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Meeting Report

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Introduction

The Open Society Institute's (OSI) long experience implementing public health programs has shown that legal advocacy is a critical and often indispensable tool for advancing public health. The populations targeted by OSI's public health programs—people who use drugs, people with HIV, sex workers, lesbian, gay, bisexual, and transgender communities, Roma, people in need of palliative care—are often socially marginalized and in need of legal advocacy to protect their human rights. Many of the public health interventions supported by OSI, such as needle exchange programs and the use of strong-acting opioids for palliative care, are restricted by law and thus only available to a small fraction of people who need them. The delivery of medical care in countries where OSI works, particularly in the former Soviet Union, rarely conforms to legal, human rights, ethical and other normative principles, leaving both patients and providers vulnerable to widespread abuses of their human rights. As developing and transitional countries reform their health systems with increasing support from the international community, laws guaranteeing transparency and freedom of information will be essential to ensure the full participation of civil society in the formulation and monitoring of health policy.

In 2005, OSI established the Law and Health Initiative (LAHI) out of recognition that the Public Health Program and its partners could not fully achieve their objectives absent increased and coordinated engagement in legal and human rights advocacy. Since Jonathan Cohen, Project Director, joined in early 2006, emphasis has been on developing priorities for engagement, making these priorities available to the Soros Foundations Network, and building the grant-making capacity of the Initiative so that funding can flow more easily. In September 2006, LAHI convened an international Strategy Working Group meeting to solicit feedback from a group of expert advisors on LAHI's proposed priorities and interim strategy for funding.

The LAHI interim strategy described six priority areas. Each of these sought to combine an element of OSI's public health portfolio with a corresponding element of OSI's law, human rights, and justice portfolio. The intent was to support collaborations between OSI's public health and human rights staff and to add value to each side, rather than to expand the mandate of any given program. The six priorities are:

1. Expanding access to legal services for socially marginalized groups
2. Advancing legal and human rights responses to HIV and AIDS
3. Promoting legal remedies for abuses within health systems
4. Creating an enabling legal framework for scaling up effective public health services
5. Supporting the legal aspects of health monitoring
6. Building a new generation of public interest health lawyers

Rather than move through each proposed priority, the Strategy Working Group meeting was framed to discuss four particularly challenging questions arising from the interim strategy paper:

1. How can LAHI best expand access to legal services for marginalized groups?
2. What is the most effective way for LAHI to develop a new generation of "public interest health lawyers"?
3. What is LAHI's most strategic contribution to the patients' rights movement?
4. What is the role of the mainstream human rights movement in advancing LAHI's issues and priorities?

Discussion of these four questions occupied the first fully day of the meeting. The second day of the meeting was devoted to individual dialogues with the directors and selected staff of each of five PHP initiatives—International Harm Reduction Development, International Palliative Care Initiative, Roma Health Project, Sexual Health and Rights Project, and health monitoring initiative—to discuss how LAHI could best collaborate with these initiatives.

This report provides a synthesis of the spirited discussion of the meeting, highlighting recommendations of concrete next steps.

Day One: Discussion of LAHI Priorities

How can LAHI best expand access to legal services for marginalized groups?

The partners of the Public Health Program working with socially marginalized groups repeatedly express the desire to integrate legal services into the health and social services they provide to their clients. Legal services not only fulfill a basic need for clients, but also improve health outcomes by providing redress against human rights violations that fuel disease vulnerability. OSI is in an ideal position to link legal services to health and social services, as it has extensive experience advocating for access to free legal aid in addition to its strong network of public health partners. Many of the partners who can potentially provide these legal services are already grantees of OSI's various human rights and rule of law programs. LAHI hopes to leverage this experience to create innovative, integrated services that further both human rights and public health goals.

This discussion explored the practical aspects of the scope, needs, and challenges of providing legal services to marginalized groups and integrating health and legal services.

Corinne Carey, the deputy director of Break the Chains and a former OSI fellow with long experience providing legal services to people who use drugs and survivors of domestic violence, framed this discussion by relating her experience in integrating legal services into harm reduction programs. She found that lack of access to legal services acted as a barrier for socially marginalized persons to gain access to health services; at times, however, the legal solutions themselves could serve as barriers. For example, the requirement under US law that a person who uses drugs be "in recovery" in order to qualify as "disabled" for the purposes of non-discrimination protection could further marginalize active drug users. Carey suggested several factors to consider when developing a legal strategy for people who use drugs: defining what legal services to provide; finding how to set up services that are both sufficient and sustainable; identifying arguments for why legal services are important; and developing partnerships to maximize impact.

"In Ukraine, there is almost no education about human rights for doctors or nurses; 99% of medical staff are unaware of what basic human rights are. No one has the right to privacy."
-Dima Groysman

The advisors queried to what extent LAHI's work should focus on providing legal services to "marginalized populations"—defined at OSI as people living with HIV, drug users, prisoners, sex workers, lesbian, gay, bisexual, and transgendered persons, Roma, and people needing palliative care—as opposed to society at large. Though marginalized groups may be more vulnerable to human rights abuses generally, in some countries and contexts (such as post-Soviet health systems) everyone is vulnerable to abuses of their rights. Dr. Dmytro (Dima) Groysman of the Vinnytsia Human Rights Group in Ukraine noted that in his country, where there is almost no education or understanding of human rights by doctors, patient records are routinely disclosed and the right to privacy is rarely enforced. Limiting one's advocacy to people who use drugs would seem in this context to miss the larger point. Dr. Robert (Bob) Newman, Director of the International Center for the Advancement of Addiction Treatment and a long-time advocate for the rights of drug users within the health system, responded that "drug user rights are everyone's rights"—that advocacy for drug users within health system should be framed as part of a larger struggle for patients' rights, and that it is strategic when advocating for drug users to note that abuses against them can go on to affect the general population.

