



NGO perspectives on HIV/AIDS in Slovenia

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• **Strengthening community-mobilisation on HIV and AIDS
in Central and Eastern Europe**

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Methodology:

- A series of interviews and visits of services related to HIV/AIDS in Ljubljana, Slovenia took place between June 20 and 27, 2005.
- C. Iliuta additionally participated in the 2nd SEEA Symposium on Addictive Behaviours and 2nd Adriatic Drug Addiction Conference (in Kranjska gora, Slovenia – on May 19-21, 2005) that prominently featured the Slovenian approaches to drug use and harm reduction.
- Follow-up interviews were carried out on October 6-9, 2006 with a selection of Slovenian HIV/AIDS NGO representatives, in parallel to the 9th European Conference on Drugs and Infections in Prisons.

Overview and key recommendations:

Overall, the public responses to HIV/AIDS in Slovenia have been quite exemplary:

- Essential services such as harm reduction services for drug users (including needle exchange and prescription of substitution treatment) have been implemented early (starting in the early 1990s) and on a scale wide enough to have a major beneficial impact. It is remarkable indeed thanks to these health services that HIV prevalence among drug users in Slovenia has been maintained at an extremely low level (less than 1%), to be compared for instance to the prevalence of 30% among drug users in nearby Italy.
- The governmental health institutions are able overall to provide quality services, including access to free and anonymous HIV testing and access to the current regimen of antiretroviral treatment for HIV/AIDS for the people who need it.

However, with regards to men who have sex with men (MSM), who clearly represent the majority of the diagnosed cases of HIV, a lot more needs to be done: the targeted funding recently provided by the Slovenian Ministry of health for prevention and support work with MSM by Slovenian NGOs is highly welcome but it remains - so far - clearly insufficient. It is most regrettable that this support has in fact been reduced in 2006 compared to 2005.

Overall, it remains extremely difficult for local NGOs in Slovenia to secure funding for their activities:

- International sources of support (such as private international foundations or the PHARE programmes of the European Commission) are basically no longer available now that Slovenia has joined the EU.
- Local funding for NGOs – either from the government or from local municipalities – remains minimal and very difficult to access. Also, private fundraising from local individuals or business donors is still not a standard practice.

With regards to HIV/AIDS notably, we trust that a greater participation of local civil society in AIDS prevention and support would be greatly beneficial – as NGOs are best able to reach the groups that are most vulnerable.


In Slovenia this would entail in particular:

- Ensuring that men who have sex with men as well as commercial sex workers have access to information and prevention tools that enable them to adopt durably safer sex practices.
- Supporting the mobilisation of People living with HIV/AIDS, to ensure they can play an active role in preserving their own health and - in the wider sense – participate in the development of HIV/AIDS programmes (prevention, support and treatment) as well as fight stigma and discrimination (in line with the "GIPA Principles" which promote the "Greater Involvement of People Living with HIV/AIDS¹"). Clearly, it remains extremely difficult for People Living with HIV/AIDS in Slovenia to speak publicly about their status. The role played by peer-support groups for People living with HIV/AIDS in Slovenia is therefore essential and needs to be strengthened.
- Maintaining a high coverage for harm-reduction services for drug users – to make sure that easy access by drug users to clean injection equipment and other health and social support is in fact guaranteed. While the 1999 Slovenian law on drugs anticipated a high involvement of local civil society in providing such services, the governmental budget for harm reduction services to be provided by NGOs has in fact been drastically reduced.

Slovenia will have the honour of being the first of the new member states of the EU to assume the presidency of the European Union (first semester 2008). In line with the best practices promoted by the European Commission, we hope that the local civil society will be involved in the definition of the priorities for this presidency. Also, we count finally upon the Slovenian government to confirm its commitment to the global response to the HIV/AIDS pandemic notably by renewing and increasing its donation to the Global Fund to Fight AIDS, Tuberculosis and Malaria.

