such cadre existed, there was no established continuous work with patients. Advocating for this purpose included negotiations with competent persons in dependence treatment programs, educating the community about the benefits from psychosocial support and their motivation to request such services, training on the "Strengthening capacities of drug treatment programs staff in working with people who use drugs" intended for employees not on managing positions in dependence treatment programs.

c) **Result:** This objective is far from reached, but during the third cycle we noticed some positive changes. The psychologist and the social worker in "Kisela Voda" started each, once weekly, to participate at the community meetings and although no significant results were noticed, having in mind the existing context, this may be considered a satisfactory achievement. Most of the dependence treatment programs in the PHI University Toxicology Clinic signed a Memorandum of understanding with HOPS – Healthy Options Project Skopje, according to which the psychologist engaged by HOPS temporarily volunteered at the Clinic, providing psychological support for patients treated for drug dependence there. This contributed for greater motivation of patients for the use of psychological services. After the end of the temporary stay of the psychologist at the Toxicology clinic, it was agreed with patients seeking psychological services to be referred to the Centre for re-socialization and rehabilitation at HOPS. In other programs, no changes were noticed, but much clearer insight into the obstacles for introducing quality psychosocial support was gained.

d) **Obstacles:** The staffing policy, i.e. the centralized system of employment and HR management, which depends on the highest political elites in Macedonia, represents a major obstacle for this objective. Nepotism and cronyism make the engagement of skilled and motivated staff, and the effective management with existing staff, impossible. Negotiating the introduction of high quality psychosocial support depends on the programs' managerial staff's ideological concepts and perceptions about the problem. Some of the managers think that dependence treatment programs should remain at the level of primary medical focus, and for those patients who are in need of additional support; there should be complementary programs separate from the dependence treatment programs. Most community members are not familiar with the benefits from psychosocial support which is why they do not seek any services, thus making attempts to pressurize authorities for a more appropriate engagement of already engaged psychologists and social workers harder.

e) **Advantages:** The awareness and openness among part of the program managers, regarding

the need of high quality psychosocial support. The requests from those community members who are in need of psychosocial support, largely contributed to this effect.

Activity: *Facilities for community meetings, socializing and topical gatherings.*

a) **Period of realization:** August 2013 – ongoing.

b) **Activity description:** The need to ensure facilities for meetings and socializing of people in the community arose as a need from other advocacy activities. The intent was to provide space at the premises where programs are located in which community members could gather, organize topical discussions or advocacy actions (Dimitrievski 2014: 16-17). This activity was achieved with partial success.

c) **Result:** Facilities were provided to people treated at two programs in “Kisela Voda”, “Dolen Shalter” and “Goren Shalter”, and people treated in “Voena Bolnica”. These premises were mostly used for socializing among patients of the specific programs. Thematic discussions arose spontaneously, during socializing time. In addition to ideas being put forward, there were no other visible initiatives for organized advocacy. Still, team members showed readiness to take responsibility and skills for animating the community.

d) **Obstacles:** At the “Klinicki Centar” and Toxicology Clinic, despite the declarative openness of employees, no premises have been made available to patients. In programs where facilities were provided, the physical limitations and routine daily engagements limited the possibilities for proactive participation. One of the major weaknesses is that particular community members with their inappropriate behaviour compromise the trust for the whole community and create risk for losing these benefits.

e) **Advantages:** Thanks to the possibility for using meeting rooms in their treatment program premises, community members were able to use their free time in more appropriate and creative manner. In “Voena Bolnica”, thanks to this opportunity, a permanent group was formed out of ten people, who are most frequent attendees at the meetings, and which represents a great basis for planning and organizing further activities.

Activity: *Initiating the discussion for introducing individual dosage of pharmacotherapy.*

a) **Realization period:** February 2014 – ongoing.

b) **Activity description:** The idea to advocate for the introduction of individual dosages for pharmacotherapy has been present since the first cycle of community monitoring and advocacy. Activities started at the beginning of 2014. Although based on the needs and requirements of the community, advocacy was postponed for a long time because of resistance which seemed insurmountable. That is why advocacy started by initiating discussion instead of putting forward a specific request for introducing individual therapy dosages. And, although initial activities are hopeful, it is obvious that the achievement of this objective will be long term and difficult.

c) **Results:** In February 2014, a process of intensive consultations with psychiatrists and treatment programs managers started. As a result, on 10.4.2014 a meeting was held between program managers, on which we formally initiated the discussion of introducing individual pharmacotherapy dosages. At the same discussion, declarative willingness for reassessing the possibilities to individually dose pharmacotherapy was expressed, and it was decided that it will be requested from the

Ministry of Health to add to the existing protocol clinical routes for treatment with more than 140 mg methadone with clearly defined steps.

d) **Obstacles:** Individual pharmacotherapy dosage, i.e. allowing for doses bigger than 120 mg, is still a taboo. In the current methadone treatment protocol, there is no detailed clinical route for treatment with methadone quantities above 140 mg (Official Gazette 36/2012: 58-59). Employees at dependence treatment programs fear that increase in dosages will have a negative effect on patients' health, but will also create a possibility to misuse the medication, which would worsen the already negative opinion of current dependence treatments. These attitudes are justified with pharmacotherapy abuse experiences, but also with the financial and political limitations set by higher competence institutions.

e) **Advantages:** Psychiatrists and managers – employed at the dependence treatment programs showed openness for discussion and consideration of the possibilities for introducing individual dosages for pharmacotherapy. Largely contributing to this was the persistence of the advocacy team, as well as the whole community monitoring and advocacy process.

Activity: Trainings for strengthening advocacy skills.

a) **Period of realization:** March 2013 – May 2014.

b) **Activity description:** Having in mind that people treated for drug dependence have no experience and knowledge for advocacy it was planned to organize advocacy training, which was held in March 2013. This training helped constitute a permanent advocacy team, but during the second advocacy cycle, in 2013, it was established that team members had the need of additional skills which would help advocacy. That is why, in line with recommendations from the second cycle (Dimitrievski 2014: 25), during the third cycle we organized a communication skills training and activism training. At the same time, the whole process was a practical training for community monitoring and advocacy.

c) **Result:** In March 2013 training was held on which an advocacy team was constituted, comprised of volunteers from the people in treatment programs covered by the monitoring and advocacy. In March 2014 training was held for developing their communication skills necessary in advocacy, and the knowledge from this training were used for further planning and acting. In May 2014 activism training was organized related to drug use policies, and on that training a plan for future short term activities was drawn up.

d) **Obstacles:** Despite expectations, with exception of the training held in March 2013, certain team members demonstrated very low level of interest for the trainings. It seemed like taking medication was their sole priority, and it constantly came up as a topic, pushing aside all other topics and not living space for any constructive solutions. The extreme lack of interest affected the advocacy team leaders, who were forced to put in exceptional efforts to consistently carry out planned activities.

e) **Advantages:** Certain team members demonstrated particular interest in training topics and initiative for further application of acquired knowledge and experience. They permanently consulted with team leaders and attempted to transfer knowledge to other community members.