It was suggested that one reason to focus on marginalized groups is that in many cases there are unavoidable factual differences in access and exclusion, notwithstanding denial by political leaders and the general population that marginalized groups, for example Roma, actually have less access to services. The experience of marginalized groups can also be a signal that reveals where societal weaknesses exist in terms of discrimination and access.

Much of the discussion focused on the practicalities of making legal referrals a routine part of medical care for certain populations who were likely to be experiencing human rights violations (e.g., people living with HIV). Several advisers noted that health systems *themselves* can also abusers of people, so this must be kept in mind when proposing to introduce lawyers into

"We must insert legal services into health services. Otherwise, we ask people to make choices based on limited resources—and a woman will usually choose to go collect her benefits rather than see her lawyer, unless both are in the same place."
-Liesl Gerntholtz

any health setting or to “co-locate” health and legal services. People who provide health services may be threatened by the thought that clients might have access to lawyers. Even when health professionals are interested in and supportive of integrating legal services into medical services, they often lack the capacity to do it. Liesl Gerntholtz of the Tshwaranang Legal Advocacy Center in South Africa pointed out that good models of integration exist in South Africa, and recommended that LAHI proceed by “asking medical practitioners to identify the needs, and then getting legal providers to suggest the best way to meet those needs.”

In addition to providing legal services, which use existing legal remedies, national-level advocacy is needed to develop and promote systemic remedies to address large-scale failures of the health system. (This is discussed further in the discussion on human rights in patient care.) More laws, however, aren’t always the answer. Binaifer Nowrojee, director of OSI’s East Africa Initiative, cited a Kenyan medicines law that was pushed by pharmaceutical companies; advocacy work needs the space to be able to challenge bad laws as well, especially given the lack of knowledge of parliamentarians in many countries.

“Even when people have access to legal services, they may not want to use them because of stigma. People will come to the office, but won’t go to court.”
-Delme Cupido

Ralf Jurgens, founder and longtime executive director of the Canadian HIV/AIDS Legal Network, pointed out that, in addition to the inherent value of providing legal services to people living who use drugs, people living with HIV, or other marginalized groups, there is “documented positive experience where this has resulted in systemic change.” The work of PIVOT legal services in Vancouver, Canada, is one example. The advisors agreed on the value of compiling a “best practices” collection on providing legal services to marginalized groups.

Even when legal services are available, other barriers often exist that keep marginalized groups from obtaining justice and enforcing their rights. Delme Cupido, who had recently joined the Open Society Initiative for Southern Africa (OSISA) after years as project coordinator for the AIDS Law Unit of the Legal Assistance Center in Namibia, talked about his experience providing legal services to people living with HIV in Namibia, where people would come to the office but resist situations that might result in disclosure of their HIV status, for example open court. Stigma may also prevent people from seeking services in the first place, raising the question of how LAHI can help people who don’t come forward.

Recommendations:

- Insert legal services into other services. Otherwise, underserved people will have make choices based on limited resources.
- Identify models of integration that already exist (e.g., Profamilia legal services, Colombia).
- Documentation is needed on providing legal services to marginalized groups. A “best practices collection” could:
    - Document lessons learned;
    - Include examples from different systems and different continents;
    - Identify what does not work;
    - Document examples of systemic change resulting from the provision of services;

    - Be used to advocate for greater global attention to the issue, and show the impact on health and human rights.
- Fund legal services projects in stages:
    - Year 1: Project design
    - Year 2: Implementation
    - Year 3: Reporting and evaluation
    - Year 4: Leveraging other funding
- Support national-level advocacy for systemic remedy mechanisms in addition to providing legal services to use existing remedies.
- Create Health Justice Fellowships to allow lawyers to partner with local health NGOs to integrate legal services and advocacy.
- Present legal services in a way that is not threatening to health providers.

What is the most effective way for LAHI to develop a new generation of "public interest health lawyers"?

The use of legal tools to promote public health requires a cadre of legal professionals who can combine their legal skills with an understanding of health issues and the challenges facing socially marginalized groups. Such "public interest health lawyers" exist in few places, and few universities offer programs that would systematically cultivate this interest. Courses and clinics on human rights rarely include a comprehensive component on health, while health law courses tend to address technical issues of health law and medical malpractice rather than issues of direct concern to OSI and its partners. OSI is well placed to develop the practice and teaching of "public interest health law," as it has supported schools of public health, law schools, medical academies, and clinical legal education programs in a number of countries. In addition, the OSI-supported Salzburg Medical Seminars provide an opportunity to develop law-and-health curricula that can subsequently be replicated at the national level.

