

Community Monitoring and Advocacy in Highly Stigmatising Circumstances: Eliminating Institutional Barriers for the Improvement of Quality of Drug Addiction Treatment Programmes in Macedonia

Background

How can we encourage activism for the improvement of the quality of addiction treatment programmes among the most stigmatised group of citizens in Macedonia? How can institutions be made to accept that people using drugs can be constructive participants in the process of improving the quality of drug addiction treatment programmes? How can drug policies be freed from ideological models of thinking and adapt to current trends and the needs of those concerned the most? According to the literature describing community monitoring and advocacy available on the internet, an impression is formed that disenfranchised communities should have the necessary motivation and capacity to independently mobilise themselves and jointly fight issues of common interest, but it is hard to bring this ideal model into reality in which, evidently, wider social and political factors should be taken in consideration. In fact, these factors are unavoidable in the process of attempting to understand challenges that people treated for addiction in Skopje are facing, in the course of their efforts to achieve higher quality addiction treatments.

Macedonia is in the middle of the Balkan Peninsula, in the southeast part of Europe. Its capital is Skopje. Macedonia used to be a federal state within the Socialist Federative Republic of Yugoslavia, but after the dissolution of Yugoslavia in 1991, it proclaimed independence and started transitioning from socialism into a democratic constitutional organisation, a process politically named "transition". The transition turned out to be much harder than expected. Initially, the extant communist ideological models were not replaced by democratic ones, but rather a clash of several ideological concepts occurred, among which the "democratic" and "nationalistic" dominate. The leading political parties have polarised

Macedonian society in few fractions, ideological and nationally determined that raised constant antagonism within the society. In their mutual struggle for power, these strived to repress all models of civic activism, considered personally threatening and any criticism was considered a threat. But, on the other hand, they counterfeited NGOs on their own, which convicted efforts to bond civic society initiatives for cooperation. Civic organisations and activists that really tried to promote humane and pragmatic values were stigmatised as money launders and as an extended arm of the cruel corporate globalisation. Unfortunately, this process is still ongoing and has taken such sway in the last several years that civil organisations and activists fearing further stigmatisation become increasingly discouraged and passive and the intensity of new initiatives is decreased.

As an example, although the assessment of the Macedonian Center for International Cooperation regarding the trust in civil society for 2013 concludes that the trust of citizens towards citizen associations has increased compared to previous years, a high level of stigmatisation can still be noticed, especially because a large percentage of the surveyed hold on the prevalent attitude that civil associations are in the service of foundations or political parties.

Drug use and addiction treatment possibilities

Nowadays there are fifteen drug addiction treatment programmes in ten different cities in Macedonia, out of which thirteen provide methadone assisted treatment, one of them

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Discriminatory and stigmatising rhetoric used for drug users is an unavoidable part of the political campaigns on local elections. They are simultaneously accompanied with a negative campaign towards the substitution therapy, especially methadone, which is presented in the public as equal to heroin, and its treatment as “taking drugs financed by the state”.

provides buprenorphine assisted treatment and one of them provides treatment without substitution, but the last one is nonoperational because of the popularity matter. All of them are now financed by the budget of the Republic of Macedonia, although some of them started with financial support from the Global Fund to Fight AIDS, Tuberculosis and Malaria. Six of these drug addiction treatment programmes, including the one that provides buprenorphine treatment, are in Skopje. Compared to the period before 2005, when only one drug addiction center, with three different programmes was operational, and it was located in Skopje, drug addiction treatment became available to bigger number of drug users, but there are still matters of coverage and quality.

There are around 10,300 opioid dependent people in Macedonia. Out of them, only 17% are currently on treatments in the ten towns that have operating programmes. The biggest problem is in the capital city, Skopje, where despite the four operating treatment centers, only 600 users are being treated, which is 16% of the assumed 3750 users. Except the limited capacity, existing treatments do not offer the needed quality due to various reasons. This creates dissatisfaction among a significant part of the patients. It arises out of the following problems:

1. Lack of psychosocial support;
2. Inappropriate packaging of medication;
3. No possibility for personalised medication dosing in the treatment;
4. Employees in some centers do not have sufficient knowledge about addiction-related problems and have an inappropriate attitude towards patients etc.

On a political level, drug-related issues are left on the margins of the political and ethnic polarisation that exists in Macedonia and are most often treated sensationistically, more in the service of daily politics than with an honest intention of finding appropriate solutions for human treatment. Whenever law makers discuss this issue, what can be identified are some values based on ideological models and the lack of willingness to find pragmatic solutions. It is difficult to understand the reasons for their indifference, but there are certain assumptions that a significant factor in this is the political rating they try to build among the public. Confirming this claim are news about the rating of political parties and separate politicians that frequently overwhelm media.