Activity: Training for "Strengthening capacities of drug treatment programs staff in working with people who use drugs".

a) **Realization period:** March 2014.

b) **Activity description:** In March 2014 two-day training was held for "Strengthening capacities of drug treatment programs staff in working with people who use drugs" at which 11 employees not on managing positions from the treatment programs in Skopje attended. According to the professional orientation, the training was attended by: 2 specialists-psychiatrists, 2 specialists-toxicologists, 3 nurses, 3 psychologists and 1 social worker. The purpose of the treatment was to sensitize employees at drug dependence treatment programs about the rights and needs of the community.

c) **Result:** During training, discussion was opened about existing treatment models, and the need to introduce an innovative approach based on patients' needs in cooperation with them. The training was an excellent opportunity to achieve closer contact with employees in dependence treatment programs, and for honest sharing of opinions and attitudes as well as about the options of establishing a comprehensive drug dependence treatment. All members were satisfied with the training, and were ready to further cooperate and participate at different events. In addition, through discussion, from the employee's perspective, the existing knowledge was confirmed and new insights were gained about the conditions of work and treatment in dependence treatment programs in Skopje.

d) **Obstacles:** During the training organization, insignificant obstacles appeared when participants were selected, which was easily overcome. During discussions, opposing positions were expressed, but that was not a significant obstacle.

e) **Advantages:** All participants were open for exchange and acceptance of different opinions and attitudes. Through the informal socializing, a more open and honest communication was achieved, which made the overcoming of disputable attitudes during discussions easier.

Activity: Magazine "Drugs – Policies and practices".

a) **Realization period:** January 2013 – May 2014.

b) **Activity description:** The primary objective of the magazine "Drugs – Policies and Practices" is to inform about current drugs-related policies and practices in Macedonia and globally and to bring down social stereotypes about drugs and about people who use drugs. The magazine is intended for people who use drugs and for the wider audience, but primarily, for people engaged in the creation and implementation of policies and practices related to drugs, students, and the academic community.

c) **Result:** The magazine's first issue came out in October 2013, and was distributed to people who use drugs, competent institutions and organizations concerned about drugs-related policies and practices, medical or social sciences higher education institutions and other stakeholders and organizations. The publication of the magazine was used to initiate a public debate on the topic "media and drugs" which was held on 21.11.2013, and on which among other things, we discussed the need to issue topical expert and scientific popular magazines, which should act as a form of a counterbalance to the more and more dominant social obscurantism. The electronic version of the "Drugs – Policies and Practices" was placed on HOPS's web site and on several other internet pages and publication aggregators. In January 2014 we created a Facebook page to promote the magazine in Macedonian, and at the time of this Report, the page had 177 registered readers. Public reaction was much more positive than expected, and according to reports, the next issue is eagerly awaited. The second issue of the magazine was published on June 2014. After the second issue, an evaluation is planned in order to assess the interest for and influence of the magazine among

readers. In April 2014, the editorial board proposed a survey to assess public opinion in Macedonia about drugs criminalization, and the results are presented in the second issue of the magazine.

d) **Obstacles:** Contrary to assumptions, it was established that it is much harder to motivate people, especially community members, to write and submit publication appropriate texts. Due to this, the preparation of the magazine took longer than planned. The delay in preparing the magazine is also influenced by two factors. First, most of the efforts for publishing the magazine are volunteering, and editorial office members are also busy with regular work obligations. Second, the existing content and design concept is still under assessment as to its popularity by readers, and new possibilities are tested out.

e) **Advantages:** The need for a topical magazine of this sort quickly draws attention, finds its readership easier, and encourages debates about policies and drug practices. "Drugs – Policies and practices" represents our support towards community monitoring and advocacy efforts.

Activity: Support and participation in the global campaign "Support. Don't punish"

a) **Realization period:** May – June 2014.

b) **Activity description:** The idea and plan for participation and support of the global campaign were developed during the activism training, held in May 2014. According to the above stated, on 26.6.2014 a public event was organized in support to the global campaign "Support. Don't punish" (IDPC 2013).

c) **Result:** As planned, we organized a press conference on which the advocacy team publicly presented its requests for improvement of the quality of treatment in Macedonia. The team also appeared with a transparent on which we had the parole "We are children of Macedonia, too".



The press conference started with one minute silence in respect to all drug users who have passed away. With this action, the policy to criminally persecute people who use drugs was judged, and condolences were expressed for the people who have passed away because of the inhumane drugs-related policies. Then the requests for improving the quality of dependence treatment programs were presented.

d) **Obstacles:** No visible obstacles.

e) **Advantages:** Enthusiasm and motivation in team members. Part of the team members were encouraged enough to publically represent the community.

5.2. Motivation, skills, dynamics and consistency of the advocacy team

When constituting the advocacy team, in April 2014, motivation for active participation was present, but also a certain reservation from taking initiative and responsibility. During the activities that followed, we started noticing oscillations in the motivation and its general decrease. According to observations and statements from team members, team members, key reasons that have had a negative effect on motivation are:

- Expecting another person to take responsibility;
- Diffidence about independent actions;
- Discord inside the advocacy team;
- Not valuing the ideas and efforts of other team members;
- Lack of knowledge or experience in advocacy;
- Lack of support from the represented community;
- Fear from possible sanctions by employees from treatment programs;
- Fear from possible clashes with individuals that exert great power and influence onto the community;
- Expectations for profit from the efforts put in.

During advocacy, it was obvious that team members did not have the appropriate skills and because of this, during the third cycle, we dedicated greater attention on improving personal capacities. Still, some team members were not open to new knowledge, which had a negative effect on the overall advocacy dynamics.

The community advocacy was carried out with a variable dynamics, but overall, the process went very slowly. The variable dynamics was affected by external factors, which depended on priorities and the mood of employees in treatment programs, but also on internal factors within the team. Internal factors here were: the mutual dependence of motivation and skills of team members, but also, other personal priorities, and how their attention was strongly focused on their pharmacotherapy. All the team members, including team leaders, despite advocacy also have other job obligations, and personal priorities which consume a large part of their time and attention. But in periods dedicated to advocacy objectives, their focus on pharmacotherapy had a negative effect on their dedication and working environment.

Although most of the team remained in its original constituents, during 2013 two of the people treated in the Toxicology clinic left. After the first member left, we could easily find a replacement, but after his replacement left, it was hard to find a new replacement, which weakened our advocacy efforts within this Program. The first Toxicology representative withdrew from the team because he got a job, and was unable to dedicate more of his time to advocacy, and the second representative was preparing to complete his treatment and reach full opioid abstinence. For the community treated in the both drug treatment programs in "Kisela Voda", there was only one representative and during the process we failed to identify another person that could help strengthen our efforts in these two programs. On the other hand, we had no trouble identifying and including people interested in advocacy from the community treated in "Voena Bolnica", who were keen on helping improve things in this program.