> *"Public interest law needs to be valued—and leadership within a university is needed to change the culture of a law school, to subtly convey to students that public interest law is part of being a good lawyer."*
> *-Rebecca Cook*

This discussion was led by Professor Rebecca Cook, who began by giving an overview of her experience at the University of Toronto (UofT) in attempting to build the capacity of law and medical students in health and human rights. She noted that the entry point for raising "normative issues" at UofT was the Center for Bioethics, and cautioned against engaging with medical schools to integrate a social justice dimension unless there is leadership within the medical school itself. Cook recommended that LAHI develop a strategy for building the capacity of lawyers to work on health issues, identify research issues that need work and will help advocates, and push the academic work to engage on both.

Rob Kushen, OSI's director of international operations, asked whether LAHI's capacity building efforts were geared more towards developing a cadre of lawyers interested in working with clients who have legal problems related to their health status (such as discrimination based on

HIV status), as opposed to attempting to create elite "technicians" specialized in particular areas of health care law (such as medical insurance). Jonathan Cohen suggested that to the extent there was a distinction between these two fields, LAHI's priority was likely to be legal action on behalf of socially marginalized groups, which is consistent with the overall objectives of the Public Health Program.

"In Southern Africa, there's not a law student at all who doesn't have a family member or friend affected by HIV."
-Delme Cupido

The advisors suggested developing internship and fellowship programs to motivate law students and new graduates to work in public interest health law. One example of current work in this area is the Health Equity and Law clinic at the University of Toronto, which the clinic's director, Joanna Erdman, described. The clinic has four purposes: to develop reflective practitioners of law; to demonstrate the interdisciplinary nature of health law; to drive professional responsibility and motivate careers in health law; and to provide legal services (though not directly to clients). The clinic includes an internship program to give students practical experience.

Ralf Jurgens noted that many students, often some of the brightest, want to practice public interest law but lack opportunities for practical training and professional placement following law school. In addition to motivating them during their education, he recommended creating opportunities for new graduates to work in the field. Delme Cupido also agreed that fellowships and practical training would stimulate new human rights lawyers. In Southern Africa, "the size of the HIV epidemic provides an opportunity" for cultivating interest in public health law, he said, as "there's not a law student at all who doesn't have a family member or friend affected by HIV."

Bob Newman recalled that in medical school, students are told that they must have an understanding of psychiatry to be optimally effective as physicians. Likewise, he suggested, law students and practicing lawyers should be taught that they must pay attention to issues of social justice and health to be effective.

The advisors also repeatedly suggested building the capacity of existing lawyers to take cases related to human rights and public health: Catherine Mumma of the Kenya National Commission on Human Rights recommended using well-timed guest speakers to inject interest into the practice of law in Kenya; Claude Cahn pointed out the need to train practitioners to work with marginalized groups. Rebecca Cook urged that practicing lawyers needed a regional, intensive short course on human rights and health in order to be effective in this area. Some examples of this already exist and should be explored further.

"There is resistance from the medical community to instituting public health training in medical schools. How would they react to human rights?"
-Judy Overall

Balazs Denes, executive director of the Hungarian Civil Liberties Union, pointed out that in situations where abuses of human rights are rampant throughout the health system, educational initiatives must target the medical profession and medical schools in addition to lawyers and law schools, in order to prevent abuses before they happen. Joanna Erdman related one example of human rights training for health providers within a medical school. Because the training is not mandatory, only some doctors will elect to attend; however, these doctors can then speak eloquently to their colleagues about the need for knowledge of human rights. Another possibility for training medical professionals is to use national re-training or continuing medical education (CME) programs: human rights and patients' rights courses can be accredited and presented to doctors for re-training credits. "Ultimately," Rebecca Cook said, "normative training should be required and included in licensing exams" for doctors.

These suggestions become more complicated in contexts of state-run medical systems. Dima Groysman related his experience from Ukraine, where the medical curriculum is designed and approved by the state, and universities cannot create their own individual curricula on any subject. Groysman, convened underground human rights events and trainings as a medical student in pre-revolutionary Ukraine, stressed that specific approaches are needed based on the context and history of medical professionals' view of human rights. Rebecca Cook added that discussion of "ethics" or "fairness" might be possible in cases where discussions of "human rights" raise red flags.

> *"Law students and practicing lawyers should be taught that they <u>must</u> pay attention to issues of social justice and health to be optimally effective as lawyers."*
> *-Bob Newman*

An animated discussion of patients' rights and engagement with medical professionals continued in the next segment of the meeting.

Recommendations:

- Establish 2-3 week regional institutes for lawyers, paralegals, and other legal professionals in health and human rights. The institutes should use case studies to teach legal professionals how to broaden their remit to include health-related cases.
- Identify a "sexy", interdisciplinary research agenda in health and human rights, and promote this agenda in universities. This could include:
    - The relationship between criminal law and health
    - Stigma and health
    - Customary law, anthropology, and health
    - Separation of church and state
    - Fairness in the health system
- Increase awareness of human rights in medical schools:
    - Introduce formal human rights education
    - Create networks of pro-patient doctors
    - Create Amnesty International chapters in medical schools
    - Begin with bioethics
- Try to get normative training required in medical schools and on licensing exams. A best practices collection can be compiled using the experience of medical schools and countries that already do this.
- Accredit new courses on human rights in countries that require membership in a medical chamber.
- Sponsor visiting professorships or speaking tours in law and health or related issues.
- Create links between health law clinics in the US and abroad.

- Hold a side meeting on health at a global clinical legal education conference or other gathering of clinical teachers.

What is LAHI's most strategic contribution to the patients' rights movement?

