The Challenges and Rewards of One NGO's Health Promotion Outreach among ROMA DRUG USERS

PERSISTENCE PAYS:

The Challenges and Rewards of One NGO's Health Promotion Outreach among Roma Drug Users

Initiative for Health Foundation (IHF)
Sofia, Bulgaria

September 2007

Author: Jeff Hoover

TABLE OF CONTENTS

ABBREVIATIONS

The following abbreviations may be found in this report:

CNF = Cooperating Netherlands Foundations for Central and Eastern Europe

GFATM = Global Fund to Fight AIDS, Tuberculosis and Malaria

IDU = injecting drug user

IHF = Initiative for Health Foundation

MoH = Ministry of Health

NGO = non-governmental organization

OSI = Open Society Institute

STD = sexually transmitted disease

ACKNOWLEDGEMENTS

The author is grateful to the assistance provided by all staff and clients at the Initiative for Health Foundation in Sofia, Bulgaria, during his visit in August 2007. Special thanks are due the organization's director, Elena Yankova, and its secretary, Anna Lyubenova. They gave generously of their time, resources, and observations.

The author also would like to acknowledge staff at the Bulgarian Red Cross's harm reduction project in Kyustendil. The project's coordinator, Stoyan Ivanov, arranged an insightful and interesting visit.

1. INTRODUCTION

1.1 Goals for this publication

This report aims to provide an overview of targeted health promotion efforts undertaken among the Roma community in Sofia, Bulgaria by a local non-governmental organization (NGO), the Initiative for Health Foundation (IHF). The primary focus is on the organization's provision of harm reduction services to Roma injecting drug users (IDUs), although other relevant and notable activities are also discussed.

This publication does not intend to offer an in-depth scientific or academic analysis of IHF's harm reduction interventions or of health promotion engagement among Roma in general. It does, however, showcase how one organization has sought to overcome significant cultural, social, and economic obstacles in an effort to work with and for an often marginalized and vulnerable minority population.

The challenges faced by the organization and its clients (not to mention potential clients) are particularly formidable. Wherever they live, including in Bulgaria, Roma are the poorest, sickest, and most discriminated against members of society. As if that were not enough, the vast majority of IHF's Roma clients experience even greater discrimination, isolation, and vulnerability because they engage in stig-

matized and often dangerous behaviors such as drug use and sex work. Gaining those individuals' trust and helping them protect themselves from harm is a slow, complicated, and sometimes frustrating undertaking. Therefore, the report also seeks to highlight the importance of flexibility, creativity, and reconsideration of standard assumptions of what constitutes "success" when addressing such challenges.

IHF's projects and activities in this area may serve as a useful model and encouragement for other civil society actors at international, national, and local levels. In particular, it is hoped that the organization's experience will prompt the following:

- other supporters and designers of harm reduction projects to focus directly on Roma and other minority populations with special needs, and
- NGOs within the Roma community itself to consider harm reduction initiatives among IDUs, sex workers, and other individuals in their midst who are in vital need of targeted health promotion assistance.

1.2 Methodology

On-site research for this publication was conducted in August 2007. Among those interviewed were IHF staff and clients as well as representatives from other local entities that work closely with the organization or have experience in service provision among IDUs or the Roma community (or both). Those entities were from the civil society, government, and private sectors. The representatives and their organizations are referenced where appropriate throughout the publication. In many instances, however, observations, assertions, and comments attributed to specific IHF personnel are not referenced directly. In such instances it should be assumed that the information was gathered by the author during a series of formal and informal interviews in Sofia from August 6–10, 2007. Whenever the name "Elena" occurs in the text, it refers to Elena Yankova, IHF's executive director.

Unless specified otherwise, all observations and information in this report are those of the author. Every effort has been made to ensure the confidentiality of clients and, when necessary, of other respondents. In such cases, names and certain other potentially identifying information may have been altered.

1.3 Defining harm reduction

In this report, "harm reduction" refers to any and all methods and actions designed to assist individuals to limit negative consequences from behaviors that place their health at risk. Among IHF clients, the most common of such behaviors are injecting drug use and sexual activity, both of which increase the possibility of contracting potentially deadly blood-borne illnesses such as HIV and hepatitis C. Those behaviors also make clients prone to serious health problems and infections, including drug use–related abscesses and sexually transmitted diseases (STDs).

As an overall concept - and as practiced by IHF - harm reduction is intended to help people protect their own health and the health of those around them. It is important to note that the harm reduction philosophy is not based on forcing or requiring the cessation of injecting drug use or other such activities that carry a health risk burden. Instead, the primary objective is to encourage behavior change in a pragmatic, compassionate manner.


ХЕПАТИТ С
„ЧЕРНАТА ЖЪЛТЕНИЦА"
ХЕЙ, АЗ СЪМ ВИРУСЪТ НА ХЕПАТИТ С.
АЗ СЪМ 10 ПЪТИ ПО-ЗАРАЗЕН ОТ ВИРУСА НА СПИН
АЗ СЪМ 5 ПЪТИ ПО-РАЗПРОСТРАНЕН ОТ ХИВ
ЖИВЕЯ В КРЪВТА И СЪМ НЕВИДИМ ЗА ЧОВЕШКОТО ОКО
ЗАРАЗЯВАМ И УБИВАМ ЧЕРНИЯ ТИ ДРОБ
КАК ДА ПРЕДПАЗИШ СЕБЕ СИ И ТВОИТЕ ПРИЯТЕЛИ:
НЕ ПОЛЗВАЙ ЧУЖДИ И МРЪСНИ ИНСТРУМЕНТИ ЗА ИНЖЕКТИРАНЕ – ИГЛИ, СПРИНЦОВКИ, ФИЛТРИ, РАЗТВОРИ, КАПАЧКИ
ИНЖЕКТИРАЙ СЕ БЕЗОПАСНО
ПОЛЗВАЙ ПРЕЗЕРВАТИВ

BOX 1 OUTREACH IN ACTION: EXAMPLE OF SERVICE DELIVERY TO ROMA IDUS

In August 2007, IHF outreach workers visited a total of 10 separate sites around Sofia on a regular basis. Depending on need, some were visited once a week and others more frequently.

Roma and non-Roma (i.e., Bulgarian) IDUs mingle occasionally, but they generally obtain services at separate locations. Some Roma clients visit IHF outreach sites in their own communities or the drop-in center in the Roma neighborhood of Fakulteta. Others, however, are more often reached at sites elsewhe re in the city.

One such site was visited during a series of stops at outreach locations on August 7, 2007. The mobile van parked outside an abandoned house along a canal just west of the city center. The house was extremely decrepit and dark; all of the windows were broken and it was surrounded by garbage, weeds, and muddy puddles. The only sign of light or activity within was a flame glimpsed through one of the broken windows. A group of five or six IDUs were inside cooking heroin.

Outreach workers did not directly approach the house. Based on experience with this group of clients, they knew that the users would come out when they were ready and approach the van directly. That did indeed happen over the next 20 minutes or so. Individual users emerged from the house one at a time and walked to the van to meet an outreach worker standing next to it. Users gave their anonymous codes or, if they did not remember theirs, they were asked a few questions - such as the letter of their first name or the month and year of their birth - so the worker could identify the code. Users were then asked what they wanted and the materials were handed out from the back of the van. Most asked for clean needles and syringes as well as condoms. Although most did not provide used needles for exchange, one user did bring a syringe full of blood for collection by the outreach staff.

All of the users at that site were Roma. Some had been homeless at times, but most lived with their

families in Roma communities and gathered at the abandoned house simply because it offered a reasonably safe and private place to inject. According to outreach staff, the group of Roma at that site moved around to different abandoned houses every few months or so. Often their dealer took the lead in finding a new space for them to inject. They generally are forced to move for one or both of the following two reasons: (1) the police begin to harass or detain them routinely at or near the site, or (2) the owners of the abandoned houses sell them or take steps toward renovation.

2. IHF: BULGARIA'S FIRST VIABLE HARM REDUCTION PROVIDER

2.1 Background and context: Surging drug use in the 1990s

In Bulgaria as elsewhere in Eastern Europe, the 1990s were a period of massive political, economic, and social change. On the one hand, ongoing transition to a market-based economy and political pluralism opened up new opportunities for many people. Yet the positive developments were also accompanied by numerous negative ones as the country's residents sought to come to terms with a very different society. The decade was marked by a steep economic downturn accompanied by high rates of unemployment and the fraying of the social welfare system. A not unrelated consequence was a sharp rise in the availability and use of heroin in the mid-1990s, particularly among the young and others who felt marginalized and isolated by the rapid changes.

Most heroin users inject the drug.
That fact raised concerns about the possibility of another epidemic - of HIV - because the sharing of needles and syringes is a particularly effective transmission route for the virus. Experience elsewhere in the world had

shown that once introduced into a drug-using community, HIV spreads rapidly unless measures are available to shut down that transmission vector. Developments elsewhere had also shown that the most effective of such measures is the widespread implementation of harm reduction services for injecting drug users (IDUs).

Comprehensive harm reduction consists of the provision to drug users of safer-injecting supplies, including clean needles and syringes, as well as HIV prevention information and referrals to relevant health and treatment services. Effective harm reduction operates under the assumption that it is important to provide such services to drug users "wherever they are". This has two meanings: (1) finding and meeting clients in their own communities and at their convenience (often through outreach), and (2) focusing on helping clients protect their health, and not on requiring them to stop using drugs unless they wish to.

The first effort to establish a comprehensive harm reduction project for IDUs in Bulgaria was undertaken by the National Center for Addictions. The center is a government agency that in 1995 had initiated a pilot project to provide substitution treatment for opiate-dependent individuals in Sofia. A nurse at the center, Elena Yankova, became one of the first outreach workers in Bulgaria as she sought to bring services and assistance directly to IDUs.

According to Elena, however, the center's effort to initiate and implement a useful harm reduction project was plagued by bureaucratic inertia, incompetence, and the apparent fact that it was a low priority project for the agency. It never truly got off the ground, she said. Recognizing the urgent need for a serious project, Elena therefore left the center in 1997 to establish, together with Dr. Zahari Nikolov, a non-governmental organization (NGO), the Initiative for Health Foundation (IHF), which would have as its sole focus the provision of health promotion services for drug users - with the key strategy being harm reduction.

Accompanying Elena were other staff members from the government agency who had significant experience in the field of addiction. IHF began providing harm reduction services to IDUs in Sofia in 1998, making it the first such viable project in the country. IHF's first director was Nikolov, and Elena succeeded him in 2001.