5.3. Self-assessment of team members

Team members are self-critical and they understand that advocacy does not always happen according to initial plans and does not always achieve set goals.

Some more realistic analysis of advocacy success take in consideration that when planning too high objectives were set and that their socio-political context has been naïvely assessed. Although advocacy objectives were directed towards the change of certain practices, it was established that these practices depend on the overall system and that in order to achieve them, long time and more effort will be needed (Spasenoski et al 2010: 14).

Still, the general assessment of the team members is that although not very visible, after considering social-political context and circumstances in dependence treatment programs, the results achieved from the advocacy were positive. Thus for example, introducing high quality psycho-social support affects the overall staffing policy in Macedonia, not only that dependence treatment program's managers. It is similar with the introduction of the practice of individual pharmacotherapy dosages. Despite the fact that the greatest responsibility here would be carried by psychiatrists, decisions are brought by higher institutional levels.

COMING OUT OF THE CLOSET?

Assessment and evaluation of advocacy efforts for the improvement of quality of drug dependence treatment programs in Skopje

6. Visibility of advocacy efforts

6.1. Visibility and evaluation from the community

According to data from the monitoring carried out during the second cycle, out of a total of 200 surveyed, out of five different dependence treatment programs, 62 (31%) of the surveyed stated that there aren't any or they don't know if there are representatives of the patients included in dependence treatment programs. Of the 138 surveyed, those who knew that there are representatives, only 80 (40%) could state some activities of the advocacy team, while the other 120 (60%) did not know what are the activities of the advocacy team, or did not answer the question. In the community, the two most well known activities of the team were the provision of a meeting and socializing space for people in treatment (n=69; 34,5%) and the advocacy of the interests of the community (n=42; 21%).⁶

Similar data to the ones just shown, are yielded by the community advocacy assessment. Community members know there are people who have taken up representing common interests, but results from their work are not visible yet. What is usually noticeable as a result are the received premises for meeting and socializing, where available, and meetings that team members have had with drug treatment programs staff.

Part of the community members are displeased with the results, and think that the people representing their interests lack authority, are insufficiently aggressive and dependent on doctors, but only a few of community members are personally ready to become involved in advocacy.

6.2. Visibility and evaluation from the employees in drug dependence treatment programs

Team members, as community representatives, have been noticed by managers of treatment programs since the start of their actions. Other employees, especially those with lesser responsibilities in the decision-making process, are less aware of the role and actions of community representatives, but this was partially resolved with the training held – “Strengthening capacities of drug treatment programs staff in working with people who use drugs”.

Similar to the reactions of the community, not all employees from the drug treatment programs are pleased with the work of community representatives. But, unlike the community, which thinks they should make more pressure, these employees do not like pressures and initiatives for change. Some employees even negate the legitimacy and credibility of advocacy team members and refuse to negotiate with them as community representatives.

On the other hand, there are employees who honestly support the initiative and endeavour to meet community representatives' demands. Some employees are so open that they eagerly await for the community to come up with more specific change demands, but are aware that what this community needs first is to strengthen its self-confidence. The success of advocacy activities is manifested in the fact that some employees have taken on the positive critique given during contacts with the advocacy team and have made appropriate changes to their daily work.

COMING OUT OF THE CLOSET?

Assessment and evaluation of advocacy efforts for the improvement of quality of drug dependence treatment programs in Skopje

7. The spirit of activism among people treated for drug dependence

7.1. Defining activism

There are numerous definitions of the term activism, and some theoreticians relate it to social movements. For the needs of this text, we shall use the definition of Ron Kassimir (Kassimir 2005: 22-23), according to which, the term activism most usually signifies a planned action, as a form of civil engagement, which leads or should lead towards social and political changes on a micro and/or macro level. This means that an action, being the result of the lack of congruence, attempts to initiate changes or actions towards actualizing certain issues within the current policy. These actions are frequently related to the wider social and global movements which may, but need not, act in line with prescribed laws or social norms.

Social movement theories strive to understand and explain why social movements and activism happen and how they are organized, in which ways do they communicate with other actors in the same field of action and why some movements are successful and others aren't. One line of thinking in social movement theories emphasizes the importance of resources a social movement has at disposal, other theories indicate to the importance of political possibilities and processes that facilitate social movements, while others emphasise processes of forming collective identities and discursive struggles that give rise to movements, i.e. activism (Anker et al 2008: 21). Each of these lines of thought contains a significant analytical potential, necessary to understand social movements such as the "drug users movement". The initial stand point we look into here is that cultural, social and political dimensions are key to the contextualization of social movements. Translating these dimensions into more specific empirical categories, we suggest that key aspects which must be taken into consideration when analyzing activism of drug users in Macedonia are: 1. The dominant public ideological and moral perception of drug use, 2. institutional, i.e. political context and 3. Political self-awareness. All three segments will be elaborated below.

7.2. Public ideological and moral perception of drug use

Drug use in Macedonia is considered an immoral act, and people who use drugs are labelled "lunatics", "social outcasts", "criminals" and similar negative etiquettes. People who use drugs are aware of the existing social perception. "They see us as some sort of lower species because we are like, hey a junky" ⁷ – he must have just stolen something or lied to somebody... Public view about people who use drugs is very low " (A HOPS, AU_MZZ2014_I_007).

That people who use drugs are the least desired group of citizens in Macedonia was confirmed by a research carried out by the Macedonian Centre for International Cooperation, back from 2010. According to this research, a high 96,8% of Macedonians do not want drug using people as their neighbours, which is significantly above all other communities such as: people dependent on alcohol – 93,6%, people with a criminal file – 84,1%, people with AIDS – 82,9%, homosexuals – 77,9% etc. (Klekovski, Kržalovski and Stojanova 2011: 20-21).

People who used to use drugs in the past and are now in treatment are only partially excluded from the general perception. The environment attempts to re-embrace them, but with visible suspicion because the fear, proverbially described as "once a junky, always a junky" prevails. That is why people treated for drug dependence cannot be completely separated from people who actively use drugs.

7.2.1. De-motivation for active engagement because of the existing stigmatization and decriminalization

"If you are using, well, you'd better not say it out loud... lest somebody should find out."

(A HOPS, AU_MZZ2014_I_007).

The stigma towards people who use drugs is definitely the biggest obstacle for the development of activism in this community. This was confirmed by all of the surveyed. There are several sources of this stigmatization. Above all, "our society does not recognize mistakes of the type endangering own health for pleasure, i.e. making a conscious decision to use drugs for pleasure which may later cause addiction. The stigma in this case does not arise from the illness of addiction, although that's possible as well, but above all, from the decision to take drugs that has brought about the addiction" (A HOPS, AU_MZZ2014_I_006). The most frequently heard public opinion is that it is their own fault, thus furthering the stigma and even the hate towards people who use drugs because it is only natural that they are unsuccessful and immoral people who because of their own pleasure destroy themselves and their families.