In every region where the Public Health Program works, patients and others seeking access to health care encounter abusive, unethical, and often life-threatening treatment within the very health systems that are expected to provide them with care and support. At the same time, doctors and other health practitioners are often constrained in their ability to provide quality care to their patients, or are unaware of how to incorporate ethical and human rights norms into their work. Socially marginalized groups, such as people who use drugs or Roma, may suffer exceptionally abusive or discriminatory treatment. The availability of effective legal remedies for both individual and systemic abuse remains slim to non-existent, while those remedies that do exist often fail to recognize the difficult constraints within which health providers work.

> *"The most strategic contribution OSI can make is to build an independent patients' rights movement. By educating people about HIV treatment, for example, the Treatment Action Campaign was able to achieve systemic change."*
> *-Liesl Gerntholtz*

This discussion explored several dimensions of patients' rights, including the tension between pursuit of remedies for individual cases of abuse and advocacy for systemic change, in an effort to identify an appropriate strategy for engagement by LAHI.

Liesl Gerntholtz suggested that "the most strategic contribution OSI can make is to build a "patients' rights movement." This movement might mirror the Treatment Action Campaign's efforts to mobilize and educate people with HIV around access to anti-retroviral treatment in South Africa, empowering them to advocate for their own rights with their doctors. Treatment literacy, she noted, can lead to people later advocating for greater, systemic changes. A patients' rights movement could include *ad hoc* groups that may not work on patients' rights as a primary issue, but would be willing to be part of a campaign. Claude Cahn of the European Roma Rights Centre agreed that an education campaign would be useful, as awareness of patients' rights in many countries is very low.

Some advisors recommended taking a wider view of patients' rights than simply identifying remedies for individual abuses in the health care system. They suggested that any efforts aimed at systemic change—that is, improvements in access to quality of health care—would have to include providers as well, and so would have to be presented in a less threatening way that also advocated for rights of providers. Bob Newman gave an example in which physicians refuse to prescribe pain medication because they fear criminal prosecution; this is as much a breach of providers' rights as those of patients. Catherine Mumma clarified that the aim is "not to compromise patients' rights for the sake of the medical profession." Rather, it is to develop a system that enables providers to respect the rights of their patients.

It is not always easy, however, to see the synergy between the rights of patients and those of providers in a context of outright abuse of patients' rights by providers. There is a distinction between supporting patients when their rights are aligned with the interest of their providers, and when their interests are not aligned.

Delme Cupido said, "Nurses and doctors don't want to work in dysfunctional health systems; often, that is what is causing abuses of people's rights." Patients and providers can work together to transform the health system, and such a transformation is in everyone's best interests. Other advisors agreed, noting that collaborative work has brought about strong movements in other areas, for example around breast cancer in the United States or palliative care for children in South Africa. Liesl Gerntholtz also pointed out that "litigation often closes the space for discussion."

Corinne Carey gave a recent example from her experience, in which a doctor had failed to produce documentation about a patient's drug relapse that could have kept him eligible for treatment and services. She stressed the importance of educating doctors about the need to protect other legal rights of their patients, because those rights have health outcomes, too. Other advisors pointed out that the sort of behavior cited by Carey might qualify as professional misconduct by the physician, and that perhaps the professional body had mechanisms to deal with this situation. Rebecca Cook added that though there is vast literature on fostering compliance in human rights fields, there hasn't been sufficient work on fostering compliance in health. Litigation strategies, she noted, were the tip of the iceberg, and thay positive reinforcements could also foster compliance with human rights norms. "In the OBGYN field, we celebrate doctors," she said.

"We need to talk to doctors about the importance of protecting other legal rights of their patients. Those rights affect health outcomes, too." -Corinne Carey

The advisors discussed the usefulness of documents such as a patients' bill of rights. Corinne Carey pointed out that delineating rights can also limit rights: certain situations might be excluded, or states may be reluctant to grant some rights. She emphasized that this happens often when affected groups, including marginalized populations, are not involved in drafting the documents.

Recommendations:

- Combine the creation of new legal remedies with use of existing ones.
- Don't limit focus to marginalized groups: in some cases, everyone's rights (e.g., confidentiality in the medical system) are being violated.
- Identify issues where the rights of patients and providers are aligned. These could include:
    - Prescription of methadone
    - Provision of abortion
    - Palliative care for children
- Work both on individual abuse (for which a patients' rights framework might be appropriate) and systemic abuse (for which doctors must be on board).
- The most strategic contribution OSI can make is to build patients' rights movements that empower patients to demand rights from their doctors and the system as a whole.

- National standards for the implementation of human rights in medicine are needed.
- Map what exists in patients' rights. This should include:
    - International consumer organizations
    - Patients' rights charters
    - International Society for Equity and Health
    - Physicians for Human Rights
    - Global Lawyers and Physicians
    - National groups
- Gather cases where systemic health issues were litigated and governments were forced to adopt guidelines, and document the effects of the litigation.
- Marginalized groups must be involved in the drafting of guidelines or rights bills for patients. This can reduce the possibility of necessary perspectives being excluded.

What is the role of the mainstream human rights movement in advancing LAHI's issues and priorities?