BOX 2

CLIENT PROFILE: 'NADIA'

"Nadia" is a 53-year-old grandmother from Tatarli, one of Sofia's Roma communities. The following were among her comments and observations during an interview in August 2007.

"I've been injecting heroin for about eight years. Now I use about three times a day. Usually I inject with a group of three or four other people, including my daughter. We gather in my house. It's best that way because we have some privacy: I'm no longer married and my children don't live with me any more.

I've been getting needles and syringes from the project since the beginning. I also get wipes and condoms and whatever else I might need. I see them one or two times a week when they do outreach.

My daughter and I hide our drug use from other people in our family... including my son, her children, and my mother. I think my son would kill me if he knew I used drugs. I would also be very ashamed if my family members and many other people around her knew I used drugs.

I can't live without drugs now. I've stopped for one or two days at a time, but no longer. But I'm afraid to get treatment because then people would probably find out I've been a user. I can't face that shame."

2.2 Building the organization

In the beginning the organization interacted with clients only through outreach. That was necessary for a couple of reasons. For one, IHF originally had a very small office and it would have been difficult to welcome clients there comfortably and confidentially (if needed).

The bigger reason, however, stemmed from concerns about the reaction of society in general. IHF's activities were poorly understood by most people, many of whom assumed they merely encouraged and promoted illegal behavior. Law enforcement authorities shared that view; as a result, the real threat of police harassment made it too dangerous for clients to visit the office. That threat was magnified by the lack of clarity as to the legal status of the organization's activities. Needle/syringe exchange and provision were not expressively prohibited, but they were not officially legal either. Staff and clients always ran the risk - and it was not uncommon for the risk to turn into reality - that determined police officers would interfere with harm reduction outreach or even detain participants for one reason or another.

The situation changed after 2000 when the Ministry of Health (MoH) adopted a regulation permitting licensed needle/syringe provision and exchange. IHF obtained a license from the municipality that year, and it has been renewed annually. Also that year,

IHF began holding seminars and workshops among the police to raise their awareness about harm reduction and drug use, with a particular focus on how, why, and where the organization conducted its outreach services.

Instances of police harassment have decreased substantially since then, thereby leaving the organization and its clients largely free to interact openly. Yet it must be stressed that the nature of the harm reduction activities and the clients served (who do after all engage in illegal activity, i.e., drug use) mean that such instances have not ceased. IHF staff report that clients are still stopped by the police on a regular basis, often for no good reason other than that the officers recognize them as drug users. Organization personnel note that due to ingrained discrimination, clients are twice as likely to be detained if they are Roma.

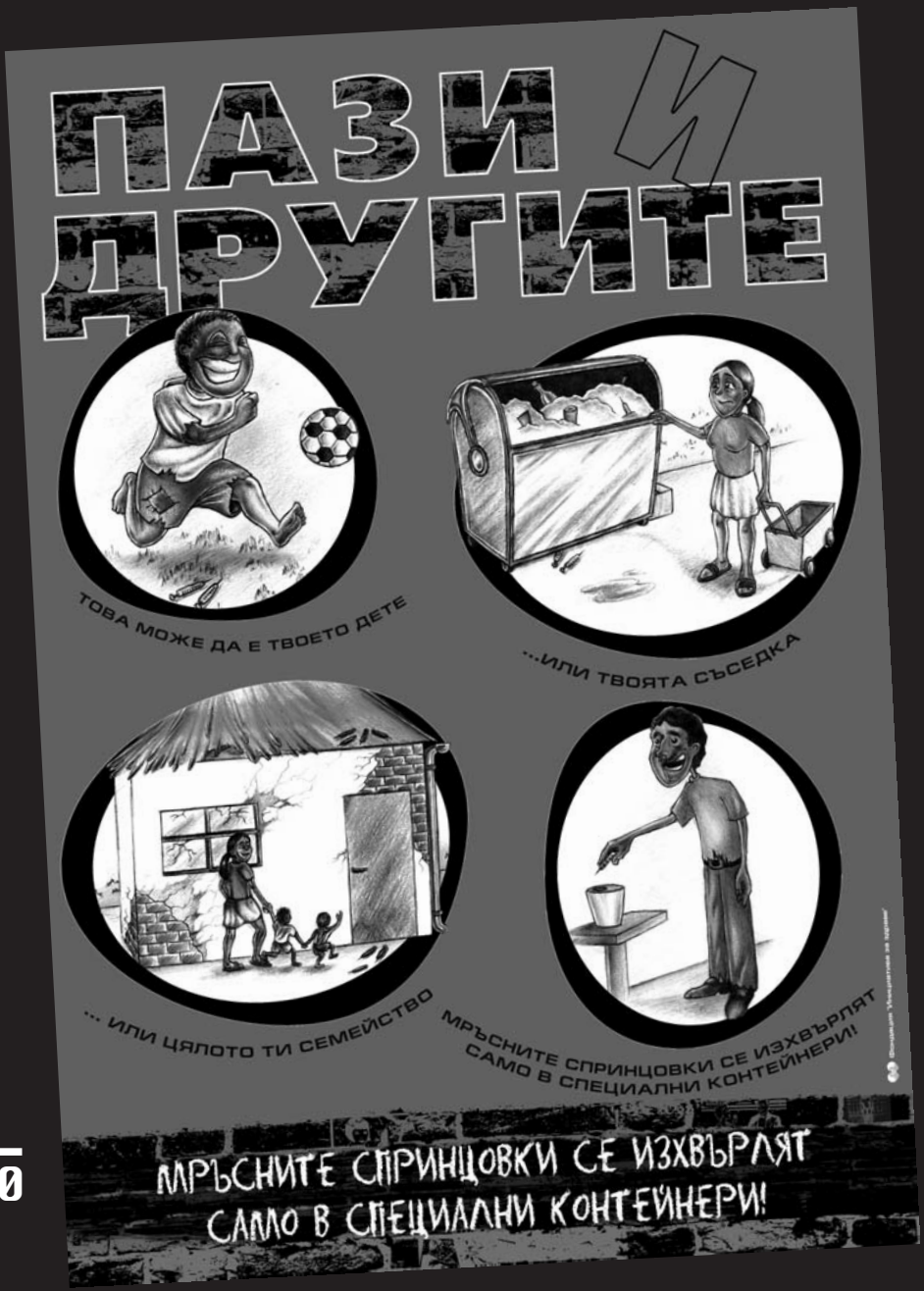
IHF originally focused on IDUs exclusively, regardless of ethnic background. As the only harm reduction provider in Sofia, a city with more than 10,000 IDUs, that remains its overall priority[1]. Yet within a couple of years of its founding the organization began broadening its activities to provide more targeted harm reduction services for population groups deemed likely to need special attention to improve efficiency and effectiveness. Throughout this process, IHF has consistently considered Roma as having the greatest need for such targeted services. One priority initiative in this regard - and the

1 According to estimates provided by IHF, and backed by the National Center for Addictions, there are an estimated 15,000 "problem drug users" in Sofia. Of those, 12,000 use heroin, with 10,000 of them injecting the drug. Although Sofia only comprises a bit more than one-seventh of the country's

one that is highlighted in this overall report - reaches out specifically to Roma IDUs.

Another notable and important project works with and for sex workers. Although most prostitutes in Sofia are not IDUs, they of course are at high risk of contracting HIV nevertheless (see Box 5). A disproportionately large number of sex workers in the city are Roma (especially street workers).

total population, it is home to between one-half and one-third of all IDUs in Bulgaria (a number currently estimated at 20,000 to 30,000). IHF staff note that amphetamine use, both injecting and not, is increasing in Sofia. However, it remains far less common than heroin use among injectors.


ПАЗИ И ДРУГИТЕ
ТОВА МОЖЕ ДА Е ТВОЕТО ДЕТЕ
...ИЛИ ТВОЯТА СЪСЕДКА
... ИЛИ ЦЯЛОТО ТИ СЕМЕЙСТВО
МРЪСНИТЕ СПРИНЦОВКИ СЕ ИЗХВЪРЛЯТ САМО В СПЕЦИАЛНИ КОНТЕЙНЕРИ!
МРЪСНИТЕ СПРИНЦОВКИ СЕ ИЗХВЪРЛЯТ САМО В СПЕЦИАЛНИ КОНТЕЙНЕРИ!

BOX 3

OUTREACH WORKER PROFILE: 'YG'

In August 2007, IHF had a total of seven outreach workers on staff. Two of them are former IDUs and clients of the organization; one of those individuals is 33-year-old "YG". The following were among her comments and observations during a series of talks in August 2007.

"I was a pretty heavy user for many of the six years I injected heroin. During that time I met Elena [Yankova, head of IHF] and some IHF outreach workers and became a client. Finally, about six years I managed to quit - I went cold turkey. I had one single relapse about six months later, but otherwise I haven't used. I was lucky because at the time I had many friends who knew I used drugs but didn't themselves. They provided a lot of support for me when I stopped. Many of them still do now.

I considered methadone while I was thinking of quitting. But ultimately I decided it wasn't for me... I was concerned about still being reliant on a drug. And as it turned out I didn't need it to quit heroin, another lucky thing for me.

After I stopped using I decided I wanted to know more about how to help others like me. For a

while I worked as a counselor at Phoenix House [the only licensed therapeutic community - i.e., intensive rehabilitation program for drug- and alcohol-dependent individuals - in Bulgaria]. Then about three and a half years ago I came to IHF to be an outreach worker. In addition to my regular job, I'm studying for an advanced degree in psychology through a correspondence course.

I like my job very much but of course there are many challenges and elements that frustrate me. One thing I find very difficult is that I can't always do more to help HIV-positive clients. For example, since I work at the organization I often know if a client has HIV. But I can't discuss it with the individual unless he or she brings it up first?it's part of our confidentiality policy regarding clients' health issues. I agree with the policy and know it's appropriate. However, right now I know at least two people I see regularly have HIV, and they are not getting appropriate care and seem to be in denial. I just have to wait until they open up to me about it, if they ever do.

I also find it frustrating sometimes when clients don't listen to advice and warnings about serious threats to their health. I'm thinking in particular about a couple of situations when we discussed injecting safety with clients. We mentioned that it was really dangerous to inject into the femoral vein, yet

some of them went ahead and did it anyway.