¹ Description of the GIPA Principle: http://www.unaids.org/en/Issues/Affected_communities/gipa.asp

Basic facts about Slovenia / overview of key published data:

<p>HIV/AIDS:</p> <p>The prevalence of HIV in Slovenia remains very low. UNAIDS estimates the HIV prevalence rate among adults aged 15 to 49 to be less than 0,1%. A cumulative total of 289 diagnosed cases of HIV/AIDS have been reported up to the 30th of June 2006 (Source IVZ RS – Slovenian Institute of Public Health). HIV infections among drug users are extremely rare (16 cases so far with no new case since 2004). This is certainly due to the extensive harm reduction programme put in place over the past 15 years in Slovenia.</p> <p><u>The majority of the newly diagnosed cases concern men who have sex with men.</u> It is suspected that several of them got contaminated abroad (notably while vacationing in western European countries).</p> <p>Medical care including antiretrovirals is provided free of charge (when covered by health insurance).</p>	<p>Drugs:</p> <p>Studies carried out in 2000 and 2001 reveal that there are about 5.3 "problem drug users" per 1000 inhabitants aged 15-64² (or a total of approximately 8000 persons). Slovenia has implemented a comprehensive health programme for drug users which includes needle exchange and substitution treatments (more than 2000 beneficiaries of methadone or buprenorphine). Substitution is available on a large scale both in the community and in prisons.</p>	<p>International Commitments on HIV/AIDS:</p> <p>Slovenia is one of the very few countries that did not provide a progress report in 2006 on the implementation of the UN Declaration of Commitment on HIV/AIDS (endorsed in 2001 by 189 member states). Slovenia has donated so far about 12 000 € to the Global Fund to Fight AIDS, TB and Malaria.</p>
<p>Population: 2 004 394 (March 2006 estimate)</p> <p>Human Development Index: 0.904 (26th) – high</p>	<p>Official language: Slovenian (also Italian and Hungarian in a few cities).</p>	 <p>Source for the map: CIA World Factbook (public domain)</p>

² "The EMCDDA defines problem drug use as intravenous drug use (IDU) or long duration/regular drug use of opiates, cocaine and/or amphetamines. Ecstasy and cannabis are not included in this category."

Challenging times for local NGOs: the impacts of EU Enlargement.

Just about all of the NGO representatives that we met stressed that their situation has become very difficult over the past few years: clearly, many Slovenian NGOs used to be supported from international sources such as American foundations or the PHARE pre-accession funds from the European Commission – and this support was no longer available after EU enlargement.

The public response clearly needs to better value the essential role played by Slovenian Civil Society. With regards to HIV/AIDS, the European Commission strongly recommended on December 15, 2005 that "national authorities [...] facilitate the sustainability of the non-governmental and community-based organisations and their involvement in policy development, implementation"³. This is clearly still not the case today in Slovenia:

- The national AIDS Committee - which was set up to oversee HIV/AIDS policies in Slovenia – has not met since 2003. We also take note that Slovenia was one of the very few countries that did not provide a progress report on the implementation of the UN Declaration of Commitment on HIV/AIDS (the "UNGASS declaration" endorsed in 2001 by 189 member states)⁴. One of the UNGASS commitments in fact states that governmental efforts on HIV/AIDS "should be complemented by the full and active participation of civil society..."

- The Ministry of Health in Slovenia initiated a specific call for tenders to implement HIV prevention for gay men in Slovenia in 2005. This initially was obviously a very positive development but (1) the budget attributed for the whole year (30000 Euros) is clearly quite minimal (2) in 2006, this call was renewed but **the budget was reduced by more than 40%** (17500 Euro per year for a two-year period).

- The Ministry of Health made verbal promises that it would help co-fund Slovenian NGOs involved in European projects funded by DG SANCO of the European Commission. This promise was then "reviewed" to mean that it would apply only to Slovenian NGOs acting as *leading beneficiary* for EU projects (which means nobody, up to now...). This lack of support proved very challenging for AIDS Foundation Robert for instance, whose role as Slovenian partner in the "AIDS ACTION and INTEGRATION Projects" was undermined in part due to lack of co-funding.

- The 1999 Slovenian Laws on Drugs⁵ specifically acknowledges the role to be played by local NGOs in primary prevention in relation to drugs (notably as providers of harm-reduction services such as needle exchange). It was anticipated also that 80% of the cost of such services would be covered by the governmental budget – assuming that NGOs agreed to work together. For that purpose, the Coalition of NGOs in the Drug Field (Zveza NVO na področju drog) was founded in 2000, and originally brought together 18 local NGOs. Regrettably, governmental support for such NGO work has dwindled over time, all the way down to zero in 2005. Clearly, it has become extremely challenging for Slovenian NGOs to maintain harm reduction services to drug users. Milan KREK, the former director⁶ for the Office for Drugs for the minister of Health confirmed when we met him that "funding NGOs is not a standard practice" – and he personally was clearly not committed to supporting NGO work. This reluctance to work with civil society is most regrettable as local NGOs are the best able to reach and to mobilize the most vulnerable populations.