OSI is a leading global funder of nongovernmental human rights organizations. Organizations with a broad human rights mandate have traditionally focused their work on civil and political rights, leaving comparatively limited resources and technical expertise to address health issues in their own right. So-called mainstream human rights groups (MHRGs) have historically limited their health work to the context of violations of civil and political rights, for example in closed institutions such as prisons. However, motivated in part by the urgency of the HIV epidemic, MHRGs have increased their health-related work in recent years. National-level human rights groups, such as the Treatment Action Campaign (South Africa) and the Hungarian Civil Liberties Union have engaged more on the right to health and patients' rights than what can be observed internationally.

"Unless we bring a human rights approach, no new technologies will be sufficient to overcome the HIV pandemic."
-Francoise Girard

This discussion explored whether and how LAHI should engage with MHRGs, at national and international levels, to further its work at the intersection of health and human rights.

Francoise Girard, director of OSI's Public Health Program, opened the discussion by relating a brief history of the engagement of MHRGs in health issues, based in part on a background paper prepared by LAHI Program Assistant Sai Jahann. Women's health (especially reproductive health), mental health, and HIV have been very important for introducing rights dialogue into health advocacy and, conversely, health dialogue into rights advocacy. Human Rights Watch, Interrights, and Global Rights, all international MHRGs, have now begun engaging on health and rights issues, including HIV and AIDS issues and women's access to health services. Girard recommended framing interventions to replicate the most effective examples of health advocacy conducted by MHRGs; the advisors should address whether LAHI should support MHRGs on the issues they are

"The principle of 'indivisibility' of human rights is gaining acceptance: the misuse of resources through government corruption limits the resources available for the provision of health services."
-Catherine Mumma

interested in or steer them in new directions, and how and whether to engage with groups that focus on civil and political rights.

Groups that traditionally focus on civil and political (CP) rights often focus on issues of discrimination when taking on health advocacy; however, as many advisors pointed out, there are systemic issues in health that CP rights (including discrimination) can't address. Catherine Mumma pointed out that the principle of "indivisibility of human rights" is gaining acceptance, as CP and ESC rights are increasingly linked in countries. For example, the misuse of resources through government corruption limits the resources that can be used for provision of health services. Research on this at a national level can be useful in furthering this idea.

"This is about changing mindsets, and about collaborating across divisions. It's possible!"
-Binaifer Nowrojee

Balazs Denes questioned why international MHRGs would get involved in health and rights debates at the national level if demand had yet to be visibly generated, for example through the filing of court cases. Several advisors also questioned the usefulness of working to convince international groups to work on health when greater potential existed for long-term partnerships with national human rights organizations that already have an interest in health-related work (or with non-human rights organization). Rob Kushen pointed out that the nature of violations of the right to health—violations against the majority, rather than a minority—makes the issue much more politically sensitive and complicates involvement for international, rather than home-grown, groups. Ralf Jurgens suggested a compromise: to engage with MHRGs on the issues of interest to them already.

Another possible way to engage MHRGs is to pursue partnerships when their presence would be useful for the national groups already undertaking health and human rights advocacy. This can vary greatly from country to country. In Ukraine, for example, Dima Groysman pointed out that MHRGs could provide much-needed evidence (often in the form of monitoring reports), as well as international "push", that his and other national organizations could use in their advocacy. Claude Cahn suggested that MHRGs could engage on Roma health in Europe, especially in pursuing justice for victims of coercive sterilization. Catherine Mumma added that international groups can contribute by influencing the international context in which national groups operate in. She said, "If there's a good international convention, national work is made easier." National organizations, which may have easier access to government, can be used as "advocacy channels" to push the right to health.

An interesting debate that surfaced during the discussion centered around the legitimacy of international human rights organizations in advocating for the right to health at a national level. Rob Kushen argued that "there's an inherent problem with asking large, multi-national groups like Human Rights Watch to take the lead on issues that are so closely connected to resource allocation, unless you have a national-level constituency first." Binaifer Nowrojee responded that the same argument is never made in the context of civil and political rights, for example lack of access to education for Roma or persecution of gay men in Kenya,

"Groups that work on civil and political rights focus on issues of discrimination in access, but there are also systemic issues that civil/political rights don't answer."
-Claude Cahn

even when there is no national-level constituency pushing these issues. Other advisors also pointed out that protection of civil and political rights also has implications for resource allocation, as protecting the rights of the accused or providing systems to ensure fair voting cost money as well.

Recommendations:

- Engage mainstream human rights groups (MHRGs) on the specific issues that they are willing to take on (for example, Roma health), and ignore them on others (for example, drug users or health spending).
- Identify situations in which MHRGs can play a key role in shaping the international context within which national human rights and health NGOs work.
- Use MHRGs to document and promote best practices.
- Foster demand for health and human rights work at the national level; this will help push MHRGs to take on health issues.

Conclusion of Day One

Throughout the first day of the LAHI Strategy Working Group Meeting, several cross-cutting themes emerged in the context of different discussions, highlighting tensions that LAHI must consider when engaging with different sectors and in various national contexts.

Advocacy for the marginalized vs. general advocacy

LAHI must consider how to justify supporting legal action on behalf of marginalized groups in contexts where the rights of the majority are routinely violated (e.g., the general lack of informed consent in Ukraine and other post-Soviet countries).

Advocacy for systemic change vs. provision of remedies for individuals

In its patients' rights strategy, LAHI must balance engagement of medical professionals in advocacy for systemic change in the health system with supporting individual patients in seeking justice, often through litigation, for abuses suffered at the hands of their health care providers. The same issue surfaced when discussion LAHI's strategy to promote access to legal services: with a limited budget, how will LAHI balance providing legal services to individuals with advocacy to change the law?