The main problem which significantly affects the quality of health protection offered to drug users, is the small number of addiction treatment centers, insufficient to cater to all those in need of treatment. Despite the established commitment towards increasing the availability of treatment and diversifying treatment options in public health institutions, (provisions of Strategy on Drugs 2006-2012), a huge number of drug dependent people are facing the problem of realising their right to treatment. The situation is most concerning in Skopje, where most municipalities face serious resistance to opening new drug addiction treatment centers, as well as announcements for shutting down and dislocating existing ones, especially during local election campaigns. Discriminatory and stigmatising rhetoric used for drug users is an unavoidable part of the political campaigns on local elections. They are simultaneously accompanied with a negative campaign towards the substitution therapy, especially methadone, which is presented in the public as equal to heroin, and its treatment as “taking drugs financed by the state”. All this has a negative effect not only on the image of drug treatment programmes, but also on the motivation of drug users and their families for starting a treatment. The assumptions about the negative effect of current socio-political circumstances on the motivations of drug addicted people to undertake more active role in representing their interests are fully confirmed when we add to this the fact that drug users are the least desired group of citizens, as identified by the Macedonian Center for International Cooperation in 2011.

However, these are not the only de-motivating factors limiting people being treated for addiction from taking a more active role in advocating for improvement of the quality of treatment programmes. It is expected that people treated by substitution therapy with methadone and buprenorphine in Macedonia, the only addiction programmes financed by the state budget, should achieve a stable condition in order to be rehabilitated and re-socialised. But, according to the assessment made by HOPS – Healthy Options Project Skopje and the Coalition 'Sexual and Health Rights of Marginalised Communities' in 2012, it was shown that addiction programmes are not fully adjusted to the needs of patients and that they are above all medically oriented. When we add to this context the attitude of Zoran Milivojević, a psychotherapist and a writer with rich



experience in work with people who use drugs, expressed in his book “The Games Drug Addicts Play”, according to whom many drug addicted people live up to the predominant social idea about the incurability of addiction and adopt a passive and dependent position in community which then leads to a vicious circle, by making them too passive to independently advocate for the improvement of the quality of their lives.

Fortunately, not all is lost. First of all, not all drug addicted people have accepted the societal idea of the incurability of drug addiction. Secondly, there are drug addicted people who manage to achieve a more stable health condition and have active social roles. Third, the undesirable socio-political context for some people is an additional instigating factor and with the appropriate support these people can contribute to the improvement of the wider community. One such example is the community monitoring and advocacy.

Community monitoring and advocacy

The initiative for community monitoring and advocacy for improvement of the quality of drug addiction treatment programmes in Skopje has existed since 2011, but started to realise in the beginning of 2012. The stakeholder community itself should advocate for improvement of certain conditions, supporting its requests with arguments and conclusions with previously performed monitoring. In fact, similar initiatives and activities have existed in Macedonia before, mostly unsuccessful or only partially successful, but in any case, exceptionally exhausting. One of the biggest weaknesses was the difficulty in encouraging and maintaining the motivation among people from the community, especially when representatives of the community needed to face and act before the institutions of the system. That is why the main dilemma when

planning the project was how to form a permanent and motivated advocacy team in which the people in-charge and the main activists would be the people on drug addictions treatment. On one hand, they were supposed to justify the trust from the community and the donors (Open Society Foundation from New York and the Foundation Open Society – Macedonia), without destroying the relations with institutions or the damage of the community, on the other hand. In order to alleviate potential risks, it was decided that there will be a step by step approach, i.e. only quick-win problems would be treated at first in order to increase the confidence of the community towards advocating for more significant changes. This meant to focus on work with service providers only and to avoid policy maker level because of the ideological matrix many times expressed in the media. The prevailing opinion was that there is still opportunity for service providers to address some changes independently and that it is good ground to start advocating. Basically, it was anticipated that service providers are part of the solution, not only of the problem, and building trust between them and the community will elevate advocacy efforts to the policy making level. Finally, it was decided to carry out an analysis of the attitudes of people treated for addictions regarding the quality of addiction treatment programmes in Skopje financed from the state budget.

