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NONGOVERNMENTAL ORGANIZATIONS AS AGENTS OF HIV-PREVENTION SERVICE PROVISION IN UKRAINE

Nongovernmental organizations constitute the only significant source of HIV prevention services in Ukraine. Many of these organizations were founded by and continue to be staffed by members of the populations most at-risk for HIV infection, particularly injection drug users. As these agencies develop and mature since their founding in the 1990s and early 2000s, their founders, directors, and staff increasingly occupy a liminal space in which they struggle to define themselves as HIV professionals with expertise in both the risks their clients face and their everyday needs, and the globalized world of HIV prevention financing and program development. This paper explores the ways in which HIV prevention service providers in Ukraine work to define this liminal space as one that enables them to traverse two seemingly disconnected worlds – one of international donors and national monitors and another of marginalized and vulnerable substance users. They formulate themselves not as elites but as experts through trainings, certifications, and networking with other similarly liminal service providers through national and international conferences, and continued expansion and refinement of services for their clients. At the same time, they remain cut off from the «inside knowledge» and decision-making power of the «true» elite, represented by AIDS clinic physicians, pharmacists, and other medical providers who control access to substitution therapy, antiretroviral medications, and other critical services and resources.

Key words: NGO, HIV prevention, HIV professionals, expertise, experts, elites.

В статье анализируется деятельность неправительственных организаций (НПО), которые являются одним из важнейших ресурсов услуг по профилактике ВИЧ в Украине. Подчеркивается, что в последнее время НПО в странах Восточной Европы часто классифицируются как принадлежащие к классу «элит», которые действуют как «агенты западных метрополий в своих странах» и характеризуются как высокооплачиваемые профессионалы с космополитическими взглядами, моделями потребления и образа жизни. Такой предполагаемый «элитарный» характер сектора НПО приводит к предположениям, что они не могут адекватно удовлетворять потребности самых уязвимых групп населения. Акцентируется внимание, что в Украине многие из неправительственных организаций, занимающиеся ВИЧ-проблемами, были созданы и продолжают включать сотрудников из числа групп населения, наиболее подверженных риску инфицирования ВИЧ, в частности потребителей инъекционных наркотиков. Показано, что учредители, директора и сотрудники этих организаций занимают лиминальное пространство, в котором они борются за то, чтобы определить себя как ВИЧ-профессионалов, имеющих экспертный опыт как в области рисков, с которыми сталкиваются их клиенты в повседневной жизни, так и в глобализованном мире финансирования профилактики ВИЧ-инфекции и разработки программ вмешательств. Исследуются способы, которые используют в своей работе поставщики услуг по профилактике ВИЧ в Украине для того, чтобы определить это лиминальное пространство как такое, что позволяет им пересечь два, казалось бы, несвязанных мира – мир международных доноров и национальных мониторингов и мир маргинальных и уязвимых потребителей психоактивных веществ. На основе результатов полевого исследования обосновывается идея о том, что сотрудники НПО определяют себя не в качестве «элит», а как экспертов, осуществляющих тренинги, сертификации и взаимодействие с другими такими же поставщиками услуг через национальные и международные конференции и дальнейшее расширение и уточнение услуг для своих клиентов. В то же время, они остаются «отрезанными» от «внутренней информации» и полно-

мочий по прийняттю рішень «істинної елітой» в лице клінічних лікарів по боротьбі со СПИДом, фармацевтів і других медичних працівників, які контролюють доступ до замісної терапії, антиретровірусним препаратам і другим важливим послугам і ресурсам. Аналізується, в якій ступені розгляд НПО в якості еліт і в отрыве от локального контекста являється методологічним артефактом, свого роду продуктом співпраці НПО і міжнародних дослідників, а не відображенням реальної, дуже складної роботи, яку продовжують здійснювати НПО, виконуючи роль «моста» між усіма зацікавленими сторонами в боротьбі з ВІЧ.

Ключевые слова: НПО, ВІЧ-профілактика, ВІЧ-професіонали, експертиза, експерти, еліта.