The surveyed people included in the outreach field research, who have bigger theoretical knowledge about these issues, describe Macedonia as a society with developed masculine norms, which means having "manly attitudes". These norms are forced onto the individual to "successfully" and "manly" handle all problems and challenges in life. Those who are unable to fit in these norms are marginalized and stigmatized, as is the case with people who use drugs. "Still, making decisions in life is not part of the autonomy of the person, but depend on many social factors, as well as on the context in which the person lives and acts" (A HOPS, AU_MZZ2014_I_006).

Stigma and decriminalization forces people who use drugs to hide on the margins of society and to avoid public events, especially concerning issues that may disclose their use of drugs. This fear of public recognition kills or limits their activism spirit, especially because in a context with such social values, public recognition as a drug user means loss of basic human rights. Thus, for example, public recognition of drug use may mean risking the possibility for employment, or for keeping one's job. "Who?... will tolerate you coming in late every second day (because of going to collect methadone therapy, author's note)? Those people, those bosses, who understand that you are on therapy, and lets you work, are so rare, so rare. There is discrimination here when it comes to work. If somebody finds out that you are on methadone therapy, he fires you immediately" (A HOPS, AU_MZZ2014_I_009). "For example, I used to work in... for four years, as a..., I was in charge of playing the program, but when they found out that..., with tests to check blood and urine. And I was a good worker. But they kicked me out just because of that. And it doesn't matter what company you go to or how good you are with let's say computers, and stuff. Let's say you go, and you put in your CV that you for example have to be late on Thursdays. And when he asks why? And you tell him the truth – so and so, I am on methadone therapy. He will not take you. You must lie. He won't give you the job, trust me! I've tried everywhere. Nobody took me in." (A HOPS, AU_MZZ2014_I_008).

The fear of public recognition is even greater because of the stigma and discrimination are not reserved solely for people who use drugs, but also their families. "When they put the puzzle together, that I was somewhere, in some TV show,... she immediately is fired as the wife to someone who is on the verge of..., if she for example works in a boutique, breaking into the boutique and robbing it. When she worked in a medical institution, her very association with me and the fact that I was let's say, a "junkie", as they love to put it, caused her sacking. After working there for seven years" (A HOPS, AU_MZZ2014_I_001 [14.04.201]).

It is interesting to point out that there is a gradation in stigmatization and discrimination of people using different types of drugs. According to respondents included in the research, stigma is stronger towards people injecting drugs, especially opioids, in comparison to those who use cannabis or

amphetamines. And there is stigma among people using different types of drugs. People using so called "light drugs" such as cannabis and amphetamines, have a bad opinion about people using opioids while people using opioids mock those who use "light drugs".

Except social stigma, people who use drugs feel they are stigmatized by medical staff in general, as well as by a smaller part of the personnel working in treatment programs. "Here's another example... about the dentists in a state owned place. When they see a F11⁸..., I still haven't done mine [teeth] because of these things. They would put scaphanders down in the basement, like astronauts, so that they could.... I mean the way they treat us like we are some sort.... I don't know, I mean, very bad." (A HOPS, AU_MZZ2014_DFG). "I know of a case when a friend of mine who went to the hospital, he was on the verge of having his leg cut off. I mean not that he was not informed or didn't know how bad it was. He just would NOT GO to the hospital!!! Because of the stigma. Because everybody will find out! " (A HOPS, AU_MZZ2014_I_007). "There's stigma from the staff [in treatment programs], as well. They do not believe that I can work and look after my family." (A HOPS, AU_MZZ2014_I_009).

Often, people treated for drug dependence that were included in this research, equalize stigma with the improper conduct of part of the staff at treatment centres. Most surveyed people stated that if they state their dissatisfaction for the violation of some of their rights, it is possible that they will be "stigmatized", and transferred from weekly to daily dosage collection regime, which they perceive as a punishment. Still this form of "punishment" cannot be considered stigmatizing, and we shall analyse this practice by competent institutions further below.

7.2.2. Self-judgement

Although not present in all surveyed community members, still self-judgement represents yet another limiting factor for personal engagement and activism. Part of the surveyed openly expressed a feeling of self-judgement because of the shame they would bring about to their families with their drug using habits. "Well, I wouldn't really talk publicly about it..., because first of all the fear from us... How can I explain this? Today... For example, today, I live here in (city, author's note) Centre, and in my neighbourhood, where I live, just today, people were commenting, saying, it's a shame, today, in the 21st century, to take drugs. What can I say? That's what they say..." (A HOPS, AU_MZZ2014_I_008).

7.3. The spirit of activism in the existing institutional and political context in Macedonia

"First of all, I don't know how much we can talk about drug user activism, in the sense in which I imagine it, because too few people have the awareness, courage, freedom of mind, and lately even, which I personally find most scary – that people are afraid to talk about such topics because we currently live in a totalitarian society to which communism was a walk in the park." (A HOPS, AU_MZZ2014_I_007).

7.3.1. Legislation as a precondition for strengthening the spirit of activism?

A small number of surveyed people have demonstrated the awareness and said that they consider the current legislation as an obstacle for more active engagement of the rights and interests of the community. Still, to the hypothetical question how can law contribute to the realization of one's rights and freedoms, and consequently intensifying the spirit of activism, most respondents agreed that if we do not punish the use and possession of drugs for personal use, this will contribute to decreasing the feelings of fear from the police and better conditions for activism. "Absolutely! It will absolutely contribute to them being more visible and encouraged, to simply gain the courage to get out on the open and talk about the problem." (A HOPS, AU_MZZ2014_I_VB).

7.3.2. De-motivation because of fear from the police

The fear from police has de-motivating effect on initiatives for active advocacy. People treated for drug dependence think that they will be exposed to police surveillance and questioning if the police finds out that they are on drugs. "People are afraid. From the police, and from the way institutions work... you become marked. Once you go out on a protest... you are basically marked and who ever meets you can stop you, control you, check you,... simply embarrass you in front of people. This is a police state, after all." (A HOPS, AU_MZZ2014_I_009). "You can't expect from drug users to step up, and declare themselves, even... they are so fearful, that I think that even if they were covered by somebody, they still wouldn't step up, because of the great fear of the police... especially now, in this period." (A HOPS, AU_MZZ2014_I_001).

7.3.3. De-motivation for active engagement because of fear from changing therapy regime

Most surveyed people on treatment stated that they do not enter into activities related to protecting their rights because they are afraid they will be transferred from weekly to daily treatment collection regime. This would mean that they would have to appear at the program to collect their therapy every day, instead of once a week. "If we protest, all we will do is make them have it in for us, and those on weekly treatment will immediately lose it... If for example I protest about something, why you are doing this, this is not nice, you can witness the chief physician putting me off therapy." (A HOPS, AU_MZZ2014_I_009).