I think we do a good job reaching a lot of people given our limited resources. I do see many unmet needs, though, most of which we can't do anything about now. It would be great to have a doctor on staff, even part-time. That would help improve our clients' health in a major way. Many of them rarely if ever get health care even if they have an emergency, like an abscess. Usually they don't know where to go, but many of them are more concerned about what will happen once they get to a hospital. Most don't have health insurance and risk being turned away even if they have an emergency [which is illegal under law]. And we still hear stories about how healthcare workers don't like drug users and may even refuse to treat them because of that.

I would like to take part in the opening of a low-cost therapeutic center through IHF. If the money is ever available, I think this would be a very important thing to do. There are far too few places in Bulgaria for those who want to enter. And of course the situation is even more difficult if you can't afford the current program.

2.3 IHF operations and services

2.3.1 Drop-in and outreach

IHF currently has two facilities in Sofia. The newer and smaller one, a drop-in center in the Fakulteta neighborhood, is discussed in greater detail in Section 3 of this report. The main office, meanwhile, is in the Borovo neighborhood in the southwest part of the city. The organization rents a modest two-story house from the municipality. Offices for staff are located there, and one of the larger downstairs rooms is also used as a drop-in center where clients can obtain safer-injection materials, advice, and referrals. The main office is open from 10 a.m. to 6 p.m., Monday through Friday.

IHF maintains some basic rules of conduct for clients entering its on-site facilities. Clients are not allowed to inject drugs there, bring drugs into or sell drugs inside the building, or be physically or verbally aggressive or abusive.

The drop-in centers at both Borovo and Fakulteta are infrequently used by clients. Most contacts are instead made through outreach. That priority is reflected in the staff composition: more than half (seven) of the 12 funded positions at IHF are for full-time outreach workers. Two of the other staff members also regularly participate in outreach: the outreach coordinator and a nurse. (The nurse currently works part-time at IHF, four hours a day.)

The outreach workers rotate responsibilities on a regular basis. At least two must be on the mobile unit (a van) that goes to various sites every day; two others are based at the Fakulteta drop-in center for the four hours a day it is open; and one or two must be based at the Borovo office to serve any clients who might come by. The nurse travels on the van three times a week, and spends one day each week at both the Borovo and Fakulteta facilities.

In August 2007, the outreach van was visiting a total of 10 sites in Sofia where IDUs gather on a regularly scheduled basis. Locations include a street in front of a cafū frequented by drug users, an abandoned house where Roma users gather to inject (see Box 1), and a street at the entrance to the Roma neighborhood of Tatarli. Changes to the sites and the schedule are either instigated by clients themselves or made only after consultation with them. Sometimes changes are determined by developments such as drug users moving to different locations to buy or inject drugs.

To preserve anonymity and confidentiality, the organization does not record clients' names or any other specific identifying information. It does, however, use a coding system to help determine the number and frequency of individuals utilizing its services. That coding system indicates, among other things, the date of birth and gender. (As part of an effort to track trends and needs, the organization also gathers information such as client's ethnicity and

district in which the client lives. Such information is collected and registered separately from the coding system, however.)

2.3.2 Services provided to all clients

Except for unusual situations when supplies are low, the following services are always provided to IDUs by the outreach van and on-site:

- clean syringes and needles;
- other safer-injection materials such as alcohol wipes and acids to help prepare drug solutions;
- creams and other basic medicines to treat skin and vein conditions;
- condoms;
- booklets and other information materials about safer injecting and potential health problems such as HIV, hepatitis, and drug use–related wounds and injuries;
- referrals to relevant and appropriate health-care facilities and personnel; and
- referrals to substitution treatment facilities, if requested.

Clients can have their blood drawn when the nurse is present. The blood is tested anonymously at a state-run facility, with results (including HIV and hepatitis status) available about a week later.

There is no formal limit on the number of syringes and needles distributed. However, outreach workers tend to try to provide only a "reasonable" number to individual clients each time. Exceptions are made for clients who serve as "gatekeepers" (see Section 2.3.3) and for clients visiting the Fakulteta drop-in center (see Section 3.4).

2.3.3 The 'gatekeeper' system

"Gatekeepers" are clients (current and former) who comprise a key part of IHF's effort to reach as many IDUs as possible, and as often as possible. Gatekeepers essentially conduct what is known in the harm reduction world as "secondary exchange", although they need not actually "exchange" supplies. Their main activity consists of collecting large numbers of safer-injection materials, including needles, syringes, condoms, and information materials, from IHF. They then distribute those items to members of the drug-using community who are unable or unwilling to visit IHF's outreach or on-site services directly.

IHF staff usually interact directly with gatekeepers by making special appointments with them to pick up supplies. Outreach workers manage these relationships. In general, the system is a mixture of informal and formal. On the one hand, there is only a verbal agreement between IHF and gatekeepers regarding the job and its responsibilities. Yet gatekeepers also receive basic training from IHF and are expected to attend an annual refresher seminar. They are not

paid for their services, but IHF usually offers them "gifts" such as cell phone vouchers on a regular basis. The organization does not directly oversee its gatekeepers' activities, but staff said they are able to monitor them because other clients regular report on their interactions with the gatekeepers.

2.4 External support and advocacy work

In addition to its own harm reduction work, IHF has provided training to staff at the other nine harm reduction projects in Bulgaria that cater to IDUs. This ongoing activity has increased in recent years because of extra funding for such activities provided by the Global Fund to Fight AIDS, Tuberculosis and Malaria (GFATM). (See Box 7 for information about the GFATM's HIV/AIDS project in Bulgaria.)

As part of its overall goal to improve the health, safety, and well-being of its clients, IHF also has been active in the effort to ease stringent drug laws at the national level. The laws have been quite strict for many years. The nadir was 2004–2006, after the government passed a zero tolerance law that made any amount of possession of an illegal drug punishable by up to 15 years in jail. Advocacy work by IHF and other organizations against such draconian provisions was instrumental in prompting a revision to the law in 2006. Since then, possession of any amount of illegal drug not regarded as "insignificant" can lead to a jail sentence of three to six years.

Although the reform was undoubtedly an improvement, the law remains problematic in the view of IHF and other advocates. The main concern is that "insignificant" is not defined; it can be interpreted in varying ways by different law enforcement officials and judges, for example. Moreover, even those found with "insignificant" amounts face penalties - including fines of at least 1,000 BGN (US$700).

IHF staff acknowledge that the country's laws, both pre- and post-reform, represent "huge risks" for clients. That is true even though the laws reportedly are enforced haphazardly - and often less frequently in and around where IHF outreach occurs. One result is that most clients do not bring used needles and syringes to exchange. They are understandably worried about being stopped and charged with illegal possession based on trace amounts found in the used supplies.

Both IHF and its clients recognize the potentially devastating consequences of incarceration for drug-dependent individuals. "Soft" harm reduction services such as counseling, support, and information about HIV are sometimes available in prisons. Yet condoms are the only major "hard" service (an actual item that can prevent transmission of HIV and other illnesses) that inmates have access to, and even then not consistently. IDUs face significant challenges because needle/syringe exchange is forbidden in the nation's penitentiary system. Moreover, appropriate and consistent treatment for drug dependency is limited.


ПАЗИ СЕБЕ СИ
АКО ПОЛЗВАЩ ЧУЖДИ ИНСТРУМЕНТИ, МОЖЕ ДА ТИ СЕ СЛУЧИ
ХЕПАТИТ
АБСЦЕСИ
СПИН
ТРОМБО-ФЛЕБИТ
ГАНГРЕНА
ЯЗВИ
АКО СЕ ИНЖЕКТИРАЩ, ВИНАГИ ПОЛЗВАЙ ЧИСТИ ИНСТРУМЕНТИ!

BOX 4

GATEKEEPER PROFILE: 'DRAGO'

Thirty-seven year old "Drago" stopped using heroin more than a decade ago and has been receiving methadone from the state-run substitution treatment program for 11 years (he was one of its first participants). He said he remains an IHF client, however, because he "sometimes" injects amphetamines and needs clean syringes and needles when doing so.

Drago and his wife, "Emy", 31, have been living together for 10 years and have been married for the past four. Since 2003 they have served as "gatekeepers" for IHF. In this primarily voluntary role, they help expand the organization's reach by bringing harm reduction materials - including safer injection supplies and condoms - to individuals in need whom project staff do not reach directly for one reason or another. In essence, they and other gatekeepers provide what is commonly known among harm reduction providers as "secondary exchange".

Drago and Emy focus largely on sex workers during their gatekeeper activities. The following were among Drago's comments and observations during an interview in August 2007 with him and Emy.

"We try to visit the office or meet the outreach van once a week - although sometimes it's not as often if we have trouble with our car, for example. It's during our visits that we get the supplies we need when we go to find the girls [sex workers]. We visit sex clubs as often as possible, even every night, as part of our agreement with IHF. We don't get paid for our work, although sometimes IHF gives us vouchers for our mobile phones. We have to go through a training course every year...it usually consists of interactive stuff like role-playing. IHF usually rents out a conference room at a nice hotel for a day. It's fun.

The main place we work is in sex clubs. I'd say that I'm a pretty open guy who gets along with everyone, so that helps make it easier for us to get into the clubs. I carry around cards saying that I'm affiliated with this project. I hand them out to bouncers and other workers, and they usually let me in. After all, they want their girls to be healthy and happy too. In two of the sex clubs we visit, about 60% of the girls are Roma. Others are more mixed. But in general, the percentage of workers who are Roma is much higher on the street than in the clubs.

Usually we hand out condoms and leaflets to girls in the clubs. What surprises me still is that many of them don't know much about HIV or how or why they need to protect themselves. Once we gave a girl some lubricant, and she thought it was something she should use for her hair... and this was a girl who had been a sex worker for several years.

Sometimes we meet opposition from pimps. We usually know them and try to work closely with them from the beginning. But they are sometimes aggressive and don't trust us. For example, some pimps are concerned that if girls' potential clients see the leaflets about HIV and other health issues, they'll think the girls aren't clean."

3. IHF'S ROMA INITIATIVE

Roma have been clients since IHF began offering harm reduction services. Shortly thereafter, in 1999, the organization first targeted services specifically for Roma when it started conducting outreach in Tatarli, one of two main Roma communities in Sofia. The following year its outreach efforts also included Fakulteta, the other (and larger) community. Within two years, Roma represented nearly 50 percent of the organization's overall clients.