У статті аналізується діяльність неурядових організацій (НУО), які є одним з найважливіших ресурсів послуг з профілактики ВІЛ в Україні. Підкреслюється, що останнім часом НУО в країнах Східної Європи часто класифікуються як такі, що належать до класу «еліт», що діють як «агенти західних метрополій у своїх країнах» та характеризуються як високооплачувані професіонали з космополітичними поглядами, моделями споживання і способу життя. Такий передбачуваний «елітарний» характер сектору НУО призвів до припущень, що вони не можуть адекватно задовольняти потреби найуразливіших груп населення. Акцентується увага на тому, що багато неурядових організацій, що займаються ВІЛ-проблемами в Україні, були створені і продовжують включати співробітників з числа груп населення, найбільш схильних до ризику інфікування ВІЛ, зокрема споживачів ін'єкційних наркотиків. Показано, що засновники, директори та співробітники цих організацій, займають лімінальний простір, в якому вони борються за те, щоб визначити себе як ВІЛ-професіоналів, які мають експертний досвід як в області ризиків, з якими стикаються їхні клієнти у повсякденному житті, так і в глобалізованому світі фінансування профілактики ВІЛ-інфекції та розробки програм втручання. Досліджуються способи, які використовують у своїй роботі постачальники послуг з профілактики ВІЛ в Україні для того, щоб визначити цей лімінальний простір як такий, що дозволяє їм перетинати два, здавалося б, незв'язаних світи – світ міжнародних донорів і національних моніторингових та світ маргінальних і вразливих споживачів психоактивних речовин. На основі результатів польового дослідження обґрунтовується ідея про те, що співробітники НУО визначають себе не в якості «еліт», а як експертів, які здійснюють тренінги, сертифікації та взаємодії з іншими такими ж постачальниками послуг через національні та міжнародні конференції та подальше розширення і уточнення послуг для своїх клієнтів. У той же час, вони залишаються «відрізнаними» від «внутрішньої інформації» та повноважень щодо прийняття рішень «істинною елітою» в особі клінічних лікарів з боротьби зі СНІДом, фармацевтів та інших медичних працівників, які контролюють доступ до замісної терапії, антиретровірусних препаратів та інших важливих послуг і ресурсів. Аналізується, якою мірою розгляд НУО в якості еліт і у відриві від локального контексту є методологічним артефактом, свого роду продуктом співпраці НУО та міжнародних дослідників, а не відображенням реальної, дуже складної роботи, яку продовжують здійснювати НУО, виконуючи роль «мосту» між усіма зацікавленими сторонами в боротьбі з ВІЛ.

Ключові слова: НУО, ВІЛ-профілактика, ВІЛ-професіонали, експертиза, експерти, еліта.

Introduction. This research¹ draws on interviews and field notes collected as part of a larger study² on the development of effective HIV prevention programs for NGOs that work people who inject drugs in Ukraine. Both HIV and substance use are significant public health problems in Ukraine. Annual HIV cases have doubled each year since 2000. In 2011, 38.4% of new infections

occurred among people who inject drugs [3; 4]. The rapid increase in HIV and substance use in the region has been attributed to economic decline, decreased police controls and increased drug availability, stigma and lack of support of substance users and people living with HIV/AIDS, and lack of a robust public health response to the epidemic. The inadequate government response to HIV is compounded by the continued criminalization of drug users, police interference in the work of NGOs, and mistreatment of people who have HIV and people who use drugs by medical and other professionals. In fact, the Ukrainian government's response to the epidemic has been so poor and mired in fiscal and other mismanagement that major international donors, including the Global Fund, no longer give money to the government for

¹ Support for this project comes from the United States' National Institutes of Drug Abuse (R01DA033644).

² For more information about the research see: «Collaborating with Ukrainian NGOs: through Researching and Training to Develop Effective, Evidence-Based HIV Prevention Programs for Drug Users» [1] and «A novel, bottom-up approach to promote evidence-based HIV prevention for people who inject drugs in Ukraine: protocol for the MICT ('Bridge') HIV prevention exchange project» [2].