³ Communication from the Commission to the Council and the European Parliament on combating HIV/AIDS within the European Union and in the neighboring countries, 2006-2009 /* COM/2005/0654 final */

⁴ Source: <http://www.unaids.org/en/Publications/2005ungassreporting/default.asp>

⁵ "Prevention of the Use of Illicit Drugs and Dealing with Consumers of Illicit Drugs Act" promulgated on November 29, 1999

⁶ The position was ended in March 2006.

By barely supporting its own local civil society, the Slovenian public response to HIV/AIDS is therefore missing out on a key opportunity to maximise the impact and the pertinence of its national health programmes.

Also, there still seem to be very few funds that are raised by NGOs from either business foundations or private individual donors: considering the fact that the Slovenian economy is quite strong, it ought to be possible for some Slovenian NGOs to raise more private funds domestically. We note however that the Slovenian Tax code does not encourage private companies to make donations to NGOs. Few Slovenian citizens so far give money to NGOs. In a recent mailing campaign by AIDS Foundation Robert, out of 200 business executives who had been personally solicited, only 2 responded by making a donation.

The multiple facets of local NGO mobilisation on HIV/AIDS in Slovenia:

- **AIDS Foundation Robert (AFR)** was established in 1995 and is dedicated to offering different forms of support to all people who are vulnerable to HIV infection. The scope of its activities increased progressively between 1995 and 2003 – and has included:

- anonymous counselling provided by telephone or via the Internet
- direct support for People Living with HIV/AIDS and their families
- information and training on HIV/AIDS
- prevention and education campaigns on HIV/AIDS

AIDS Foundation Robert became a leading provider of needle exchange services, outreach and social support for drug users. It runs notably the STIGMA Project: a 'Drop-In' Day centre in Ljubljana (in 2004: 10,549 contacts with 1,320 different drug users). STIGMA originally was a self-support NGO for drug users which implemented needle-exchange services that merged with AIDS Foundation Robert in 2000.



Since 2003, regrettably AIDS Foundation Robert has found itself in a most challenging situation:

- Grants it used to receive from the national government were not renewed. AFR was then left with only municipal support (targeted for the drop-in centre) as well as support provided in kind (clean injection equipment and other materials) by the Ministry of Health.
- Several of its staff members left the organisation to "restart" the STIGMA NGO. We find ourselves today therefore with both a STIGMA Project run by AFR and the STIGMA NGO that also runs a drop-in centre....

Today AIDS Foundation Robert is obliged to depend primarily upon volunteer work and a few private individual donations to maintain its work. In 2006, the NGO CARS - the association for prevention for vulnerable groups - was specifically founded as a sister organisation of AIDS Foundation Robert to ensure the sustainability of projects initiated by AIDS Foundation Robert.



- The **VIRUS Project** was started in 1997 by medical students and is now a project run by the Slovenian Medical Students' Organisation (www.dsms.net). On a yearly basis (notably on December 1st for World AIDS Day), volunteers design innovative communications campaigns that target primarily Slovenian youth. They also organize training sessions on HIV/AIDS and intervene occasionally in primary schools.

- The NGO **SKUC-Magnus** focuses primarily on defending the rights of gay men in Slovenia. It was one of the NGOs that advocated for the right for gay and lesbian couples to marry (which eventually led to the recent adoption of a "partnership law" which recognizes gay and lesbian unions). SKUC Magnus has also integrated HIV/AIDS prevention as a part of its mission: information on safer-sex practices is regularly included in its colourful publication (called "1XY" and which is in part funded by the Dutch Embassy in Slovenia). Miran SOLINC, one of the leaders of SKUC-Magnus considers HIV prevention for gay men must be closely linked to the mobilisation of the gay community as a whole. He makes sure for instance to distribute condoms and to promote safer-sex at the parties for gay men that are organised at the "Tiffany Club". For the first time in 2005, the Slovenian Ministry of Health has funded the HIV/AIDS prevention work carried out by SKUC-Magnus. This public grant however was reduced in 2006... Miran Solinc recommends that more emphasis be placed on the prevention, testing, and treatment for all Sexually Transmitted Infections (HIV, syphilis, gonorrhoea...), which are clearly a growing concern among gay men in Slovenia.

- **There are a few informal support groups for People Living with HIV/AIDS** in Slovenia. The participants share information about HIV/AIDS (notably information on treatments) via the Internet and in meetings. Their work remains very discrete for fear of stigma and discrimination.