Patients vs. providers

The interests of patients are their providers are sometimes aligned, sometimes not. This is a threshold issue for many of the issues LAHI is proposing to address, particularly the integration of legal services into health settings (which is much likelier to succeed where the services are not targeted at malpractice or wrongdoing by doctors) and the promotion of patients' rights (which should not be at the expense of providers' rights, and should be complementary to providers' rights in most instances).

Building on good practice

There are some groups in some places that have worked on each of LAHI's priorities. LAHI must endeavor to compile "best practices" and learn from the experiences of other groups both to increase the effectiveness of its own work and to advocate for greater engagement by other advocacy groups and donors.

Health issues vs. health status

LAHI must decide whether its emphasis will lie in supporting health-related legal action (e.g., on issues such as informed consent, insurance, privacy) or in supporting a range of legal actions on behalf of groups marginalized by their health status (e.g., people living with HIV, drug users, sex workers). Different activities to build capacity will follow from each of these goals: for the former, for example, LAHI should train health lawyers; for the latter, LAHI should work to build public interest lawyers who are comfortable working with marginalized groups.

Repressive vs. permissive environments

Interventions may be impossible in some contexts. Throughout the day, advisors pointed out that some suggested activities would be impossible in their countries due to the political situation or the prevailing attitude of the population. LAHI must consider how much to invest in advocacy in these repressive environments rather than focusing on contexts where more significant change may be possible.

Considering these tensions and the invaluable advice generated in this meeting, LAHI will revise its strategy for presentation to the Public Health Program's Global Health Advisory Committee and implementation in 2007 and beyond.

Day Two: Collaboration between LAHI and Other PHP Initiatives

The second day of the LAHI Strategy Working Group Meeting focused on possible collaborations between LAHI and each of five other initiatives within the OSI Public Health Program (PHP). An abbreviated version of each of these discussions follows; more detailed information, including information about specific funding proposals, is described in the transcript of the meeting.

Health Monitoring Initiatives

PHP Deputy Director Roxana Bonnell led a discussion about how LAHI might participate in increasing PHP work on civil society monitoring of government and multilateral health policies, programs and budgets. Catherine Mumma noted that the issue of corruption in health spending can and should be framed as a human rights issue in Africa, and that OSI might help build the capacity of human rights groups to take on this issue. She also suggested a regional project to monitor government implementation of the Abuja commitment to spend 15% of national budgets on health care. Ralf Jurgens emphasized that there may be particular aspects of national and international health spending of interest to LAHI, such as how much global spending was channeled to human rights approaches to HIV as a percentage of overall spending, or how much global spending was channeled to law-enforcement as opposed to harm-reduction approaches to drug addiction.

"The threat of a lawsuit is often enough to prompt governments to disclose information." -Balazs Denes

Much of the discussion on health monitoring focused on the use of freedom of information (FOI) laws to gain access to public records about health policies, programs and budgets. It was suggested that LAHI develop and support trainings for journalists and NGOs interested in using FOI laws for the purpose of health monitoring. Balazs Denes suggested there would be a very favorable response from NGOs if LAHI invited proposals from human rights groups in Central and Eastern Europe to test FOI laws with health-related requests; even better, he suggested, would be a regional initiative in which LAHI supported an identical health-related FOI request in numerous countries at the same time and compared the results. Others noted that existing FOI legislation may not represent a promising model of transparency in some countries, and that LAHI should consider supporting advocacy, perhaps jointly with the Open Society Justice Initiative, to amend these models where necessary. Both the Kenyan and Ukrainian models of FOI legislation were cited as in need of reform.

International Harm Reduction Development

OSI's International Harm Reduction Development Program (IHRD) supports a range of advocacy activities to expand access to harm reduction services in Central and Eastern Europe and the former Soviet Union, and increasingly Southeast Asia. IHRD Deputy Director Daniel Wolfe recounted a litany of legal issues that impede the ability of people who use drugs to gain access to and benefit from harm reduction services. These include: laws criminalizing simple possession of drugs or authorizing random urine testing for suspected drug use; forced drug rehabilitation and other abuses occurring in health settings; registration of drug users in national registries, and discrimination against registered users in access to employment and housing; legal restrictions on access to substitution treatment with methadone; failure of health providers to provide adequate information to prevent drug overdose; systemic discrimination against drug users in access to antiretroviral treatment for HIV; denial of addiction services in prisons and jails; and denial of health care based on lack of proof of identity documents. "Since we work with illicit drug users, no part of our work isn't touched by the law," Wolfe stated.

"Since we work with illicit drug users, no part of our work isn't touched by the law." -Daniel Wolfe

Bob Newman noted that legal rights were not only a pre-condition for access to harm reduction services, but that conversely, access to harm reduction services such as substitution treatment were essential to allowing drug users to manage their drug addiction and thus gain the full benefit of legal services. It was also noted that tying legal services to harm reduction services was only possible where the latter existed legally; thus, it would be somewhat futile to attempt to integrate legal services into methadone clinics in Russia, where methadone is illegal.