HIV-related programs. Instead, the Global Fund partnered with several national nongovernmental organizations, including the International HIV/AIDS Alliance and the Network for People Living with HIV/AIDS, and then distributed funds to regional and local sub-grantee NGOs. Yet, the 2013-2014 events that have been called the 'Ukrainian Crisis', and subsequent armed conflict in Ukraine brought new challenges to the NGOs working on HIV issues [5].

It is from this cadre of local and sub-grantee NGOs that we recruited agencies to participate in our study. We work with 8 organizations from cities³ in Ukraine with the highest HIV and substance use rates in the country, particularly the eastern and southern regions. We purposely recruited NGOs to reflect real-world variability in terms of agency history, size, mission, and context. In May and June 2013, we conducted a total of 39 in-depth interviews with staff and directors at the organizations, and conducted multi-day site visits at each agency. The interviews explored the history of the NGO, current and future agency goals, the interviewee's personal history of involvement in HIV prevention, and experience working with drug users. During the site visits, researchers accompanied staff on street-based outreach efforts, mobile van trips with the purpose of needle exchange and other harm reduction related activities, and spent time at agency community centers.

Methodological point of departure. NGOs in Eastern Europe are frequently categorized as belonging to a class of «elites that act as «agents of Western metropolises in their countries [6] characterized as highly paid professionals affiliated with cosmopolitan attitudes, consumption patterns, and lifestyles. The use of NGOs to address health problems has been criticized for funneling resources primarily to elites and undermining already atrophied public sector health systems and solutions [7; 8]. The presumed «elite» nature of the NGO sector has led to suggestions that it cannot adequately meet the needs of the most vulnerable populations [7].

Based on our preliminary field data, we question the extent to which the vision of NGOs as elite and removed from the local context is a methodological artifact—a product of the type of NGOs that may engage with international researchers—rather than a reflection of the real, challenging work NGOs continue to do and the important role of «bridge» they serve between key stakeholders in fighting HIV. As we illus-

trate below, the skills required to successfully reach and engage with difficult clients contrast with those necessary for success if NGOs are viewed as an «elite formation» In this paper, we use the areas of personal backgrounds, training and certification, and collaboration to challenge a model of NGOs as elite structures. We highlight the ways in which these agencies' founders, directors, and staff increasingly occupy a liminal space and work to define this space as one that enables them to traverse two seemingly disconnected worlds – one of international donors and national monitors and another of marginalized and vulnerable substance users.

Preliminary research findings. In this paper we focus on two issues that are important for the reflection of the NGO's role in HIV prevention service provision, and which have been underestimated in other research and policy-making: personal background and education and certification. We regard personal background and certification as individual and institutional factors that shape who gets involved in HIV prevention service provision and how their involvement is legitimized. Inclusion of these factors in our analysis allows us to explore how NGO staff define their own self-positioning in a liminal space of encounters of disconnected worlds – one of international donors and national monitors and another of marginalized and vulnerable substance users.

Personal Backgrounds. The directors, staff, and volunteers of Ukrainian HIV prevention and substance use organizations come to work in this field and for HIV-focused NGOs from diverse work, life, and educational backgrounds and for myriad motivations. While some are current or former drug users, many others are not. As one program director suggested, people do not work in HIV service organizations «by accident» (Mykolaiv, Interview with IDU director). In general, staff and directors came to work in these organizations and on these topics not as stepping stone to higher paying⁴ or more prestigious work but through personal connections to and experiences with HIV or substance use issues. In fact, a good number of agency personnel we interviewed had left more prestigious and better-paid professional positions to pursue NGO-based advocacy. In the context of working with and developing programs for substance users and people living with HIV, being close to the community and understanding their lives and problems – particularly based on personal experience – is a highly valued asset.

The staff at one HIV service NGO in a mid-sized industrial city invited us to ride along

³ Dnipropetrovsk, Kyiv, Mykolaiv, Odesa, Poltava, Simferopol, Slavyansk, Zaporizhia. The first phase of the research have been conducted in 2012 – 2013, before the annexation of Crimea, and Simferopol has been included as an Ukrainian city.