Although it began seeking out and serving Roma clients two years earlier, IHF did not initiate a Roma-specific project until 2001, when the Open Society Institute (OSI) first provided support for such an initiative. In addition to supporting the project's direct and ongoing operations, OSI's funds were also used by the NGO to host seminars on service delivery among ethnic minorities. IHF organized four such trainings over two years (2001 and 2002). Participants included local civil society groups from across Eastern Europe, all of whom were already working with or considering expanding services among hard-to-reach populations such as Roma.

OSI's most recent support for IHF's Roma project consisted of a one-year grant through September 2007. Those funds helped sustain a drop-in center in Fakulteta that had been established originally within a project funded by the Cooperating Netherlands

Foundations for Central and Eastern Europe (CNF). OSI's grant also helped fund activities and expenses not covered by the MoH, which through the country's GFATM grant provides IHF with most supplies (needles, syringes, condoms, etc.) and also offers indirect support such as charging below-market rent for the project's facilities. IHF's GFATM contract has been renewed every year since the initiative began in 2004. (See Box 7 for more information about the GFATM's HIV/AIDS project in Bulgaria.)

3.1 Why and how Roma's needs are greatest

IHF's early and consistent priority toward serving Roma is based on one simple fact: the needs are greatest within that community in Sofia.

According to the most recent official data, Roma comprise about 5 percent of the nation's population, some 400,000 people. Some observers believe, however, that a more accurate estimate could be as high as 800,000, or a bit more than 10 percent of the total. Regardless of the actual number, there is no doubt that Roma are poorer, less educated, and more likely to be unemployed than the Bulgarian population in general. Numerous factors contribute to their low economic and social status. For one thing, Roma are part of a distinct culture with unique traditions and values. They tend to live apart from the overall population in their own neighborhoods,

usually by choice but sometimes because of outside pressure. Many primarily speak the Romani language.

The Roma population's comparably limited prospects have barely improved over centuries of persistent stigma and discrimination on the part of the rest of the population, including governments at all levels in many parts of the country. Their overall economic situation arguably has gotten worse since the collapse of the Soviet era totalitarian regime, which tended at the very least to guarantee more jobs and a minimum level of support to all residents.

All of these factors contribute to the dismal state of Roma health. Statistics and observations all confirm that they lag far behind the overall population in nearly every health indicator. For example, Roma live 10 years less on average; infant mortality rates among Roma are 28/1000, compared with 9.9/1000 for Bulgarians and 17/1000 for Turks in Bulgaria; and Roma represent about 50 percent of all tuberculosis (TB) cases, according to analysis undertaken during the drafting of the National Program for Prevention and Control of TB 2007–2011.

An estimated half of all Roma lack health insurance, usually because they do not have jobs (at least in the formal sector). This greatly limits their access to both preventive and regular care. For many, the only option is to wait until the situation becomes an emergency, in which case care is provided free of charge at public-sector facilities.

Cultural factors also influence healthcare access and utilization among Roma. As noted by staff at IHF and other NGOs in Sofia, they include the following:

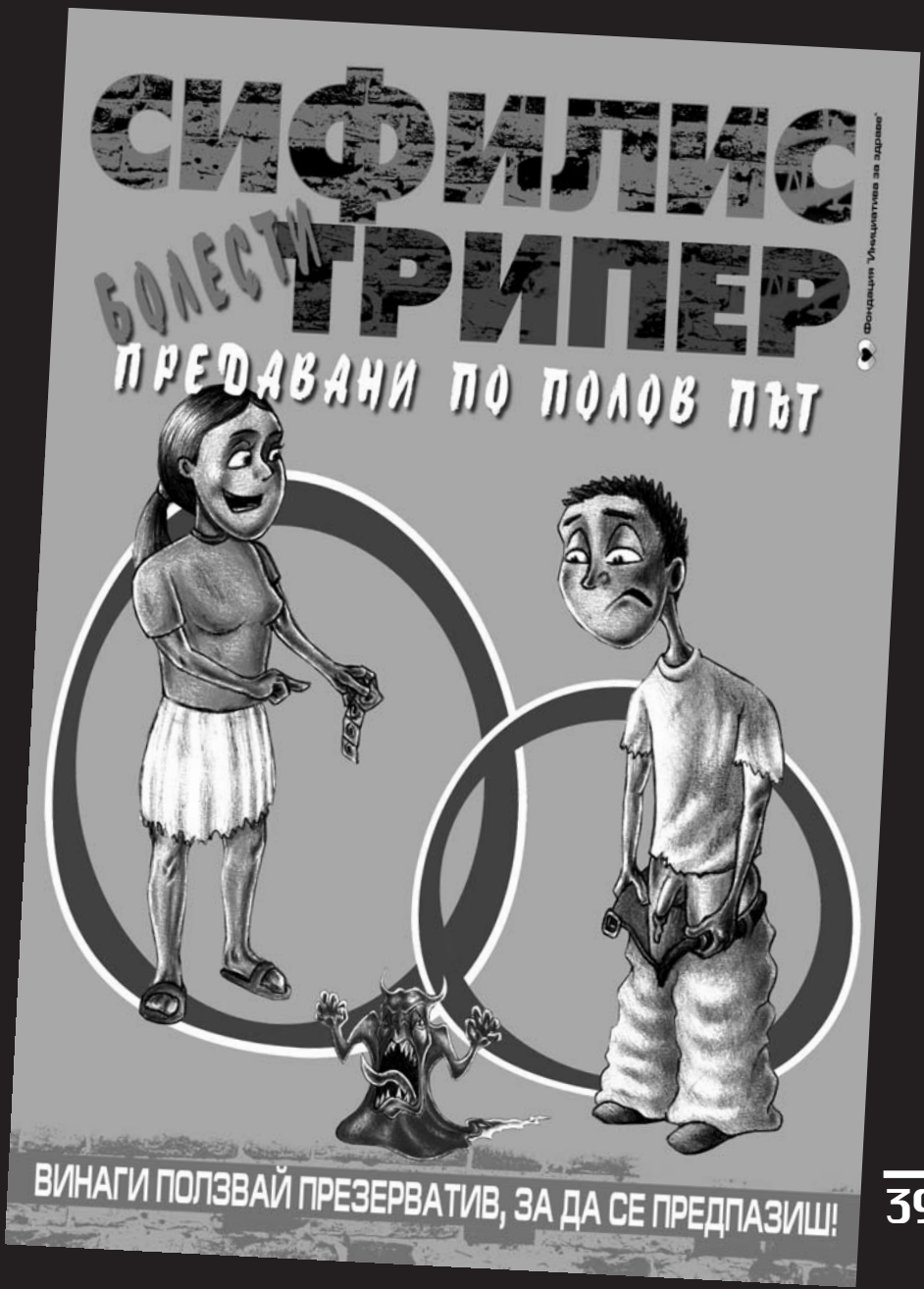
- *Low levels of education*, which means that many Roma are unaware of services available to them and have difficulty communicating their needs when seeking assistance. The education gap stems at least in part from the fact that formal education has not been traditionally valued within most Roma communities. As a result, children often drop out of school early, sometimes after only three or five years of formal schooling. A significant social emphasis on virginity among girls prompts some parents to remove their daughters from school as they near puberty - this is done out of fears that they will be "stolen" and perhaps compromised[2]. Roma also tend to be married at a much younger age, often when they are teenagers.
- *Health* per se *is a relatively low priority*. Observers note that Roma community values place higher priority on family and children, in general, than they do on education or individual and public health. As noted by the director of one NGO that works with Roma, "There is the idea that health is just a matter of good luck, and that there's nothing you can do about it."[3]
- *A double standard for men and women*, with the former expected to have "experi-

2 Interview with Radosveta Stamenkova from the Bulgarian Family Planning and Sexual Health Association in Sofia, August 8, 2007. The association works closely with IHF on many Roma-related issues, especially those regarding the health of girls and women.

3 Ibid.

ence" in regards to sex while women are expected to be virgins (at marriage) and to be faithful. The consequences of such attitudes come across quite clearly in regards to condom use, for example. It is not considered appropriate to use condoms within the family, even if one or the other partner is aware of (or suspects) behavior that could increase risk for HIV, STDs, etc.

- *Poor quality of health care provided*, a situation due primarily to stigma, discrimination, insufficient motivation, or difficulties in communication. Such barriers are directly related to fact that nearly all healthcare providers, from doctors to nurses to administrative staff, are non-Roma. Distrust of outsiders, a cultural factor still common within many Roma communities, may make Roma less inclined to try to obtain necessary care. In addition, healthcare providers often have their own prejudices and stereotypes that they are unable or unwilling to overcome. (The creation of Roma health mediators, as described in Box 9, is one innovative project that seeks to bridge these gaps.)


СИФИЛИС
БОЛЕСТИ
ТРИПЕР
ПРЕДАВАНИ ПО ПОЛОВ ПЪТ
ВИНАГИ ПОЛЗВАЙ ПРЕЗЕРВАТИВ, ЗА ДА СЕ ПРЕДПАЗИШ!

BOX 5

IHF'S HARM REDUCTION AMONG

SEX WORKERS

In addition to IDUs, sex workers in Sofia have been provided harm reduction services by IHF over the years. The initial project among this population began in 2001, with support from the Open Society Institute (OSI) over the first four years. IHF was forced to suspend the project in 2006 due to lack of funding. However, as of August 2007 it had received support from Cooperating Netherlands Foundations for Central and Eastern Europe (CNF) to re-start it in September 2007.

There are two main components of the project, which is conducted via outreach exclusively. One element focuses on individuals who work in sex clubs (also known somewhat euphemistically as "massage parlors"), with the other and more extensive prong being among street workers. One outreach worker said that on a typical evening up to 70 contacts were made among both groups in total.

According to the most recent IHF data from September 2006 (when the project was suspended), Roma comprised a total of 391 of the 597 sex workers the project had contacted. Their share therefore was about 65 percent. Compared with those who work in sex clubs, street workers are even more likely to be Roma. Street workers are paid less and face greater risks of harassment or abuse from police, including shakedowns for money. Those sobering facts offer further proof that Roma face far greater challenges in protecting their health and thus require specific, targeted initiatives.[1]

The project also has made contact with an unusually high percentage of male and transgendered sex workers - two sub-populations notoriously difficult to reach. A total of 102 sex workers (about 17 percent) of the 597 counted in September 2006 were members of these two groups. Of those, more than half (64) were Roma. All male and transgendered clients of the project worked on the streets.