Much of the discussion focused on the challenge of "selling" the issue of drug users' rights to NGOs and other donors. Jonathan Cohen noted that organizations with a mandate to address the legal and human rights aspects of HIV and AIDS (e.g., the Canadian HIV/AIDS Legal Network, the AIDS Law Project in South Africa, and the HIV/AIDS Program of Human Rights Watch) were obvious partners, as these groups typically demonstrated a willingness to take on unpopular causes affecting socially marginalized groups. A promising collaboration between LAHI and IHRD might be to seed the creation of more such NGOs in the regions where IHRD works. An even deeper, long-term challenge was persuading other donors to support this work, so that NGOs do not instinctively turn only to OSI to address legal challenges related to drug use.

> *"Dying in agony is a good example of a human rights violation. It should not be permitted."*
> *-Charles Cleeland*

International Palliative Care Initiative

The International Palliative Care Initiative supports access to palliative care worldwide, with a particular focus on creating an enabling legal and policy framework for access to strong-acting opioid pain medication. It was pointed out that in addition to supporting these legal efforts, LAHI might use palliative care services as an entry point for a range of legal assistance related to dying, such as wills and estates, guardianship, and power of attorney. Such issues take on a particular poignancy and urgency in the context of the epidemic of HIV and AIDS in Africa. Palliative care providers are natural partners for legal services because they are already oriented toward a patient-centered approach that focuses on holistic needs and broad quality-of-life issues.

This discussion included members of the IPCI's Technical Advisory Committee (TAC), who broadly supported collaboration with LAHI. Between them, LAHI and IPCI's advisors suggested several promising routes of collaboration, including: studying and replicating successful uses of the courts to gain access to essential medicines; using legal strategies to expand access to palliative care in prisons; training palliative care advocates in the use of human rights tools to further access to pain medication, as embodied in the Korea Declaration on Hospice and Palliative Care; reviewing relevant jurisprudence and legal strategies to further access to pain medication; and bringing together doctors and lawyers at the national level to develop a common platform on palliative care as an element of human rights and human dignity. As Kath DeFillipe said, "Palliative care practitioners need to be empowered to be better advocates for patients and families." Several advisors debated whether, normatively, the right to palliative care is rooted in the right to health care or is more broadly linked to human dignity and the right to be free from cruel and inhuman treatment.

> *"What's the recourse for patients who spend money for treatment that's futile, because they're not offered palliative care?"*
> *-David Joranson*

Roma Health Project

Representatives from PHP's Roma Health Project (RHP) asked LAHI's advisors to suggest ways of engaging human rights NGOs in Roma health issues, determining the existing state of health-related legal services for Roma, and formulating legal actions to address abuses of the rights of Roma in health systems. The overall priority of RHP is to advance equal access to health care for Romani communities in Bulgaria, Macedonia, Romania, and Serbia. Two ongoing barriers to achieving impact in this area are limited capacity and engagement of Roma NGOs in addressing health issues, and lack of quality data on unequal access to health care among Roma. RHP had begun to develop two projects jointly with LAHI in 2006: a grant to the European Roma Rights Center to conduct advocacy based on their 2006 report, "Ambulance Not on the Way: The Disgrace of Health Care for Roma in Europe"; and a grant to Romani CRISS to file complaints of abuse within health settings to hospital ombudspersons and other remedial mechanisms.

Initial discussion focused on the best way to engage mainstream human rights organizations in issues of Roma health. Rob Kushen described this as a "huge challenge," saying it would be difficult to build a sustained program within a human rights organization on this issue, even if RHP succeeded in getting them to do one or two reports; a better avenue, he suggested, would be to build the capacity of Roma NGOs to take on health issues within a human rights framework. Claude Cahn suggested that narrowing the issues beyond "Roma health" would be critical to any effort to engage NGOs, as the subject was simply too broad.

"It will be a difficult challenge to get a human rights organization to build a sustained program on Roma health."
-Rob Kushen

Discussion then turned to the question of what law-based remedies were available to address abuses against Roma in the health system. Romani CRISS proposed to take complaints to medical ethics boards based on reports of abuse they were hearing as health mediators, but Rob Kushen cautioned that health mediators enjoyed close connections to the government and could undermine this relationship if they began reporting human rights abuses. Jonathan Cohen noted that LAHI was commissioning a global mapping of legal remedies within health systems, and that this would eventually be translated into a series of practical country manuals that could be used by Roma NGOs and others seeking to introduce human rights standards into health care.

The issue of collecting disaggregated ethnic data about health care access and indicators arose as a potential threshold to advancing work on Roma health. Advisers suggested that this would be essential to meeting the evidentiary burden required for a discrimination claim. Claude Cahn pointed out that this was a fraught issue within the Roma community given the legacy of using ethnic data for invidious purposes such as coercive sterilization. Roxana Bonnell noted that this issue was "off the table" for the time being at OSI, at least until such time as Roma NGOs had the capacity and interest to take on health issues. Catherine Mumma advised, based on her experience negotiation provisions of the UN disability convention, that collecting ethnic data about health was probably acceptable as long as NGOs were collecting the data, not the state.

Finally, Delme Cupido queried what specific issues had motivated RHP to place such a strong emphasis on Roma women's health. Claude Cahn suggested that the issue of coerced sterilization of Romani women warranted making this a priority, and that much work remained to be done on this issue despite some advances in recent years.