⁴ In fact, however, some did come to NGOs for better pay (Mykolaiv coordinator interview; Simferopol resource center director).

with them on the mobile outreach route, a bus from which social and medical workers offered a range of services to the NGOs clients. That day the destination was the city's ring road, where rendezvous had been scheduled with two groups of commercial sex workers, many of whom also were injecting drug users. At the first rendezvous spot, our guide Alina bounded out of the van and invited clients into the van one-by-one to receive services, including needle exchange, condom distribution, and HIV/STD testing. We asked Alina what is most challenging about outreach work. She said, «It's really hard when clients are high, and not in a state of mind to absorb the information they are getting». She admitted that working in HIV prevention services is physically and emotionally taxing, and said the most rewarding aspect is when clients begin to change their lives, and their health improves. As we approached the second agreed-upon stop, Alina noticed that the highway police were hanging about. Fearing for clients' safety, Alina aborted the stop and we returned instead to the agency's office.

When we resumed our interview with Alina later that day, we learned that although Alina had begun her tenure at the NGO as a social worker, now she was «coordinator of prevention programs», a role that meant she coordinated all of the NGO's projects. She characterized herself as «sort of the public face of the organization's project activities». Although Alina was not expected to work in the mobile clinic herself, she explained that she often did so because remaining involved in the lives of CSWs is still very rewarding for her. Alina explained that she enjoyed the opportunity to do different kinds of work, including oral surveys with injection drug users as part of research projects and participating in and developing trainings to build new programs for the agency. Alina and others traversed a broad 'territory' of activist duties. During our site visits, we witnessed staff working «in the trenches» with injecting drug users during outreach activities and then returning to the agency to finish organizational duties such as project administration and training development. The staff we interviewed did not see such outreach as incongruent with their other organizational duties but rather as integral to them.

Legitimization through certification. In addition to HIV-related training, staff, directors, and volunteers can be trained and certified in a wide range of topics and skills, including harm reduction strategies, management, program evaluation, advocacy for drug users, group facilitation, legal issues, case management, and publishing (Mykolaiv IDU director; Odessa, HIV prevention director).

Importantly, countering previous critiques [9; 10; 11], these trainings should not be viewed

as top-down information dissemination programs in which information and knowledge flows from the «elites» to the «non-elites.» Indeed, it was not uncommon to hear of training programs in which doctors, law enforcement, and other elite personnel were the initiates, and HIV service providers, including former and current commercial sex workers and drug users and their advocates, were the experts. In general, we were struck by the extent to which agency staff genuinely value these trainings, for a variety of reasons. On the one hand, training, skill-building, and programming innovation are seen as ways to improve an agency's grant proposals and help them achieve or maintain stable funding for their programs. Similarly, trainings are valued as a way for agencies to stay up-to-date on the newest approaches to HIV prevention and substance abuse. On the other hand, trainings are an important venue through which NGOs share their own ideas, information, and experiences with others working in the field and learn different approaches being used by other agencies (Mykolaiv IDU director interview).

Perhaps more powerful is the way in which NGOs use certification and professionalization to legitimize their work with some of the most marginalized and neglected populations in Ukraine. The HIV prevention sphere is decidedly marginalized due to the stigma associated with people who have the disease and the populations at greatest risk. As the HIV prevention director of one organization (Odessa) lamented, state and local governments do not value their work and social workers are not respected, primarily evidenced by the low pay of social workers (Kyiv MIO interview). Legitimizing their work is important given that medical providers – and others who control necessary resources for those populations that agencies work with, including police and other authorities – often have negative views of NGOs' clients (HIV patients, drug users, sex workers, marginally housed) (Odessa, Dnipropetrovsk director interview, Odessa). One strategy is to *conduct trainings* – in addition to *attending trainings* – to legitimize the work of NGOs and their perspective on drug users and HIV. Particularly striking was one agency that engaged active drug users and HIV-positive clients to conduct trainings with medics and other health care professionals to promote new, ethical ways of treating HIV-positive or substance-using patients (Mykolaiv Field notes 5/17/13; Mykolaiv IDU director interview).