According to IHF staff in August 2007, the project to be resumed in September 2007 would be broadly similar to the earlier one. It consists of mobile outreach three nights a week, with a van stopping at several sex clubs as well as along

1 Sex work is conducted in a rather murky legal framework. Accepting money for sex is decriminalized; however, pimping is against the law and those prosecuted for it face criminal charges.

streets in Sofia where sex workers congregate. Two outreach workers at a minimum are in the van at all times. As requested, the following materials and services are provided through mobile outreach:

- a maximum of 12 condoms to each individual contact, with more handed out if she or he serves as a "gatekeeper" and distributes to others. A contact may be a pimp as well as an actual sex worker;
- printed material (i.e., booklets) containing information about HIV, STDs, and other health issues;
- referrals for specialized care, such as gynecological services;
- blood drawing to test for HIV, hepatitis, and other potential infections. This service is only provided when a nurse accompanies the outreach workers, which happens three or four times a month; the nurse also offers pre- and post-test counseling. The results are typically available after one week, and individuals are told they may obtain them from the van at their convenience; and
- safer-injection materials (i.e., syringes, needles, alcohol wipes, etc.). Such materials are provided relatively infrequently because only 10 percent of sex worker clients are IDUs.

IHF also plans to offer a few new services when the project resumes, including pregnancy tests and emergency contraception. Staff also expressed the hope to develop and implement workshops on pregnancy care, delivery, and caring for infants and young children. Those new services are expected to be particularly useful for Roma sex workers, who have a relatively high pregnancy rate.

3.2 Roma client numbers

The presence of just one of three overarching social characteristics - substandard health care, high levels of poverty, and limited prospects - could increase the level of potentially dangerous behaviors within the Roma community. Taken together, they make for an especially lethal combination. One consequence is that Roma are disproportionately represented among the city's IDU and sex worker communities.

Drug use is a fluid and often furtive activity wherever it occurs. Therefore, no reliable statistics currently exist as to the number and percentage of Bulgaria's 20,000–30,000 IDUs who are Roma.[4] The best recent estimates for Sofia, home to perhaps half of the nation's IDUs, can be obtained from the code-based (thus anonymous and confidential) information collected by IHF as part of is harm reduction efforts.[5]

Roma have made up nearly half of all IHF's drug-injecting clients for several years. In 2005, for example, they comprised 40 percent of both overall contacts and unique clients. In the first six months of July, 47 percent and 42 percent, respectively, of overall contacts and unique clients were Roma. For the period from the beginning of 2005 to July 2007, about 43 percent of the 5,672 total contacts were with Roma clients. Of the 1,318 unique clients during that period, 42 percent were Roma.

Roma representation among sex workers is even greater. For example, the majority of sex workers on the street - the most dangerous and low-paying rung

4 Two studies released in 2001 provide some indication, albeit limited and out of date, as to drug use among Roma in Sofia. The National Statistical Institute reported that year that some 70,000 to 80,000 Roma lived in Sofia. Another report, from the World Bank, estimated that between 1,000 and 1,500 of them injected drugs, usually heroin.

5 All of the data in this section were provided by IHF in August 2007.

on the sex work hierarchy - in Sofia are Roma. (See Box 5 for more information about IHF's outreach among sex workers.)

Their share is even higher among those engaged in both potentially risky behaviors. Between January 2005 and July 2007, IHF made 826 total contacts with individuals who both inject drugs and engage in sex work. Of those, 89 percent were Roma. Seventy-six percent of the 92 unique dual-risk clients contacted during that period were Roma.

IHF staff also reported that they distributed a total of 145,780 syringes and 64,616 condoms among Roma clients from January 2005 to July 2007. That works out to a monthly average of 4,702 syringes and 2,085 condoms.

The numbers prove that demand clearly exists. Yet they tell only part of the story behind Roma IDUs' more extensive need for assistance. Because Roma tend to be poorer and more isolated, they often find it difficult to travel to places where health services are available for them. They are therefore less likely to get treatment for injection-related wounds, for example. Roma IDUs also have a more difficult time obtaining safer-injection materials, even with IHF's project in place. One key reason is simple discrimination. Although it is legal under Bulgarian law to buy needles and syringes in pharmacies, staff at many of them refuse to sell to Roma. They act this way out of a belief that catering to Roma IDUs will prompt non-Roma patrons to avoid their stores.

BOX 6

SUBSTITUTION TREATMENT IN SOFIA:

UNMET NEEDS DUE TO CAPACITY LIMITATIONS

Substitution treatment for opiate-dependent IDUs first became available in Bulgaria in 1995. At that time, the government began providing methadone through a pilot project in Sofia. Twelve years later, in August 2007, a total of about 1,700 people were receiving substitution treatment - mostly methadone, with a smaller number on Substitol at some facilities - in seven programs across the country. Five of those programs are in Sofia, serving some 1,400 patients overall: one public and free (through the State Addictions Hospital), and four operated by private companies. With about 400 patients, the public-sector program is the largest.

Nearly all individuals interviewed for this report said the need and demand for substitution treatment far exceed the supply in Sofia. The state-

BOX 6

run program was described as poorly staffed and financed, which meant that it was limited to taking on priority patients only (those who were HIV-positive or pregnant).[1] Tsveta Raycheva, the director of the National Center for Addictions, said the program received far too little financial assistance from the Ministry of Health to run as comprehensively as needed. She also pointed to an obstacle that had proved equally insurmountable: the difficulty in finding qualified professionals who were willing to work with drug users.[2]

The four private companies are unable to fully address the unmet need for several reasons. For one thing, they must sign annual licenses with the Ministry of Health that cap the number of clients they can provide with substitution treatment. According to Dr. Malin Stoyanov, the director of one such private service ("Trust for Health"), all were operating at full capacity in August 2007.[3]

Moreover, it is unlikely that private companies could be expected to address the problem on their own. The main issue is that although they appear to offer a higher quality of care and a wide range of services - including regular psychological counseling - their services are not free. The monthly fee at "Trust for Health" is 180 BGN (US$125), for example. That is far beyond

1 Dr. Malin Stoyanov, the executive director of "Trust for Health", a private company offering substitution treatment, said there was only one doctor serving the nearly 400 patients at the state-run program. Stoyanov worked at the National Center for Addictions for eight years before leaving in 2005. He said there were "far too many patients" for the limited number of staff there to treat properly and comprehensively. (Interviewed August 8, 2007)

2 Interviewed August 8, 2007 in Sofia.

3 Interviewed August 8, 2007 in Sofia. In August 2007, Stoyanov's company had a limit of 150 patients on methadone and 60 on Substitol. He said he and operators of other private services were working to lift the caps on patient numbers. (Interviewed August 8, 2007).

the reach of most drug users, especially Roma. (Stoyanov acknowledged in August 2007 that just 3 of the 210 patients on substitution treatment at his company were Roma.)

Roma are also disproportionately represented among patients at the free state-run program. The main reason for that, according to both staff from IHF and the National Center for Addictions, is that Roma IDUs are less inclined to seek out such treatment and tend to find it more difficult to meet program requirements if they do.[4] One important obstacle is their more limited access to easy and convenient transportation from their neighborhoods to the state-run facility where methadone is dispensed.

There was nearly universal agreement among all stakeholders that the best way to include greater numbers of Roma would be to provide substitution treatment free of charge directly inside a Roma community - and simultaneously to implement a comprehensive outreach initiative to increase uptake. At the time this report was being prepared, though, neither the government nor any civil society organization was seriously considering such a possibility. (Some IHF staff members said they are keen to open a treatment facility of that sort within the community. Yet they said they also recognize that financial limitations preclude achieving that goal in the near-term.[5])

4 Tsveta Raycheva, the director of the National Center for Addictions, provided one such example. She noted that although there are staff at her agency with responsibility for helping Roma meet program criteria, they often are overstretched for time. (Interviewed on August 8, 2007)

5 Among those who mentioned such a facility were Elena Yankova, IHF's executive director, and Yuliya Georgieva, an outreach worker.

Meanwhile, poorer patients (Roma or not) must make do with the one state-run program?if they are lucky enough to get accepted into it. Several patients interviewed for this report were receiving methadone through that program. Few were satisfied with their care.

According to "Tony", who has been receiving methadone for 11 years, the staff at the state-run program "don't really care that much" and offer him very little in reality. "They just give you something to drink, and that's it."[6]

Another client, "Drago", also has been a patient in the state-run program for 11 years. He said the biggest problem is lack of flexibility:[7]

> *I go two times a week to get my methadone at the center. That isn't convenient. It gets in the way of my life. For example, I can't even travel to Greece or even easily take a trip within the country. Once my wife and I were staying along the Black Sea for a few months, and I had to come back to Sofia every week just to get methadone. That's a long trip and it's expensive.*
>
> *At the time there was no methadone program outside of Sofia. Now there's one in Varna, on the coast. But it probably wouldn't have made any difference if it had existed when I was staying on the coast. Most projects give priority to local residents, and they usually have only a limited number of spots.*

6 Interviewed August 7, 2007 in Sofia.

7 Interviewed August 7, 2007 in Sofia.

IHF staff echo such concerns. One outreach worker, Rumen Donski, has been on methadone through the state-run program for seven years. He said the lack of sufficient capacity and expertise was a major problem with significant consequences for patients. He noted the following:[8]

> *Some of the doctors, especially the new ones, don't have much information or awareness about addiction. As a result they often aren't as flexible as they might be, such as giving extra doses to longstanding clients so they don't have to come in so often. Another big problem is understaffing at all levels of the program. This makes it difficult for them to follow through with clients or even to lose track of them. For example, there was a client who died, and 10 days later the project tried to contact him to tell him that he would be terminated from the project if he didn't show up soon.*

8 Interviewed August 9, 2007 in Sofia.

3.3 IHF's first step: Outreach within Roma communities

IHF staff acknowledge that one reason for the disproportionately large share of Roma clients (when compared to the overall population) is that Romani individuals tend to visit the project more regularly. Staff attribute that fact to ongoing efforts to make access easier for Roma clients. The first step was to do outreach directly within the two Roma communities in Sofia, an effort that began in 1999. The second was to establish a drop-in center in one of them, Fakulteta, in 2006. IHF staff believe both of these steps have been critical to the ongoing process of building trust within the community as a whole, not just among clients. From the beginning it was clear that longstanding isolation and distrust of outsiders meant that extra attention and resources would need to be focused on efforts to reach Roma in need.