"So if somebody who is in treatment would decide to speak up or fight, let's say, he doesn't even have to go on TV..., but to be active in his group. And if certain physicians understand... or medical staff in general, find out that this and that person talks against the staff, he will encounter an obstacle. So when I went out on TV, I had this in mind, and I knew that would not be able to do more than put me on the daily regime, and I was ready for that. Now, I am not certain how much are other people ready to risk their comfort, in order to, so to put it, resolve a problem which touches not only them, but also a wider mass of people. The fear, patients have fear from regime changes, I don't know, urine tests, and they consider these things related to their health as an attack to their person or as a side effect from taking up a certain activity and because of that, they have a barrier from talking openly against all the things that actually happen, daily in centres where they are treated." (A HOPS, AU_MZZ2014_I_001).

If these statements are true, then this poses a serious problem not only for the development of activism among people who are treated for dependence, but also for the quality of treatments in

general, because it threatens the doctor-patient trust.

7.3.4. Formal self-organization in grass-root organizations

There is no formal active grass root ⁹ organization of drug using people in Macedonia. Historically, HOPS, as an organization, came about as an initiative of people who have used drugs and it first worked as a true "grass root" organization, which in time extended its professional structure. In the past ten years there have been two attempts to form two new grass root organizations. The first attempt was the forming of a Macedonian Association of Drug Users (MADU), in 2001, and the second attempt came in 2002 when the organization "Passage" was formed. Both were the initiative of HOPS – Healthy Options Project Skopje. And while MADU never lived, "Passage" was formally registered and was quite active at one time. One of the more significant activities of "Passage" was the issuing of a fanzine ¹⁰ covering various topics relevant to people who use drugs. Still, although this organization still formally exists, it has not had an activity for a while.

The inexistence of an active grass root organization is certainly a limiting factor to the activism motivation of people in Macedonia who use drugs. Still, even if there were such organizations, in this specific case, an organization of people who use drugs, it would not be enough to make them capable advocates for their own rights and needs. Namely, if organization members haven't developed political awareness for activism and activist dedication, their rights struggle would be futile. The system in which we live has found ways to relativise political activism in several ways. It destroys the culture of debating and critical thinking through the media, by showing cheap emotional program based on popular sentiment and "safe territories", something completely different from the nature of activism that imply public domain – a sphere where there is permanent antagonism and means going out of one's comfort zone (Maširević 2005: 301-310; Veselinović 2005: 273-288). The oppression people who use drugs feel in Macedonia, does not mean counter-proportional development of motivation and political awareness, as pointed out by Abhijit Das when describing the conditions for active community participation (Das 2013: 7).

7.4. Political self-awareness: Conditions for the development of activism spirit among people treated for drug dependence compared to the conditions for development of the activism spirit in the LGBT community

People who use drugs in Macedonia are a mirror of the society we live in. Thus, they do not differ from the majority of citizens in Macedonia when it comes to political awareness. Simply, there is no sufficiently developed awareness about representing a community's interests in order to achieve common goals. Namely, as most people in Macedonia, most people who use or have used drugs, above all try to gain personal benefit from the circumstances in which they exist. It's only rare that people who are using or have used drugs have publicly advocated towards achieving goals of interest to the community, such as for example, advocating for improving social relations to people who use drugs, changing the legislation related to drugs, etc. People in treatment with methadone or buprenorphine substitution therapy fight for community's rights only to the point that ensures them maintenance of their personal comfort position in the drug dependence treatment program. That line of comfort most often means weekly instead of daily pharmacotherapy collection regime, avoiding triage which might lead to decrease of pharmacotherapy, as any surplus of it could be sold for existential purposes, and in the worst case, losing the status of the doctor's "favourite".

The underdeveloped political awareness is only a consequence of the lack of awareness for

one's own rights, in this case not being familiar with the right to treatment, which is one of the basic reasons for passivization. This is confirmed by people from the community. "Well, we do not know our own rights. For example, I know nothing about my treatment related rights." (A HOPS, AU_MZZ2014_I_008).

In the community of people who are using/have used drugs, and the LGBT community (Lesbian, Gay, Bisexual and Transgender people), as two socially marginalized groups/communities, historically speaking, one can notice a set of similarities when it comes to the active engagement for advocating for their rights, especially during the HIV crisis. The need to understand the reasons for activism (de)motivation of people who use drugs has initiated the need to compare the conditions for active engagement with another socially marginalized community, which similar to drug users, suffers stigmatization and discrimination, almost worldwide. The first expectations were that comparison with the LGBT community may give more specific insights related primarily to motivation and the advocacy approach strategies, especially having in mind that the LGBT community in Macedonia has created the grounds for a movement and shows much larger visibility and more serious activism results.

7.4.1. The spirit of activism of the LGBT community

Most of the surveyed who were part of the field research, state that the reason for their active participation in the struggle for LGBT rights was the fact that they felt like they belonged to a sexual minority in a society burdened with conservative "traditional" values. For them, experiences of shame, hiding, self-accusation and stigma put them in a position from which they wanted to get out through activism, or as one of the surveyed stated: "...you come to a point when, I don't know, you feel the need to give resistance." (A HOPS, AU_MZZ2014_I_003).

Still for most of the interviewed, except for two, beginnings of their activism were conditioned by "coming out of the closet". Coming out of the closet is a figure of speech used primarily lesbians, gay men, bisexuals and transgender people for public expression of their sexual orientation or gender identity. Activism means clear and open discussion in the first person when it comes to the rights of the belonging group. Still, for many young LGBT people coming out of the closet is impossible exactly because of those experiences of shame, fear and stigma which they would face if they declared themselves members of this community. So then, the feelings of shame and fear among some people are an instigator to become activist, while for others they serve as an obstacle or a de-motivating factor for their activation in the fight for LGBT rights. It was indicative that in group discussions and interviews activists, sharing their feelings of shame and fear, most often related them to their families. Namely, for most of the surveyed coming out the closet is accompanied with fear because of the shame they may cause to their families, more than the shame they might suffer. One of the interviewed persons, who made his "coming out" in the media, stated that that was possible only after the death of his parents. He says in his interview: "My folks, my dad has passed away, and my mom just died, so I didn't have..., you know, because of them..., the pain I would cause them. They knew about me, but you know..." (A HOPS, AU_MZZ2014_I_002). Even in cases when parents are familiar and declaratively accept the sexual orientation of their child, there is a silent consent that it's an information that stays within the realms of the family, and the home, and it is desirable that for the wider circle of relatives, friends, neighbours, one would "stay in the closed", i.e. that sexual orientation is something to be hidden from the environment.

Activism as a public activity seriously challenges this condition of semi-obscurity and exposes LGBT activists to a larger risk of discrimination and stigma compared to LGBT community members who are not activists. But, on the other hand, for part of the LGBT community members this condition generates a potential for expressing their activist spirit. Namely, part of the researches said that despite all the stigma, violence and hate speech they have been exposed to, the feeling of

belonging to a community gives them strength and drive. To be part of the community, for some of them, means to belong somewhere and it is far better than living a double life, hiding, lying or living a life pretending to be something they are not. Some of the surveyed even thing that this should be the key axis of activism in Macedonia today, i.e. that the focus should be placed on building the community exactly through strategies of belonging. Despite such political attitudes, most of the surveyed agree that the LGBT community is heterogeneous, rather unorganized, with an unclear political voice and with absence of solidarity as a key characteristic of the feeling of comradeship they are striving to achieve. A reason for this is that they are most often in the position of fake comfort offered by the anonymity or hiding of LGBT people. The result of this position of fake comfort is the complete political passivization of this community, which has been left to expressing its freedom only virtually (through social networks for gay men on the internet) or by going out on gay friendly places, and less often so in the public and political discourse. But, almost all interviewees, except one, agree that the LGBT rights fight must be fought by community representatives, i.e. those who identify as lesbians, gay men, bisexuals, and transgender people and those who empathise with the needs of this community.