Views from 'inside': bridging worlds. Ukrainian HIV service providing NGOs simultaneously struggle to maintain their original goals and proximity to those most in need of their services, and embrace the potential opportunities that national and international organizations,

fundings, and researchers represent. Research-derived, evidence-based programs are seen as something to enhance and improve services, and in some cases something that agencies seek out rather than as something imposed on them (Dnipropetrovsk, Interview with program coordinator). At the same time, some agencies carefully deliberate whether to submit applications for new projects or respond to calls for proposals, considering the extent to which they can connect with new target groups, continue to serve existing clients, or maintain cooperative rather than competitive relationships with other agencies in the area (e.g., Mykolaiv IDU director interview; Poltava field notes 5/24). This agency-driven model of program development, however is not true of all NGOs working on these issues. One Associate Director explained that their HIV prevention programs have always been donor driven, and even strong, innovative proposals are dismissed by funders in favor of programs that meet the funder's agenda (Simferopol interview with Associate Director).

Entities such as the Alliance are an important source of information, for example regarding epidemiological trends and programming ideas, including manualized «pre-packaged» interventions. But as potentially valuable as such information and programming guidance is, it is not always feasible to implement things in a step-by-step way (Odessa, HIV prevention director). Moreover, while national or regional initiatives may prompt agencies to focus on particular topics or strategies with clients, sometimes these efforts are more performative until the «real» work of the agency can be conducted. In one telling example observed during a street outreach program, a social worker tried to implement the «theme of the week» by asking clients about tuberculosis symptoms and hepatitis awareness. The majority of clients dismissed the hepatitis information and TB survey, making jokes at every turn and turning the whole exercise into a painful farce for the social worker. However, the social workers still held private consultations with each client under the guise of «having a cigarette» together and discussed lingering health issues, family matters, and other pressing concerns with clients (Dnipropetrovsk Field notes, 5/28). This example highlights the potential divide between donors' agendas and the real, everyday needs of agency clients, and the ways in which service providers juggle to incorporate both into their work.

Conclusion. The Ukrainian NGOs we encountered during our research bear very little resemblance to a «new elite» of English-speaking

experts or a class of «deskkilled volunteers» or technocratic specialists [6]. Rather, the NGO staff and directors have very specific skills that are difficult to reproduce through trainings but that are built through first-hand experience with marginalized populations. From this perspective, perhaps it is more accurate to view NGOs' role (as it is seen from 'inside' of NGOs – by their staff) as «bridges» or «nodes,» bringing together international donors, police, clients, government, and medical providers. However, this «symbiotic» relationship (Kyiv, Associate Director interview) remains elusive, evidenced by persistent tensions over who should receive and distribute funding from international donors, which agencies should serve as the coordinating body of country and regional HIV programs, and who is best suited to deliver services to populations in need – NGOs, medical providers, or the government. Several interviewees at various agencies raised questions about who should be responsible for HIV prevention in general. They concluded that it should be the responsibility of the state but in the absence of a competent cadre of workers in the state sphere to do the work, NGOs stepped in to fill this role. Moreover, the general lack of flexibility NGO staff are given by funders – particularly the Alliance – to innovate in programs and agency focus, suggests a hierarchy of NGOs in which money is funneled to on-the-ground HIV service providing NGOs through large coordinating and monitoring organizations that have access to funding streams and the international sphere but are largely detached from clients and the messier, less glamorous aspects of HIV prevention and harm reduction.

It is important to keep in mind that while the NGOs in our study have carved out a particular niche in which they are navigate the worlds of their clients, state medical systems and bureaucracies, and national and international donors, on the whole such NGOs involved in HIV and substance use issues have little prestige due to the stigmatized nature of their clients and their problems. The role of NGOs in HIV prevention in Ukraine and their relationship to each other, the government, and national and international organizations is called into question as the Global Fund contemplates withdrawing support for HIV prevention in Ukraine in the near future. How such an abrupt disappearance of support for these organizations will affect the HIV prevention landscape in Ukraine, and which NGOs survive the withdrawal of international donor funds may provide even more answers to questions of elite versus non-elite NGOs.

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