IHF faced - and still faces - some major obstacles even as it has placed significant priority on working with and for Roma IDUs. First of all, IHF is not a Roma NGO. With few exceptions over the years (see Section 4), its staff have always been ethnic Bulgarian. The organization initially was seen as unwelcome outsiders, an impression not improved by the nature of its activities. As with most people unfamiliar with harm reduction, most Roma assumed it would increase drug use. That was not a popular assumption in a community where such

behavior was reaching epidemic levels among the young. It is not unheard of for drug dealers to be beaten severely by other community members, for example, in a local version of vigilante justice.

How did IHF go about overcoming this and other barriers? Two words cannot be underestimated: patience and persistence. The organization did not rush in. To some extent, it waited to be invited - and then accepted that uptake would build slowly at first as clients overcame their suspicions.

Before doing anything else, Elena Yankova, IHF's executive director, and other staff members visited key Roma leaders in both Tatarli and Fakulteta. That initial step was taken in recognition of and respect for the hierarchical nature of most Roma communities. Elena and her colleagues explained all aspects of the project, focusing specifically on its emphasis on protecting the health of Roma individuals who injected drugs. They discussed the problems and needs of existing Roma clients (confidentially, of course.) And they presented examples of positive results elsewhere from such projects, stressing meanwhile that they did not condone or encourage drug use. After some consideration, the leaders were receptive to the project. They promised to spread the word throughout the community and be responsible for removing any obstacles that might arise as IHF conducted outreach.

The actual initiation of outreach in Tatarli, in May 1999, was eased with the help of existing Roma

clients who lived in the neighborhood. They introduced their drug-using friends to project staff and suggested that they become clients. However, many of those potential new clients were suspicious of IHF's intentions at first. Among other things, they could not understand why an organization was willing and able to visit their community every day and provide services free of charge (and anonymously). In their experience, few if any outside organizations had ever offered such direct help - and done so with open, friendly, nonjudgmental attitudes. The suspicions were so extensive and widespread early on that sometimes just one or two clients would visit an outreach site during each individual stop.

Persistence paid off, though. IHF's outreach workers continued to show up consistently at the same locations. They arrived at scheduled times and stayed even if no one dropped by to visit the outreach van. This offered proof to local clients that the organization was serious about its commitment and was prepared to accept and work within community structures. Within a few months the number of clients began to increase. The harm reduction services provided by outreach workers in Roma communities are the same as those offered elsewhere. (See Section 2.3.2 for a list of specific services.

For the most part, there has been little open hostility or opposition to IHF's work inside the Roma communities. According to Elena, the one signifi-

cant problem in this regard occurred in 2000, when a group of Roma surrounded outreach workers and their van in Fakulteta. Based on the belief that the project was encouraging drug use, members off the small crowd began yelling at the workers and then throwing stones. The workers quickly drove off. Shortly thereafter, Reni Dyankova - an experienced outreach worker - visited local leaders again for extensive consultations. She said that she understood local residents' ire toward drug dealers and frustration about drug use. She stressed, however, that IHF seeks to work only with individual users, not dealers. The users, Reni noted, are the ones most at risk from potential adverse health consequences, and they often have nowhere else to turn. There have been no similar problems since that consultation took place.

IHF outreach workers have also sought to be as creative as possible when determining when, where, and how to provide services in Roma communities. For example, a few years ago they noticed that several clients earned money by cleaning windows of cars stopped at a railroad crossing in Fakulteta. They therefore decided to provide outreach at that site. The location was changed only after police harassment and changing habits caused the number of actual and potential clients there to dwindle significantly.


ХИВ
СПИН
ВЗЕМИ И СЕ ОПРАВИ
НЕ ПОЛЗВАЙ ЧУЖДИ ИНСТРУМЕНТИ!
ВИНАГИ ПОЛЗВАЙ ПРЕЗЕРВАТИВИ
ПРИ СЕКСУАЛНИТЕ СИ КОНТАКТИ!
ИЗСЛЕДВАЙ СЕ!
ТАКА ЩЕ СЕ ПРЕДПАЗИШ ОТ ХИВ/СПИН

3.4 Establishing the Roma drop-in center

The establishment of a drop-in center in Fakulteta, in 2006, was IHF's most recent effort to increase Roma clients' access to its services. CNF provided an initial grant to create the center, with OSI stepping in to cover its operation under the one-year grant provided in 2006.

Organization staff consulted with local clients in advance, asking them about potentially convenient locations, preferred hours of operation, and types of assistance they desired. They subsequently sought to accommodate the feedback as fully as possible.

The center consists of two brightly painted rooms on the second floor of a municipality-owned building that also contains offices for a Roma NGO, Aver, and a few dentists. Two IHF outreach workers are available at the center for four hours (12 noon to 4 p.m.), Monday through Friday. They offer clients nearly the exact same services provided during outreach - needles, syringes, condoms, informational booklets, etc. One exception is that there is a limit of 10 syringes and 20 needles for each individual visit, unless the client brings in a larger number to exchange. The limit was imposed for two reasons: (1) to stimulate more frequent visits to the center, and (2) because of previous experience indicating that some Roma clients were selling syringes and needles they obtained from IHF.

Many of the health information materials available at the center, and also now through outreach, were created and designed specifically for Roma. This means, for example, that the language is a bit simpler (in response to lower-than-average education levels) and the human characters in the drawings appear to be Roma.

IHF staff acknowledges some problems and limitations over the first year of the drop-in center's operation. In particular, they concede that usage is not as high as they had anticipated or hoped. As of August 2007, according to staff, the center was visited by four or five clients a day at most. Most of them are interested solely in picking up needed supplies and stay only a few minutes. Their reluctance to linger has not come as a surprise to most IHF workers, who have seen similar patterns during their outreach work among Roma. As noted previously, what the drop-in center would and would not offer, at least initially, was determined through consideration of existing trends. As noted by one long-time outreach worker, Yuliya Georgieva, "There's no reason to have a big community center on site."

The lower-than-expected uptake has not diminished IHF's enthusiasm or support for the Fakulteta drop-in center, however. Staff continue to believe it is a vital part of their overall harm reduction strategy among Roma. If the organization's initial experience with outreach years earlier is any guide, then clients' usage of the center will increase over time as they become more comfortable with the idea. Once again, IHF is being patient and persistent.

BOX 7

GLOBAL FUND'S IMPACT ON IHF, HARM REDUCTION, AND ROMA

Until relatively recently IHF was one of the few consistent providers of harm reduction services in Bulgaria. The number of projects increased after the country received an HIV/AIDS grant from the Global Fund to Fight AIDS, Tuberculosis and Malaria (GFATM). More than US$15.7 million in GFATM funds are due to be disbursed by the Ministry of Health (MoH), the grant's national-level manager (Principal Recipient), over the five-year period ending in December 2008.

A significant chunk of those funds has been allocated to support harm reduction among specific high-risk groups, including IDUs and sex workers. With the support of the GFATM, a total of 10 harm reduction projects for drug users were operating in Bulgaria by August 2007. The grant agreement specifies that all be operated by NGOs,

preferably those that are local and based within at-risk communities. IHF has provided training to all nine other project implementers in areas including harm reduction design and delivery, HIV prevention, and human rights issues related to drug users.

It is important to note that the analysis undertaken during the preparation of the GFATM program concluded that the Roma community was particularly vulnerable to HIV because of the "rapidly developing desocialization of this community, the social isolation, low economical culture and high unemployment, lack of social skills," and presence of "high--risk behaviors such as prostitution, drug use, criminal activities, and mobility."[1] This led to one component of the GFATM project emphasizing the need to "decrease of risky sexual behavior and drug injecting practices among Roma community".

IHF's Roma project does not receive direct GFATM funding. The organization has, however, signed regular agreements (renewed annually) to receive GFATM-supported supplies and materials from the MoH for its overall harm reduction efforts. The majority of the syringes and needles it dispenses are provided by the MoH, for example.

Challenges of GFATM project

IHF's arrangement with the GFATM (through the MoH) undoubtedly lowers the organization's costs. Yet IHF staff expressed concern with elements of the GFATM project, as noted below:

1 This text is from the MoH's "National Program for Prevention and Control of AIDS and STDs 2001-2007". Available online (in Bulgarian only) at www.mh.government.bg/program_and_strategies.php (accessed August 28, 2007).

Excessive government control.
One complaint by IHF personnel centers on insufficient participation of the civil society in the project coordination. IHF's executive director, Elena Yankova, is a member of the Country Coordination Mechanism (CCM), the GFATM-mandated national-level body that is charged with advising and supporting the grant administration. She said the NGOs included in the CCM could hardly be effective mostly because their influence is weak. "People are afraid to speak up [and challenge the government] because they may then lose money for own projects," she said.

Substandard quality of supplies.
Perhaps more importantly for IHF clients, at least in the direct sense, are issues regarding the poor quality of supplies provided by the MoH. IHF's drug-using clients regularly complain about the syringes and needles provided by Etropal, the Bulgarian company that won the national GFATM tender. Clients reportedly have said, for example, that Etropal's needles are not sharp enough and that the syringes do not have an appropriate "vacuum" effect. Such complaints cannot be dismissed because they may prompt IDUs to forego the use of the supplies, thereby raising health risks. Moreover, IHF risks losing its clients' hard-won respect. As Yankova noted, "If we give out poor-quality supplies or those that clients don't like, we lose their trust."

IFH staff reported that they have lodged numerous complaints with the MoH, but have been told that there is nothing the ministry can do since all documentation on file indicates that the company has met all of the tender requirements.

Procurement delays.
Staff from both IHF and another harm reduction project, in Kyustendil, said the MoH regular fails to deliver vital supplies and materials in a timely basis. This is not such a huge problem with IHF, which is relatively well-funded and thus can find ways to cover procurement shortfalls. Smaller organizations have a much more difficult time keeping their projects operating. Their IDU clients, Roma or not, are at a much greater risk of having their vital supplies suspended when local organizations face delays in receiving promised harm reduction materials. The coordinator of the Kyustendil project said he on occasion had resorted to driving his own car to the MoH's supply depot in Sofia to pick up materials that the agency was contracted to provide directly to his office.[2]

2 Interview with Stoyan Ivanov in Kyustendil on August 10, 2007.

4. NOTABLE CHALLENGES AND OBSTACLES

Since it began in 1999, IHF's Roma initiative has encountered numerous challenges and obstacles over the years. Some of those challenges, and how the organization has responded to them, are discussed in Section 3. This section lists other notable challenges: some are specific to the organization, others refer to Roma communities, and still others are related to harm reduction in Bulgaria in general.