7.4.2. The spirit of activism in people on drug dependence treatment

Similar to LGBT rights activists, people treated for drug dependence also point out the experiences of shame, fear and stigma, but as demotivation reasons, i.e. as obstacles towards them becoming active. Drug users relate these feelings of shame and fear to their families, i.e. for them the most frequent fear is that of bringing shame to their families, even though the family is familiar with their status. Again, the shame to the family is related to the expected judging from the wider population and society in general.

Just like in the LGBT community, the activism of people treated for drug dependences is a public activity, which means speaking in the first person, disclosing one's status of drug user in the public. Most interviewees stated this as an obstacle for their activism, relating it, in addition to the shame on the family, with the feeling of self-stigmatization. Namely, wider stereotypes about drug users as immoral, criminals, dangerous, are seen by drug users as obstacles in putting forward their needs before the institutions of the system. Part of them assume (although they have never actually tried) that institutions of the system would not want to hear or communicate with a man who is known to use/have used drugs. This leads us to the conclusion that the experiences of stigma and shame are much more present and stronger in people treated for dependence than in the LGBT community. The research also showed that these experiences in people treated for drug dependence can exceptionally rarely become instigators for activism, and much more often are only a pressurizing and de-motivating factors.

Based on the circumstances described, coming out of the closet for people treated for drug dependences becomes a much more serious problem. Part of them think that social stigma towards people who use drugs is bigger than that towards the LGBT community. One of the main reasons for this is the legal ban on the use of drugs, as a result of which the police and the public consider these people criminals, which is not the case with the LGBT. One of the surveyed, an activist for the rights of people treated for dependence, who himself talks openly and publicly about his status, shared with us the following: "I am what I am, I have never been ashamed of what I am, and that is how I have acted, I have never asked from anybody to blur my face, mutate my voice, on the contrary I have always insisted that they show the original video. Well this has cost me... not me personally, but my wife was sacked from four jobs, but I guess that's some price you have to pay if you are going to do this." (A HOPS, AU_MZZ2014_I_001 [14.04.2014]).

Most of the surveyed who are treated for drug dependence feel belonging to this community and consider the comradeship as a source of power and driving force, and consequently, as a motive for

activism. The greater feeling of belonging to the community among people treated for drug dependence as compared to the LGBT community, may be due to their daily social relations (sharing drugs, receiving treatment in the same place etc.), but, of course, also the fact that they are exposed to far greater stigmatization and marginalization. In that way, this comradeship (physical, but also identity-wise) becomes a replacement for the rest of the world, i.e. a potential for creating a parallel world not unknown for people who use drugs across the world. This potential may represent an exceptionally fruitful grounds for activism, if the described obstacles are overcome.

Hence, coming out of the closet, facing stigma and shame, and accepting the belonging to a certain community, may be said to be two points which these two communities (LGBT and drug users) share as key factors for (de)motivation for activism. Still, it should be emphasized that there are certain differences which in the most part, can be perceived as reasons for weaker activism development among drug users, as compared to LGBT people.

7.4.3. Who can dedicate themselves to activism: Differences in activism possibilities between LGBT and people treated for drug dependence

Despite the fact that these two groups can build political alliances, still, these are two completely different groups and mobilization obstacles in drug users are much bigger and stronger compared to sexual minorities. However, even in detecting the differences, we think that we can draw conclusions and recommendations for increased mobilization of drug users. Exactly because of this, we have focused on these differences and sought in them a possible solution for the development of an organized and politically clear activism in people who use drugs.

We already mentioned that stigma, with its paralyzing effect on activism, is bigger in people treated for drug dependence than in LGBT.

One of the reasons for this is the absence of international solidarity or wide-spread discourses and traditions about this form of activism which would encourage or be a referent point of activists for the drug users' rights. Many of the activists in the LGBT community which we interviewed pointed to this form of international support exactly, and all the international policies and documents, as well as global (particularly Western) commitments for equality and tolerance of sexual minorities. Unfortunately, people with experience in drug use, can rarely find other states with positive examples, they can rarely cite mainstream scientific research offering different knowledge and producing different truths, and all this has an effect on the motivation for activism, on changes in the self-perception and changes in the perception of the public concerning the destruction of their stereotypes and myths about people who use/have used drugs.

Because of this, one of the surveyed people, with more theoretical knowledge, thinks that it is necessary to carry out an anthropological study among people who use drugs, which would study their lives, discover worlds they create, especially in the marginal spaces they inhabit, and these insights can be used as a tool for further political struggle. In this way similar to the "queer" ¹¹ movement" which is a reaction to the mainstream LGBT activism, and which as a movement has exceptionally many touch-points with the activism of people who use/have used drugs. Furthermore, this interviewee thinks that it is equally important to carry out a psychosocial study which would give insight into how these people build their subjectivities, based on the influences in their lives, the emotional relations they build, their social position etc. This knowledge can serve as a basis for political mobilization, as an encouragement, and above all, as the basis for overcoming stigma, particularly self-stigmatization. At the same time, all that the international public and movements, but also science, produces as contemporary values, policies and knowledge, should be made available to people in Macedonia with drug using experiences.

Another key difference in the activism between LGBT and drug users is the necessity of health

services for drug users, generally for survival, but also for social operability. Most of the people treated for drug dependence and activists among them, agree that activism is only really possible for those of them who are “stable patients” i.e. people in drug dependence treatment who have reached a certain stable condition of managing their dependence and can meet regular life obligations. Active drug users dedicate most of their life to providing opioids for the day, and those in treatment, but still unstable, have other priorities, most often related to the treatment itself.

“That you first have to accept who you are. What you want from yourself? Maybe somebody doesn’t even think of himself as a user or addict, and he wouldn’t fight for those rights, I mean, whose rights? He’s ashamed of himself, let’s say.” (A HOPS, AU_MZZ2014_I_004).

“Look, to start talking publicly you should first get to know yourself, and then go through the solution or the perception – who am I, what am I for, and what am I doing about it? Once you resolve all this, that’s when the next moves come.” (A HOPS, AU_MZZ2014_I_007).

“Here, activists could be realistically, 90% of the people on methadone treatment. Who have put their dependence under control, at least in that specific moment. Otherwise what will they do with their free time? Even active users, as well.... but that may be harder... he gets into a crisis, and he like sits through the meeting? Plus, you need to get dope ¹² like all the time, right? He has to go chase the dope daily, right? About what activities are we talking here? How much can he really do? So, maybe in the beginning he can, but.... That’s all a bit shaky.” (A HOPS, AU_MZZ2014_I_004).