Sexual Health and Rights Project

Having been established around the same time as LAHI, the Sexual Health and Rights Project (SHARP) has since its inception been dedicated to incorporating legal and human rights strategies into its advocacy on behalf of socially marginalized groups. SHARP hired a LAHI adviser, Ali Miller, who led this discussion along with SHARP Program Associate Rachel Thomas. Miller and Thomas clarified that while abuses of sexual rights occur across multiple populations, SHARP's priority was to focus on groups that were marginalized even within this broad class, namely, sex workers, LGBT communities, and people living with HIV. They asked the advisers to identify "key issues arising within the field of sexual health that implicate legal and human rights questions." While some ideas were put forth, this discussion ended up being very wide-ranging and involved a lot of back-and-forth about SHARP's precise approach to sexual health and rights.

A question arose as to whether, as in the case of harm reduction, there is a community of sexual health NGOs that are interested in using legal and tools to advance the rights of sex workers and LGBT communities. Balazs Denes said it was "very hard to find organizations that are not using a paternalistic approach to sex work." Ali Miller asked whether and how it was possible to support sex workers can speak for themselves in the absence of these NGOs. Liesl Gerntholtz cited the example of the South African Sex Worker Education and Advocacy Team (SWEAT) as a group that has worked with sex workers to take cases of dismissal of sex workers from escort agencies to the Commission for Conciliation, Mediation and Arbitration (CCMA) on the grounds of breach of contract. It was agreed that finding legal advocacy groups willing to work with sex workers in a "non-patronizing" way should be one of SHARP's goals.

"There are many examples of countries where services are provided even though legal restrictions exist. There are also many places where legal restrictions are absent and, still, there are no services."
-Ralf Jurgens

The discussion then turned to the issue of criminal law reform and the fact that anti-prostitution laws can facilitate abuse of sex workers by police. Catherine Mumma said there was a need to engage in law reform efforts in Kenya, where "there's a lot of abuse directed at sex workers just because they are sex workers," and "some of this is facilitated by laws that can't really be interpreted." Liesl Gerntholtz said there were advocacy opportunities in South Africa, as the South African Law Reform Commission was investigating sex work with a view toward eventual law reform. In addition, a legislators recently proposed an addition to South Africa's sexual offenses bill that would criminalize the clients of sex workers (but not sex workers themselves), a model that has existed in Sweden with reportedly dubious benefits for sex workers' rights.

Finally, it was asked whether HIV/AIDS service providers that reach sex workers directly with condoms and other health services might integrate legal services into their work. This would fit very well with LAHI's mandate to co-locate legal services and health services, something LAHI is supporting in the context of harm reduction. Ralf Jurgens suggested it would make most sense to propose this to HIV/AIDS groups that are already interested, as typically HIV/AIDS service providers are already struggling to accomplish too much with too few resources. Delme Cupido suggested that individual legal representation (e.g., against charges for violating loitering laws) might work better than systemic law reform in countries where the latter is not favored by the political environment. He agreed that “HIV is a reasonable entry point” for the delivery of such services and for arguments that sex workers should not suffer discrimination and other human rights abuses.

Law and Health Initiative
Strategy Working Group Meeting

Open Society Institute
New York, NY
September 11-12, 2006

Meeting Agenda

Day 1: September 11, 2006
Setting Law and Health Priorities

08:30 Breakfast

09:00 Welcome

09:05 Introductions

09:35 History and overview of Law and Health at OSI

10:15 Question 1: *How can LAHI best expand access to legal services for marginalized groups?*

- What concrete targets should be established in the coming years?
- What are the principal barriers to achieving these targets?
- What strategic partnerships would help overcome these barriers?

Facilitator: Corinne Carey

11:25 Tea break

11:40 Question 2: *What is the most effective way for LAHI to develop a new generation of "public interest health lawyers"?*

- What works (and what doesn't) in terms of building health law programs in universities?
- How can university-based health law programs promote the development of independent civil society?
- How might LAHI promote increased clinical legal education in health?

Facilitators: Rebecca Cook and Joanna Erdman

12:50 Lunch

13:30 Question 3: *What is LAHI's most strategic contribution to the patients' rights movement?*

- Who is doing the most effective legal work in the area of patients' rights?
- How (and where) can LAHI secure tangible legal victories in this area?
- What can LAHI contribute to patients' rights work that other organizations and foundations are not contributing?

Facilitator: Judy Overall

14:40 Question 4: *What is the role of the mainstream human rights movement in advancing LAHI's issues and priorities?*

- What is the most effective health advocacy currently being conducted by mainstream human rights groups?
- What types of health issues are mainstream human rights groups most interested in, and how can LAHI support them?
- How should organizations focused on civil and political rights best approach health rights?

Facilitator: Francoise Girard

15:50 Tea break

16:05 Working groups

17:15 Adjourn

18:30 Dinner (*Sapphire*, 1845 Broadway)

Day 2: September 12, 2006
Applying Priorities to Issue Areas

08:30 Breakfast

09:00 Recap of Day 1

09:15 Working groups report back

10:45 Tea break

11:00 Issue area 1: Harm reduction
Kasia Malinowska-Sempruch and Daniel Wolfe

12:15 Lunch and discussion: Issue area 2: Roma health
Roxana Bonnell and Heather Doyle

13:30 Issue area 2: Sexual health and rights
Ali Miller and Rachel Thomas

14:45 Issue area 3: Health media and monitoring
Roxana Bonnell

16:15 Tea break

16:30 Issue area 4: Palliative Care
Mary Callaway and Kathy Foley

17:30 Adjourn

Law and Health Initiative
Strategy Working Group Meeting

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