Finding and retaining Roma staff.
IHF currently has no Roma employees. Organization staff acknowledge that this fact impedes its effectiveness to some extent when working in and with members of such an insular community. It is not for lack of trying. IHF has long made it a priority to identify, hire, and train Roma individuals, especially as outreach workers. Yet few Roma apply for such jobs, even when urged to do so. Those who do apply often have limited education backgrounds. Moreover, experience to date points to constraints related to inadequate work discipline and, for women in particular, difficult-to-resist community expectations.

At one point, for example, the organization had two Roma outreach workers, both of whom were also clients (and thus active IDUs). Neither lasted even a year. One left when she became pregnant

and did not feel it would be appropriate to work when she had primary responsibility for caring for her family. The other worker, meanwhile, was fired after repeated violations of several internal rules and policies governing employment. In hindsight, some IHF staff believe that they perhaps acted too hastily in their zeal to bring on board Roma employees. Neither of the two individuals was adequately prepared for the work, staff concede, because they had limited education and work experience in general.

However, IHF and other organizations that work with and for Roma are optimistic that existing employment-related challenges will be overcome. Radosveta Stamenkova, the executive director of the Bulgarian Family Planning and Sexual Health Association, said that she has seen a small but growing number of Roma, even women, becoming more directly involved in helping improve the health and well-being of fellow community members.[6] She added that her organization is trying to encourage that trend by making compromises when working with Roma. She cited one example of when she waived an internal policy that stipulated that only individuals being trained could attend relevant workshops and classes. Waiving this requirement made it possible for some Roma women to attend - because they could be accompanied by at least one family member and thus be seen to be protecting their virtue and honor.

6 Interviewed in Sofia on August 8, 2007.

Patriarchal nature of Roma society.
Roma communities are largely dominated by one or more informal leaders, all of them men. Outsiders are usually greeted with hostility or opposition unless they are supported by these influential individuals. As noted in Section 3.3, IHF therefore needed to focus at both the top level (Roma leaders) and among a far lower level (IDUs, most of whom are not only young but marginalized even within their community).

The project's success depends on keeping both relationships solid. That requires constant attention because changes regularly occur in both categories. In August 2007, in fact, some IHF staff did express concern that their relations with newer Roma leaders were not as strong or extensive as with their predecessors. One short-term IHF goal is to place renewed emphasis on identifying and building better relationships with the most important community leaders.

Lack of substitution treatment.
IHF staff report that many Roma clients are interested in enrolling in substitution treatment programs. Yet as noted in Box 6, space is limited in the public-sector program, which is the only realistic option for most Roma because it is offered free of charge. Such a situation represents a major obstacle to comprehensive harm reduction delivery in general, not just among Roma. The health and well-being of many IDUs would be greatly enhanced by improved availability and access to substitution treatment.

Roma NGOs' lack of interest in harm reduction. A number of viable local NGOs are run by and/or staffed primarily by Roma. Not one of them is involved in harm reduction in Sofia, even though the scourge of injecting drug use has been widely recognized in Roma communities for several years. IHF staff are of the opinion that inherent cultural conservatism is the main reason for Roma NGOs' disinclination to provide such services for drug users. Although unsuccessful so far, an ongoing IHF objective is to establish a partnership with at least one Roma NGO. That development would likely increase the project's reach and, equally importantly, boost community support for harm reduction and other services for drug users.

Funding shortfalls. IHF receives most of its funding from international civil society organizations such as OSI. However, Bulgaria's accession to the European Union (in January 2007) has led most external donors to no longer consider the country to be a priority recipient. They are therefore phasing out or at least reducing their activities in Bulgaria.

According to IHF's executive director, Elena Yankova, donors' withdrawals are premature because Bulgaria "remains a poor country" and the state has not stepped in as most donors expect. Nor, she said, have there been any indications that it will in the near future. In her opinion, many government officials continue to distrust the civil soci-

ety sector even as it has steadily grown since the fall of the authoritarian regime in the early 1990s.

Elena noted, for example, that as of August 2007 IHF had received no dedicated funds for its Roma initiative following the end of OSI's one-year grant, in September. She said the organization was seeking assistance from the municipality, albeit with little success to date. Elena added, however, that there was no immediate risk to the project in general. The organization had decided to shift funds from other sources, such as the GFATM, to keep it running. This option is not ideal in the long-term, of course.

Long-term sustainability. Another looming problem centers on the sustainability of many harm reduction projects after the GFATM ends in 2009. Local NGOs operating them today may not be able or interested in finding funds to continue the projects. Elena Yankova estimated that the number of harm reduction projects in Bulgaria could shrink from ten to as few as five. That would represent a huge blow to the health of hundreds if not thousands of needy IDUs, including many Roma.

BOX 8

REACHING ROMA IDUS IN KYUSTENDIL

IHF's harm reduction project is one of 10 in Bulgaria that receive financial and material support from the GFATM, through the Ministry of Health (MoH), to operate among IDUs. Some of the others also provide services and assistance within and to Roma communities in their cities. One such project operates in Kyustendil, a small city of 30,000 people about 90 kilometers (60 miles) outside Sofia, near the Macedonian border. The city has a high share of Roma, nearly one-third of all residents.

Operated by the local office of the Bulgarian Red Cross, the Kyustendil harm reduction project is much smaller than IHF's in Sofia. Yet it shares many of the same priorities and challenges and thus offers an interesting example of how harm reduction among IDUs, particularly Roma, can be provided in a somewhat different environment.

According to Stoyan Ivanov, the project's coordinator since its inception, Kyustendil had long been known as a city with relatively high rates of drug use. However, no harm reduction services

were available to IDUs when the MoH selected the city as a site for one of its GFATM-supported projects - and then selected the Bulgarian Red Cross to implement it. At the time, staff at the local organization had no experience or expertise in harm reduction. IHF provided intensive initial training to Ivanov and other project personnel and has continued to offer follow-up support on an as-needed basis.

The project eventually began operation in 2004. Ivanov said the first challenge was reaching IDUs and building a client base.[1] He said he focused first on "cold" contacts, such as by visiting parks and other places where drug users gathered, observing their behavior and habits, and then striking up conversations with them. This went on for months as he sought to explain his objectives and gain their trust. Eventually he was successful in this effort and began to provide services to an ever-growing number of individuals, many of whom subsequently heard about the initiative through word of mouth.

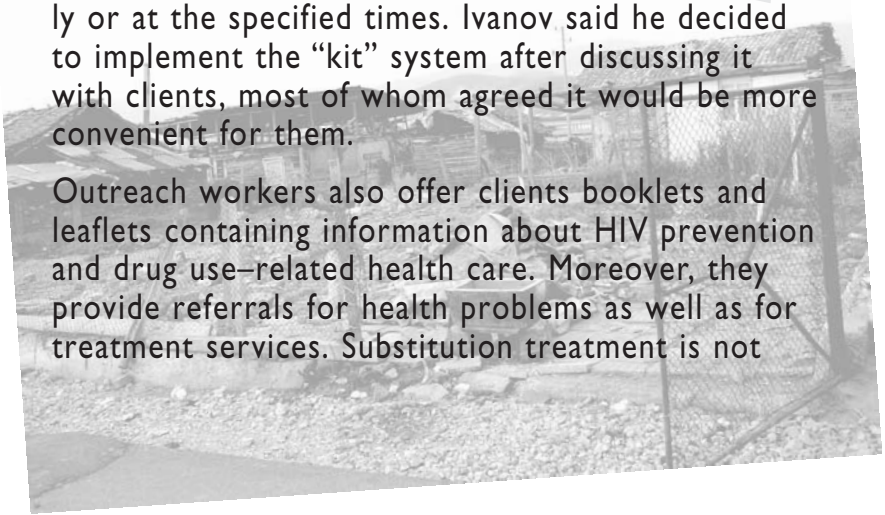
Service delivery in August 2007

As of August 2007, the project had more than 200 individual clients, about 90 percent of them male, according to Ivanov. Some 70 percent of all clients are Roma who live in the city's "Iztok" neighborhood. Nearly all clients inject heroin. At 5 BGN (US$3.50) a dose, heroin can be bought in Kyustendil for less than half the average price in Sofia.

1 Unless specified otherwise, the information and observations in this section were obtained during an interview with Stoyan Ivanov in Kyustendil on August 10, 2007.

The project operates almost exclusively on an outreach basis, at least partly because it has limited space to provide on-site assistance to clients in its one-room office. Five days a week (Monday through Friday), the project's three outreach workers visit Iztok during the late morning, usually stopping for an hour or so at each of two designated places in the neighborhood. They visit again in the evening three days a week. In addition, they visit non-Roma neighborhoods five times a week, usually in the afternoon. Ivanov said the project generally reaches about 20 to 25 clients every day in total.

Safer-injection supplies are distributed to clients in a different manner than by IHF in Sofia. Individuals in Kyustendil are provided with pre-made "kits", each of which contains 6 syringes, 12 to 18 needles (depending on the kind), 6 alcohol wipes, 6 caps, and 1 packet of lemon acid. In general, each person can receive one kit each day. Exceptions are made for clients who have agreed to bring kits and other supplies to needy individuals in the community who are unable or unwilling to visit the outreach sites directly or at the specified times. Ivanov said he decided to implement the "kit" system after discussing it with clients, most of whom agreed it would be more convenient for them.



Outreach workers also offer clients booklets and leaflets containing information about HIV prevention and drug use–related health care. Moreover, they provide referrals for health problems as well as for treatment services. Substitution treatment is not

available in Kyustendil; clients who interested in entering a program are referred to Sofia, although capacity constraints in the capital limit their ability to participate even if they wish to.

The Kyustendil project does not have nurses or other specially trained healthcare personnel on staff. That is the main reason it cannot directly provide blood testing services for HIV, hepatitis C, and other conditions for which IDUs are at a risk. Project staff instead organize testing campaigns three or four times a year and announce them in advance among clients. The day-long campaigns are organized in conjunction with doctors and other staff at a healthcare clinic in the middle of the Roma neighborhood. Testing is provided on an anonymous basis at that clinic, built and operated by Adra, an international NGO.

The campaigns are organized to be as convenient as possible for Roma clients. Ivanov acknowledged, however, that the majority of them have not been tested for HIV and exhibit little interest in doing so. He believes the main reason is not fear or ignorance—instead, it is that most Roma clients consider it a hassle to be tested. One of the project's ongoing priorities is to encourage them to take the time to be tested at least once, and then on an ongoing basis if possible. (Ivanov noted in comparison that nearly all of his project's Bulgarian clients had been tested for HIV.)