“Another thing which is very important about the organization and activism. A large part..., when I’ve travelled abroad, a large number of “user organizations” are lead by people in treatment, and that’s because drug users are in a permanent daily rush chasing after money or the right dose, which leaves them very little free time.” (A HOPS, AU_MZZ2014_I_001).

In order to increase activism potential, it is of exceptional importance to provide full treatment for people in treatment from dependence, which except substitution therapy should also include psycho-social treatment, and a developed re-socialization program. Still it should not be forgotten about the fact that most of the stable patients at the moment when they enter into stable phase, what to step out of the community and significantly diminish their participation in that group’s social dynamics. You can look at this as a two way investment. Activism and engagement of people treated for dependence can help improve treatment, especially the re-socialization component, but also better quality treatment could encourage activism.

Finally, another key difference between LGBT activism and activism for the rights of drug users. It is the over-medicalization of the drug problem. Drug users who were part of this research, relate activism exclusively to their medical rights as part of the corpus of human rights, but by doing so they position drug use exceptionally in the sphere of medical discourse, ignoring a whole other set of experiences, emotions, social relations, values and attitudes which have an huge influence on the marginalization of this community. Still, a significant part of drug users in treatment used exactly their patient position and their understanding of dependence (and oftentimes, the use of drugs in general) as an illness, in order to cope with the stigma and shame. Namely, one significant part of the interviewees, when talking about prejudices and stigma, have on several occasions stated that this is, after all, an illness, that they are ill and that stigma is undeserved. Unlike this, the LGBT community is often perceived as ill, i.e. homosexuality is perceived as an illness by a large portion of the public. Still, LGBT community members reject these positions finding in them, rather than flight from the stigma, a source of stigma and shame. One of the reasons for this is the possibility of the LGBT community to call onto one of the dominant slogans “Born this way” which offers a different view point, as something they have no control over, nor a choice, unlike people who use drugs who, even after accepting their dependence as illness, still carry the burden of judgement by the majority, because this illness has been caused by the conscious choice to use drugs. In such social constellation, and in such political, economic and social system, all important reasons and influences that turn the use of drugs into dependence are negated, and dependence is considered solely as a fallback of the person, due to his/her weak character or improper lifestyle. In such a social context,

it is exceptionally difficult to seek the potential in the medical discourses, and in regards to the political mobilization, the potential can be sought in human rights discourses and the possible empathy or pity by the majority. What we can learn from the LGBT movement is the slow dissociation from medical discourses and widening perspectives of the activism context from its current state – as a struggle only for medical rights.

8. Conclusion

The general conclusion from the assessment of the community monitoring and advocacy activities is that set objectives have been partially achieved. Activities had weak intensity and it was established that representatives of people treated for dependence need more knowledge and experience for more intensive advocacy of the community and in the community. The main reason for this is that set aims and objectives were too ambitious and wide, which is only confirmed by the general objective "Improving the quality in drug dependence treatment programs". Although the achievement of this aim was carried out through a set of short-term and seemingly easily achievable aims and objectives, it was soon established that in the current socio-political context, described in Chapter 3.2., and in the lack of an environment supportive of activism, as described in Chapter 8, no quick wins towards changes in the structure of the health system can be expected.

Still, with the methodology for evaluation of the activities within the community monitoring and advocacy, as recommended by Abhijit Das (Das 2013: 11-17), new perspectives were opened when assessing success. It was confirmed that through the active participation in the process of monitoring and advocacy, the evaluator gets a clearer idea about the process and context in which a given process takes place.

Regardless of the fact that the main objective, in the current process, has not been fully realized, we confirmed the applicability of the methodology for community monitoring and advocacy, for the purposes of initiating activism and motivating people in dependence treatment towards self-advocacy rights and interests. Having in mind the existing socio-political context, activities described in Chapter 6 may be assessed as successful. According to plan, an advocacy team was formed, from which a few highly motivated individuals stood out, ready to continue to represent the rights and interests of people treated in dependence treatment programs in Skopje. Although with a varying dynamics, and with frequent drops in motivation, this team carried out several advocacy activities directed both at improving the quality of dependence treatment programs, and at animating the community for more active self-advocacy. During the process, due to personal reasons, several changes in the team occurred, but those who remained, were consistent up to the end of evaluation, and confirmed their spirit of activism, and the intent to continue advocacy efforts. On 26 June, 2014, some of the team members held a press conference for the Macedonian media supporting the global campaign "Support. Don't punish." (IDPC 2013) and used to occasion to express dissatisfaction from the criminal policies in force for people who use drugs, and to express condolences for all the people who have died from drug use. They also presented their requirements for improvement of the quality of drug dependence treatment programs. Through the monitoring and advocacy activities, people treated in dependence treatment programs in Skopje, were included as equal negotiators in the existing drug dependence treatment programs in Skopje financed by the state budget. In three of the four included programs, they received a meeting room, where they could hold meetings, topical events and socialize, which made the communication with and animation of the other members of the community easier.

During the second and third cycle, we paid more attention to the visibility of our advocacy efforts. Although, not fully according to expectations, almost 70% of the community members now know that there are representatives of their rights and interests in dependence treatment programs and more than half of them can identify the main activities of the advocacy team.¹³ Managers at the treatment programs were familiarized with the advocacy process from its start, and in the second and third cycle of monitoring and evaluation, we made efforts to better acquaint a wider scope of employees at these programs. As a result, we received a wider declarative support and approval of the initiative and readiness for cooperation. Still, despite results achieved, the visibility of the advocacy efforts was small.

The eighth chapter, which was planned to be an addendum to this document, grew into its key part, which excellently complements the context described in Chapter 3.2., and explains the large

part of the weaknesses and obstacles provided in chapters 6 and 7. The public ideological and moral perception of drugs and drug use practices is in close relation to the political and institutional context and has an extremely limiting effect on the political self-awareness of people who use drugs or being treated for drug dependences, as well as people who have used drugs, in general. Their exposure to stigmatization and discrimination, and political persecution due to drug use habits causes the sense of shame in people using/who have used drugs, and forces them to accept their marginal status imposed by society and the laws. In the lack of a supportive environment, people treated for dependence avoid public appearances and due to that suffer discrimination and try to achieve their rights and needs in alternative ways, instead by using constitutionally and legally guaranteed rights and measures (Dimitrievski and Boškova 2012: 18-47).

The comparison of the conditions for development of the spirit of activism with the LGBT movement, shows that the over-medicalization of drug use practices, the dependence on pharmacotherapy, and the lack of support by serious anthropological and sociological studies, limit the potential for activism even in people who are treated for dependence and who show initiative to advocate for their own and for the rights and needs of the community. Thus, instead of resistance and initiative in the community induced by stigmatization and discrimination, as is the case with LGBT, the stated limitations force people treated for drug dependence to completely adopt the ascribed social status and passivize.