We take note that none of the persons that we met mentioned specific work being done with **commercial sex-workers**. We are aware that we did not have the time to meet the totality of the Slovenian actors of HIV/AIDS prevention and support – but we remain puzzled that the health situation of commercial sex workers in Slovenia does not seem to be very high on the agenda.

The great successes of harm-reduction services for drug users

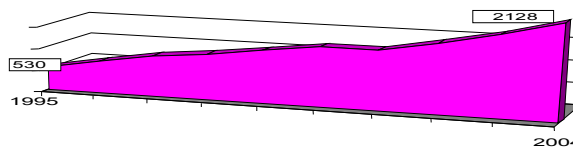
The early and forceful implementation of harm reduction in Slovenia ensured that HIV/AIDS among drug users has remained very low (less than 1% of Intravenous drug users are HIV positive). This great success is made even more evident in the region of Goriška on the Italian border. Where on the Italian side up to 30% of drug users are HIV positive, this rate has been maintained on a very low level on the Slovenian side thanks to the easy access to clean injection equipment and to adequate information and support for drug users.

Needle exchange started very early in Slovenia: the first centre was opened in 1992 in Ljubljana – thanks to the mobilisation of drug users and former drug users in the NGO Stigma. The Stigma project focused on needle exchange was eventually run by AIDS Foundation Robert: it developed over time and distributed up to 190 000 injection kits (in 2005) to drug users. AFR also developed outreach projects and a drop-in centre for drug users.

The Network of Centres for Prevention and Treatment of Drug Addiction was established in 1995 and provides substitution treatment (mostly methadone but also buprenorphine and slow-release morphine) as well as drug-free rehabilitation and detoxification services. As shown in the graphic bellow, the number of patients benefiting from the prescription of methadone has increased over time (more than 2200 today). **Slovenia can be counted among the countries in Europe that maintain the most advanced and comprehensive substitution treatment services for drug users.**



• National coverage of 19 treatment centres for drug users.



• Number of patients being prescribed methadone in Slovenia
(illustrations from a presentation made by Dr. Kastelic)

With regards to drug treatments, the Slovenian government respects its commitment and remains willing to increase the scope of funding that is attributed every year – and this hopefully corresponds to the actual local needs. The national budget for the Centres for the Prevention and Treatment of Drug Addiction increased from 200 000 Euros in 1995 to more than 2 million Euros today – and this covers primarily the cost of substitution treatment and rehabilitation services.

- We hope that the efficiency of the abstinence-based programmes that are also provided will be evaluated: the success rate overall of such programmes at the international level is known to be very low. A scientific literature review carried out by the Open Society Institute suggests that programmes "based on substitution treatment have better outcomes than those that promote only abstinence."⁷

- As mentioned above, we regret that the Slovenian government does not sustainably and reliably fund the essential outreach work and needle exchange programmes run by NGOs in Slovenia.

Substitution treatment is also available in Slovenian prisons (in the Ljubljana prison for instance, 55 out of the 255 inmates receive methadone).

Just as everywhere else in Europe, Hepatitis C remains a serious health problem for injecting drug users: about 30% of the estimated 10,000 drug users in Slovenia are Hepatitis C positive.

Dr. Kastelic, the director of the Centre for treatment for drug addiction in Ljubljana, is also a very active member of SEEA, the South Eastern Adriatic Addiction Treatment Network. This network is dedicated to promoting new strategies and approaches in drug addiction treatment and drug abuse care in the region.

Access to testing and medical care.

Access to free and anonymous HIV testing is available (including pre-test and post test counselling). This service is provided in the main big cities in Slovenia – and general practitioners can also prescribe it to their patients - but it seems that people from smaller cities prefer to come to the testing centres in the capital city of Ljubljana as they feel their privacy will be better protected that way. Also, HIV tests are systematically proposed to all pregnant women.

The NGO Skuc Magnus recommends that access to voluntary and anonymous HIV testing services in Slovenia be further expanded. A yearly study carried out among men who have sex with men since 1996 (voluntary free anonymous non-related test on HIV antibodies with saliva tests in gay clubs) has revealed that up to 3% of the participants are HIV positive. The HIV epidemic is clearly present among men who

⁷ Evidence for Harm Reduction - November 2004 - International Harm Reduction Development Program

have sex with men in Slovenia: easy and streamlined access to HIV testing is therefore essential. Skuc Magnus already systematically promotes HIV testing in all of its publications: such efforts need to be supported and developed by Slovenian Health authorities.

Slovenian law strictly protects the confidentiality of medical data such as the HIV status of individuals. Recent reforms have been implemented to ensure greater protection of databases containing medical information.