Goals and obstacles

Ivanov said he would like to increase the number and scope of services the project currently offers. His two main priorities would be to (1) hire a nurse, who could take blood tests and provide related counseling services on a regular basis, and (2) create a drop-in center so that clients could get safer-injection kits and other resources whenever they needed them.

Both of these steps would take additional funds, however, and the project's annual budget has not increased substantially. The project currently has only one source of funding: the GFATM. That reliance raises additional concerns about project sustainability after the GFATM project ends in 2009, especially since it appears unlikely that the Bulgarian Red Cross would cover costs on its own. Ivanov said that he would like to continue the project beyond that date. Yet, he said, as of August 2007 he had not sought to identify additional funding sources because he has been so focused on getting the project up and running.

According to Ivanov, that effort - creating a project from nothing and working to operate it smoothly - has been hampered somewhat by one key challenge: high staff turnover among outreach workers. He said it was difficult to attract qualified, interested, and motivated individuals in a city such as Kyustendil, from which many young people are interested in moving when they are able. As in Sofia, it is even more difficult to find, train, and retain Roma outreach workers.

OUTREACH WORKER PROFILE: ALEXANDER RANGELOV

In August 2007, a total of three outreach workers were on staff at the Bulgarian Red Cross's Roma harm reduction project in Kyustendil. One of them, 21-year-old Alexander, was Roma. The following were among his comments and observations during an interview in August 2007.

"I've been an outreach worker here for two years now. I joined not long after I graduated from secondary school. I had no specific training before in this kind of work, although I was the head of the health club in my school.

I was interested in applying for this job because I knew there was a serious drug problem in my community. I was somewhat sheltered from it then because I didn't know anyone directly who used drugs. That has changed though, and not just because of my work. I've seen several of my classmates start using drugs since leaving school, for example.

This worries me because many young people don't know much about how and why drug use can be so dangerous. They also don't know anything about HIV or STDs. Their parents often don't know about these things either...and if they do, they are uncomfortable talking about them with their kids.

From what I've seen, I think the situation can only be improved through better prevention in schools. Specialists and experts could help create prevention

REACHING ROMA IDUS

KYUSTENDIL

BOX 8

programs that are culturally specific for Roma. These programs must use language and symbols that are understandable across the community, yet at the same time be very clear about issues like drug use and sex.

We are a conservative community in many ways, so some people think that such openness promotes drug use. I'd say that the majority don't feel that way, however. They understand that the only way to really help change things is to have open and honest discussion about these issues. I really believe that educational campaigns and prevention programs can make a difference. If people know even a little about the risks, they are less likely to ever pick up a syringe.

I know it would be a great thing to get more Roma involved in this project, but at the same time I understand why it's been difficult for the director to find anyone else. I think the main problem is lack of education. It's true that many people in the community do not consider education to be very important. A lot of kids leave school after their eighth year, often because their parents pull them out. I was lucky because my parents believe education is a major priority... they motivated me to stay in school."

5. CONCLUSIONS AND LESSONS LEARNED

Although necessary to recognize and respond to, the obstacles IHF faces in delivering harm reduction services to Roma are far outweighed by the initiative's positive outcomes. The most important: Since January 2005 alone, more than 1,300 Roma IDUs have visited IHF's outreach sites and drop-in centers. Most of them have had no other reliable and consistent source for safer-injection materials, pragmatic information about protecting their health, or nonjudgmental and experienced advice delivered anonymously and confidentially.

Every single syringe or condom handed out by the project diminishes the risk of the recipient being infected with HIV or hepatitis, both potentially fatal illnesses. That fact alone has enormous repercussions not only for each individual client, but also for his or her drug-use and sexual partners, family members, and for public health in general. The existence of harm reduction projects such as IHF's is one key reason that HIV prevalence in Bulgaria has remained relatively low. According to the Joint United Nations Programme on HIV/AIDS (UNAIDS), fewer than 1,000 Bulgarians were living with HIV at the end of 2006, which translates into adult prevalence lower than 0.1 percent.[7]

7 As per UNAIDS website: www.unaids.org/en/Regions_Countries/Countries/bulgaria.asp (accessed August 28, 2007).

IDUs and Roma remain uniquely vulnerable, however. Unless undertaken safely and with clean materials, injecting drug use poses the greatest risk of any behavior for contracting HIV and hepatitis C. Vulnerability among Roma results from a combination of poverty, stigma, discrimination, and abysmally low access to appropriate health care. Roma IDUs face double the risk because they fall within both categories. That reason alone makes an iron-clad case for introducing, sustaining, and solidifying harm reduction initiatives targeted specifically at marginalized communities such as Roma - no matter in which country they live.

IHF's Roma project remains a work in progress. Yet eight years of operation have yielded numerous important observations. The first one is that such targeted projects can be effective and useful, no matter how daunting the prospect. A few other lessons learned are summarized briefly below.

Anonymity and confidentiality are essential. Few IDUs, Roma or not, are comfortable utilizing services in which they must provide their names or other identifying information. It is relatively easy to implement coding systems that safeguard clients' right to confidentiality yet also allow project staff to collect necessary statistics.

Patience is essential. Gaining the trust of vulnerable populations is a time-consuming process. Often it is necessary to take baby steps, especially

when launching a harm reduction project among Roma and other insular or stigmatized communities. Big steps can be stressful to community members who are inherently suspicious of attention from the outside. A rushed project will likely fail. Before proceeding, project developers would be wise to take the time to understand how a community operates and what its members respond to.

An approach that seems to work for one group will not always work for another. Roma are economically, politically, culturally, and socially different from the general population. So are all other distinct groups, hard to reach or not. Existing or potential clients are best placed to identify useful strategies and plans for effective harm reduction and other health promotion efforts.

BOX 9 ROMA HEALTH MEDIATORS

The funding of "Roma health mediators" has been one of the more promising recent initiatives designed to improve the Roma community's access to comprehensive health care in Bulgaria. It is also unusual in that the government is directly involved and to date appears committed to ensuring its success.

Launched in 2004, the initiative focuses on training Roma individuals to serve as links or "bridges" between their own communities and local healthcare systems, which are almost unanimously staffed by non-Roma. The goal is to identify and overcome the numerous impediments - primarily cultural, but also economic and educational - that limit the inclination or ability of community members to seek out and obtain health care, particularly preventive care.

Mediators are trained to achieve these goals by focusing on both sides of the equation. On the one hand, they seek to raise awareness within

Roma communities as to how, when, where, and why to place greater priority on health care. At the same time, they focus on improving providers' understanding of, sensitivity to, and response to cultural differences between themselves and Roma. According to Vasilka, a Roma health mediator in Kyustendil, the training emphasizes five areas:[1]

- prevention among children, with the goal of increasing access to (and reducing suspicion within the community of) vaccinations;
- improving communications skills among both caregivers and patients, with the goal of increasing frank and open discussions about health issues;
- increasing Roma individuals' ability to negotiate institutions and systems, including advising them of how systems work and where to go for care;
- sexual and reproductive health issues, especially regarding preventive care; and
- issues regarding drug use, including how and when providers might refer patients to organizations providing harm reduction services.

The initiative is funded by the Ministry of Health, which transfers money to municipalities to hire mediators. According to Radosveta Stamenkova, the executive director of the Bulgarian Family Planning and Sexual Health Association, some 65 Roma health mediators had been trained as of August 2007.[2] Stamenkova, whose organization has been closely involved with the project since

1 Vasilka mentioned these focus areas during an interview in Kyustendil on August 10, 2007.

2 Interviewed in Sofia on August 8, 2007.

ROMA HEALTH MEDIATORS

its inception, said some key measures of success at this early stage have been linked to mediators encouraging Roma mothers to seek out care and then escorting them to providers. She said one result has been a boost in immunization levels among Roma infants and children.

Stamenkova added that she believed the initiative would be improved if greater attention should be paid to increasing demand for mediators' services. In her opinion, that objective could be achieved by encouraging mediators to do more extensive direct outreach within Roma communities.

There are also signs, she noted, that the initiative has been somewhat slow to get moving smoothly and effectively. In some cases evidence of this shortcoming can be found in personnel limitations. For example, there are three funded posts for Roma health mediators in the city of Kyustendil, which has a disproportionately large Roma population. Yet only one of them was filled at the time research for this report was conducted in August 2007.[3] Observers anticipate that the extent and likelihood of such gaps will be reduced as more mediators are trained and their roles more fully integrated in healthcare provision in general.

3 Interview with Vasilka, a Roma health mediator in Kyustendil (August 10, 2007).

BOX 10

CLIENT PROFILE: 'T'

"T.", 47, is an IHF client from Fakulteta, one of Sofia's Roma communities. The following were among his comments and observations during an interview in August 2007.

"I moved to Sofia from the country with my family when I was a teenager. I've been living here in Fakulteta since then.

I started using drugs about 14 years ago. I've reused needles in the past, but I've never shared with other people. Now I inject heroin about five times a day. It's expensive for me... I'd say I spend about 36 BGN [US$24] on heroin.

I've been a client of the project for about six or seven years. I usually see them two or three times a week - sometimes during outreach and sometimes at the drop-in center. I take just about everything they can give me, including clean needles and syringes and condoms. I had my blood tested once at the center too.

For me, the project is particularly good because I feel like a man when I come here [to receive services]. By that I mean that they treat me like a normal human being. They respect me. That helps

CLIENT PROFILE: 'T'

me get by because sometimes I don't feel much respect in my neighborhood. A lot of people in the community know I use drugs; it's really not much of a secret. People have come up to me and said things like, 'You have a good family and you're almost 50 years old. Why do you keep using drugs? What's wrong with you?" My children sometimes will ignore me and refuse to speak to me when they're with their friends. They are ashamed of me, and that makes me ashamed.

I would like to get some treatment some day, but I've heard from friends that the program isn't good. They tell me the doctors aren't good people and that they don't speak to patients like normal people. Like I said, it's important for me to feel like a normal man."

SISTENCE PAYS PERSISTENCE PAYS PERSISTENCE PAYS PERSISTENCE PA

Initiative for Health Foundation (IHF)
Sofia, Bulgaria

With the support of:

OPEN SOCIETY INSTITUTE
Public Health Program

SISTENCE PAYS PERSISTENCE PAYS PERSISTENCE PAYS PERSISTENCE PA