Having in mind the conclusions stated, the final assessment is that community monitoring and advocacy activities have managed to encourage the spirit of activism in part of the people in treatment at dependence treatment programs in Skopje, have animated part of the community, and have caused significant changes in dependence treatment programs. With that, a great foundation for further action has been created. Results and experiences described in this document shall be used for advancing advocacy efforts towards the improvement of the quality of services of dependence treatment programs in Skopje, and we believe they will be of use to all others who plan to advocate for the same objectives.

9. Recommendations

The efforts of the community monitoring and advocacy have created a good basis for further improvement of the quality of dependence treatment programs in Skopje and it is exceptionally important to find a way to sustain and develop advocacy activities.

For the successful development of advocacy, it is recommended that most of the support should be directed towards team members, who show more motivation and initiative, without insisting on reciprocity in covering included dependence treatment programs.

It is desirable for set objectives to be more realistic and easily achievable. That way potential demotivation will be avoided, positive experiences will be more readily available, and capacities will be built towards advocating on higher political levels.

Advocacy should develop in three directions. Firstly, advocacy within the community towards strengthening civil awareness, which will help harmonize values and attitudes, consolidate efforts and strengthen activism spirit. Secondly, advocacy of the community towards institutions creating and implementing policies, which will lead to overcoming institutional stereotypes and introducing humane policies for drugs and treatment of drug dependences. Thirdly, community advocacy in the public sphere, in order to initiate a debate for humanization of the people using/who have used drugs.

A key aspect, which should be given more attention, is the development of the civil awareness in advocacy team members. Furthermore, advocacy teams should work on developing civil awareness in other community members. This looks rather utopian at the moment, given the existing socio-political context, but it is the only way to create a true critical mass that can cause bigger changes.

Regardless of experiences so far, advocacy team members should continue to receive moral and professional support from people trained in advocacy, planning, management, communication, institutional communication and other skills with which we can ensure effectiveness of advocacy efforts. For that aim, advocacy teams can and should cooperate with other citizen associations and exchange experiences with similar groups/movements in Macedonia and abroad.

Despite the fact that certain representatives have a highly developed activism sense, the weak financial power of people treated for dependence should not be overlooked and ways should be found to cover material costs for advocacy efforts.

Successful advocacy examples should be used to spur motivation in people treated in the same or another treatment program, and thus create a critical mass which would be used for advocacy on higher political level.

10. Field data

A HOPS, interview, AU_MZZ2014_I_001

A HOPS, interview, AU_MZZ2014_I_002

A HOPS, interview, AU_MZZ2014_I_003

A HOPS, interview, AU_MZZ2014_I_004

A HOPS, interview, AU_MZZ2014_I_005

A HOPS, interview, AU_MZZ2014_I_006

A HOPS, interview, AU_MZZ2014_I_007

A HOPS, interview, AU_MZZ2014_I_008

A HOPS, interview, AU_MZZ2014_I_009

A HOPS, interview, AU_MZZ2014_I_010

A HOPS, focus group discussion, AU_MZZ2014_DFG_Klinicki [9.4.2013]

A HOPS, focus group discussion, AU_MZZ2014_DFG_KV [10.4.2014]

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A HOPS, focus group discussion, AU_MZZ2014_DFG_LG

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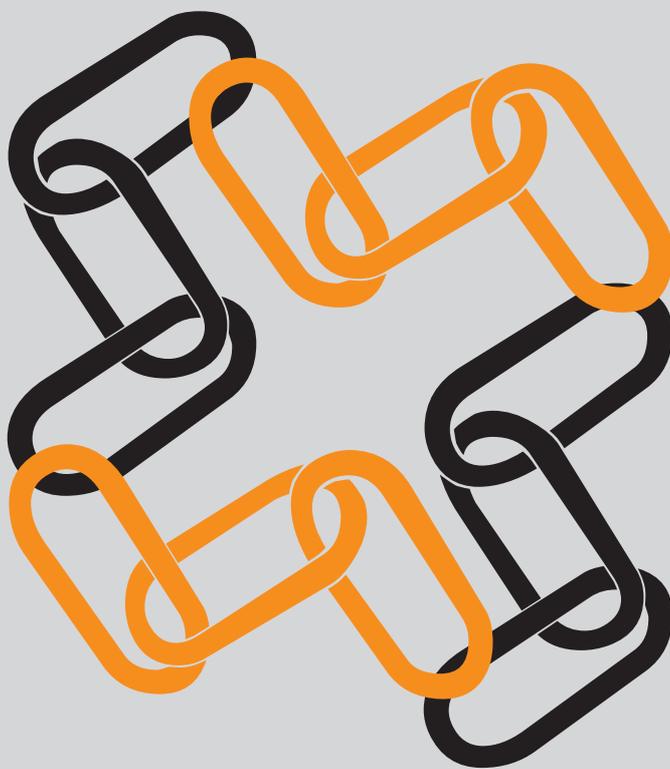
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COMING OUT OF THE CLOSET?

*Assessment and evaluation of advocacy efforts for the improvement of
quality of drug dependence treatment programs in Skopje*

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Assessment and evaluation of advocacy efforts for the improvement of quality of drug dependence treatment programs in Skopje

12. References

- 1 This activity was later cancelled, i.e. indefinitely postponed, and the reasons are described in Chapter 6, i.e. in the activity brief: Advocacy for changes in the manner of testing for possible relapses.
 - 2 Among citizens more recognizable under the term capitalism.
 - 3 Nepotism most usually means employment and/or giving business deals to relatives or close friends.
 - 4 Cronyism is the assignment of managing positions to unqualified relatives or close friends.
 - 5 LGBT – lesbian, gay, bisexual and transgender people.
 - 6 For more information, please, see: Dimitrievski 2014: 20-23.
 - 7 “Junky”- a derogatory term for a person using drugs, most often opioids; people belonging to the community sometimes use this word. It is assumed that this term originated in the USA in the 1920s, and the credit for its popularization is ascribed to William S. Burroughs.
 - 8 A code denoting drug dependent persons according to the International Classification of Diseases.
 - 9 The term “grass root” is most often used to denote the initiatives, movements and organizations encouraged by the community itself, i.e. from individuals representing the interests of the community they themselves belong to.
 - 10 A type of amateur, most often non-commercial publication. A portmanteau term composed of “fan” and “magazine”, i.e. “-zine”, thereby deriving “fanzine”.
 - 11 Queer is a term usually meaning „weird“, „unusual“, „unhealthy“. In the XIX. Century this term was used as a pejorative term for homosexuals, but at the end of the XX century LGBT appropriate it as a term to denote people with non-heterosexual identities or for those who disagree with the exclusivity of heterosexual identities.
 - 12 Street term for heroin.
 - 13 For more on these results in Dimitrievski 2014.
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HOPS

Healthy Options Project Skopje



Coalition "Sexual and Health Rights of
Marginalized Communities"

Поддржано од:



и Фондации Отворено општество
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