The specific activities started in December 2011 with an analysis of the laws and other legal documents that regulate the problem of drugs in Macedonia. The legal analysis enabled a referent position for monitoring and defined the minimum standards for the quality of state financed drug addiction treatment programmes in Skopje. In accordance with the initial plan, the community monitoring and advocacy started right after the completion of the legal analysis, based on which questions were asked that were a later subject of monitoring. From this point onwards, a more direct inclusion of the community happened. Community representatives were included in the final design of questions and in the carrying out of the monitoring on field (in existing drug treatment centers in Skopje). Still, the final analysis was carried out by a person that was not part of the community. During monitoring, advocacy started but on a smaller scale. This phase meant forming a consultative body comprising of representatives from competent

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A bigger emphasis of advocacy was placed on the activities in 2013, again as a response to the findings and recommendations from the community monitoring carried out the previous year. In the first half of 2013, training was held where the representatives of the community identified weaknesses in the addiction treatment programmes and priorities for advocacy that would lead to improved quality of these programmes.

institutions, and attended by one representative of the community, whose function was to provide directions for finalising the results of the monitoring. Through the work of the consultative body, the first advocacy results appeared to be felt when one of the members of the consultative body started implementing minor changes regarding use of facilities in the institution under its competence, based on the monitoring findings.

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1. Patients shall be included in the decision making process and in the committee for acceptance of new patients;
2. Saliva testing shall be used instead of urine testing in addiction programmes;
3. To include psycho-social therapy in methadone and buprenorphine programmes.

For more effective action by participants of the training, several representatives were selected who formed a Coordinative Advocacy Body (CAB) which enabled more active inclusion in the community advocacy process. Still, circumstances were far from ideal, especially because members of the CAB do not possess many advocacy skills and are relatively dependent on project managers who help in negotiations with programme representatives.

How did the health system react?

Most of the employees and coordinators of the treatment centers reacted constructively and accepted cooperation for change of identified issues. A small number were not thrilled and started a series of criticisms and accusations that the report is not realistic and questioned HOPS and the programmes it is carrying out. Still, they did not terminate cooperation, but additional efforts were needed in order to overcome inter organisational clashes.

Seen as a whole, advocacy began slowly, but with different intensity in different addiction programmes. There are a total of four programmes for addiction treatment in Skopje which are financed from the state budget. With three of these programmes an initial cooperation was established and the proposal for participation of patients in making decisions in programmes was adopted. Only in one programme difficulties were encountered, mostly because of the lack of willfulness for cooperation by the manager, but we expect to resolve this positively. The initiative for sputum instead of urine testing has been temporarily stalled because of the fear that this might cause anger among those few patients who misuse pharmacotherapy, but who are sufficiently influential to de-stabilise advocacy efforts. It was proven that advocacy for psychosocial support is harder to achieve and that this does not depend only on the treatment programmes but on other institutional barriers as well, as for instance bureaucracy and cronyism. Namely, the coordinator of one of the methadone centers cannot make a single decision without an approval and a signature from the head of the institution, who, again depends on the government's employment policy. When it comes to employing new staff in these centers like social workers and psychologist in this case, it is not enough to have just an approval from the director of the institution. The consent from the Ministry of Health is necessary for the institution's human resource policy. Still, members of the Coordinative Advocacy Body are already working on developing ideas for activities that will avoid bureaucracy and lead to provision of psychosocial support.

Especially worth pointing out is that some of the members of the CAB have started independent initiatives for workshops, debates and wider



community involvement and have achieved a members are actively involved in planning activities for 2014, thereby fully meeting the community monitoring and advocacy methodology. significant improvement in the cooperation with programmes for treatment of addictions, thus encouraging other CAB members to start acting more intensively. Individual initiatives have strengthened enthusiasm at the CAB and its for 2014, thereby fully meeting the community monitoring and advocacy methodology.

Drug addiction treated people and decision makers at the same table

The most significant benefit from this process was the final recognition and acceptance of people treated for addiction as the key factor in negotiations with decision makers. The presence of a representative of the community in the counseling body together with decision makers and policy makers is a significant step towards representing their rights. This practice continues in the development of a system for regular meetings among representatives of the community and the responsible persons from the treatment centers. At these meetings, benefits and deficiencies of treatment programmes are discussed, as well as the problems faced by the patients. The purpose is

to improve the quality of the treatment programme in accordance with the needs of the patients, and for that we need joint activities and a dialogue among patients and employees in the programmes. This achievement may be common for other communities and not worth pointing out, but having in mind the context described earlier, it can be considered a significant achievement.

Still, despite the progress so far, capacities for independent advocacy by the community are far from ideal. Members of the CAB are in discord between the wish for positive changes, the non-beneficial position with regard to authorities in addiction programmes and the resistance from a small group of members of the same community and employees in programmes that can disrupt advocacy efforts. When all these circumstances are added to the previously described socio-political context in Macedonia, it is evident that the CAB is facing a big challenge and it needs a major support, for strengthening its own capacities. This is a process that demands great patience and does not allow posing too big responsibilities to representatives of the community, at least not at the beginning. But, one thing is certain, **NOTHING CAN BE DONE FOR THE COMMUNITY, WITHOUT INCLUDING THE COMMUNITY.**

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