Dr. Janez TOMAZIC and his colleagues at the clinic for infectious diseases in Ljubljana.

115 people are being provided antiretroviral treatments (ARVs) for HIV/AIDS at the clinic for infectious diseases in Ljubljana. The Slovenian insurance system covers all the related costs. The Slovenian health system pays the regular prices of the branded versions of ARVs – which means that overall the cost of care per patient is estimated to reach about 16,000 Euros per person per year. Three general practitioners in Slovenia provide the majority of HIV/AIDS treatment and medical care in Slovenia - which is available only in Ljubljana: they closely follow guidelines established at the European and international level – and so far, the high cost of ARVs has not been an issue (second line and third line regimens are accessible to the people that need it).

On rare occasions, foreign patients with HIV who do not have health insurance in Slovenia have come to seek medical care (the few that are cited come from the province of Kosovo and from Croatia.). Some have been provided treatment free of charge (this is decided on a case-by-case basis with the Ministry of Health - when their situation is considered to be "life threatening").

The need for stronger information and prevention campaigns on HIV/AIDS in Slovenia:

The European Commission released in October 2006 the result of the study "Eurobarometer on AIDS Prevention"⁸. **When compared to the 25 member states of the EU, the Slovenian general population still clearly lacks basic knowledge on HIV/AIDS.** 39% of the respondents in Slovenia for instance wrongly believe that it is possible to contract HIV by "eating a meal prepared by someone who has AIDS or who is HIV positive" (on this question specifically, the rate of wrong answers is higher in Slovenia than in all other members states of the EU, with the exception of Lithuania and Hungary...).

These results suggest that the risk of stigma and discrimination for People Living with HIV/AIDS is extremely high in Slovenia: this may explain why so far only 2 HIV positive Slovenians have ever spoken publicly about their HIV status (and, as a matter of fact, both faced problems because of this revelation).

In that context, it is most regrettable that the Slovenian NGOs which want to carry out information and prevention campaigns on HIV/AIDS find only very little support from either the public governmental sector or from the private sector: there is probably a clear need for information campaigns about the real situation of people living with HIV/AIDS.

Other studies have revealed at the same time that, thankfully, awareness of HIV/AIDS is high among young people (probably due to successful campaigns for young people). Condom use among young people is relatively high (more than 70% during the first time they have intercourse).

⁸ http://ec.europa.eu/public_opinion/index_en.htm

Slovenia's international commitment

For a small country, Slovenia assumes a relatively important role on the international stage:

- As an elected member of the Security Council of the United Nations for the period 1998-1999, Slovenia played a very constructive role fostering consensus.
- More recently, Janez DRNOVŠEK, the president of the republic of Slovenia has personally strongly advocated for a greater international response to the humanitarian crisis in Darfur.
- Slovenia is among the rare new member states of the European Union to have donated funds to the Global Fund to Fight AIDS, TB, and Malaria (the only other being Hungary). This donation however was modest (about 12,000 Euros) and so far has yet to be renewed...

Many local Slovenian civil society actors have also been active on the international level:

- Several Slovenian NGOs have been active in raising funds and mobilizing Slovenian public opinion about development issues: notably, a fair trade shop was recently opened in Ljubljana.
- Slovenia has been active in developing preventive programmes for vulnerable groups (prisons...), awareness raising for safe sex and successful campaigns for young people which were also introduced internationally (this was enabled notably by Dr. Leskovsek)
- AIDS Foundation Robert has hosted several training sessions and study visits for NGOs and governmental representatives from other countries.
- Slovenian actors for health services for drugs users (notably Dr. Kastelic) have been extremely active in sharing and promoting good practices with other countries, especially among Balkan countries.

In the first half of 2008, Slovenia will be the first of the new EU member states to hold the presidency of the European Union. The scope and the quality of the involvement of the Slovenian Civil society in the preparation of this presidency is yet to be specified.

- Such open practices are clearly strongly encouraged by the European Commission, for instance as part of its "Plan D" on "Democracy, Dialogue and Debate" which are designed to rejuvenate and strengthen the links between European citizens with our European institutions.
- Regarding HIV/AIDS and other health issues affecting vulnerable groups, this could be a good occasion to further promote the strong Slovenian health practices with regards to drug users (notably with regards to access to substitution) and to better acknowledge the role of local Slovenian NGOs that are active in the fields of HIV/AIDS prevention and support.

List of the Slovenian organizations met to produce this report:

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