Advancing the Sexual and Reproductive Health and Human Rights of Injecting Drug Users Living with HIV

*A POLICY BRIEFING

Thirty-six year-old Ukrainian mother of one Yana Komopkav is HIV-positive. Yana works as a social worker assisting people infected and affected by HIV in the city of Donetsk. Credits: Carlos Cazalis/Corbis

Advancing the Sexual and Reproductive Health and Human Rights of People Living with HIV: A Guidance Package[1] is a detailed and comprehensive report that describes the key areas of policy and practice change needed to advance the sexual and reproductive health and human rights of people living with HIV.

In order to examine issues that affect specific populations key-population specific Policy Briefings to compliment the Guidance Package have been created. Five key populations affected by HIV have been selected: men who have sex with men; sex workers; injecting drug users; prisoners and migrant populations. This Policy Briefing focuses on injecting drug users living with HIV and aims to provide advice and support to those advocating for the sexual and reproductive health (SRH) and human rights of injecting drug users at a national and international level.

WHY FOCUS ON INJECTING DRUG USERS

People who inject drugs are a population for whom HIV infection adds urgent health and human rights issues to an already powerful set of factors leading to social stigma and marginalisation. The United Nations estimates that illegal drugs such as heroin, cocaine and amphetamines are injected by some 16 million people around the world. Many of these people are dependent upon the drugs they use, and may suffer severe withdrawal symptoms without them.[2] There is strong social prejudice against the recognition that injecting drug users (IDUs) living with HIV possess sexual and reproductive needs and rights, that they may experience erotic desires and wish to have children and raise families. These needs and rights are taken for granted by much of the general population, and considered a basic part of being human. This Policy Briefing seeks to normalise sexual pleasure, child-bearing and child-rearing for the IDU living with HIV community, to examine the problems that stand in the way of this recognition of basic human needs and rights, and to propose ways in which policy-makers, service providers, clinicians and civil society can address these obstacles to health, happiness and fulfilment.

This Policy Briefing seeks to discover the key needs and rights of this community around sexual and reproductive health. While many of these issues cut across the entire population of people living with HIV, and acknowledging that some individuals will be members of several of these groups, it is nonetheless true that IDUs face a specific set of disadvantages and multiple exclusions.

Consultations with IDUs living with HIV indicate that the key issues facing their population include, but are not limited to:

- Criminalisation of drugs.
- Widespread prejudice against people who use drugs.
- In some regions, lack of opiate substitution therapy and harm reduction services.
- The gap between formal rights and entitlements, and the actual delivery of these on the ground, which is often due to the attitudes prevalent amongst clinical staff.
- Fear that HIV-positive IDU parents will lose custody of children, whether by legal or cultural mechanisms.
- Fear of accessing SRH services due to legal repercussions of drug use.
- Lack of information about drugs and pregnancy.
- Denial of healthcare services such as ARV treatment (ART) due to drug use.
- Prevalence of Hepatitis C (HCV), tuberculosis (TB) and other diseases that also impact on the IDU community.
- Issues around contraception.

HOW THIS POLICY BRIEFING WAS DEVELOPED

This Policy Briefing was prepared in consultation with the IDU living with HIV community, the elaboration of which was led by the International Network of People who Use Drugs (INPUD) in collaboration with GNP+. A reference group composed of IDUs living with HIV activists provided INPUD with themes and issues to be covered, and commented on the draft at various stages.

SEXUAL AND REPRODUCTIVE HEALTH NEEDS AND RIGHTS OF IDUS LIVING WITH HIV

The major problems facing injecting drug users living with HIV stem from the social and cultural prejudices that cluster around drug consumption; this is undoubtedly linked to the illegal status of drugs. This fact recently prompted Anand Grover, UN Special Rapporteur on the right of everyone to the highest attainable state of health, to state that "the criminalisation of these practices actually hinders the right to health of all persons."[3] However, while drug use remains criminalised, the clash between drug policy and health and human rights policy is a reality that IDUs living with HIV are forced to confront in their daily lives. The United Nations fully recognises the intimate link between health and human rights, and has said so in numerous resolutions.[4] This right is explicitly extended to people who use drugs. Yet prejudice against IDUs underlies numerous problems faced by this population: these can include denial of Opiate Substitution Therapy (OST) (despite its proven scientific efficacy), refusal of Anti-Retroviral Therapy (ART) due to continuing drug use, and lack of scientifically proven harm reduction interventions such as Needle and Syringe Programmes (NSPs). These types of problems vary across geographical location; there are countries in which such therapies and services are themselves against the law. Just as problematic, however, is *the reality gap*—the distance between what is formally available to IDUs, such as harm reduction services, equipment and OST, and the *actual practice on the ground*; in Asia, for example, IDUs inform us that staff have an "abstinence culture".[5] These staff attitudes push clients toward abstinence against their wishes, and in contravention of their formal rights.

In specific reference to sexual and reproductive health needs, perhaps the greatest fear for IDUs is having their children forcibly removed by the state. Profound anxieties linked to anticipated legal repercussions exist around approaching sexual and reproductive health services regarding pregnancy and childbirth. Requirements for contraception and prophylaxis exist, and both male and female condoms must be made available by right. The combination of illness and drug dependence often results in poverty, and it is essential that needs for housing and shelter, as well as other social entitlements such as financial support, must be available. Needs, of course, vary by gender, age and so on - these specific necessities will be addressed in later pages.

NOTE ON CRACK, HIV & SEXUAL AND REPRODUCTIVE HEALTH RIGHTS

People who inject drugs are and should remain the primary focus of HIV prevention work with people who use drugs. However, stimulant users, and particularly people who use crack, have a heightened risk of HIV exposure. While transmission routes are not as clear cut as with people who inject drugs, people who use crack are clearly a distinct population affected by HIV. There are a number of factors informing the pattern of exposure of people who use crack. They include drug related risk, sexual health risks, depleted immune systems, association with other populations that have high levels of exposure to HIV, and engagement in the sex trade. These risks are coupled with the disinhibition and compulsive behaviour patterns associated with crack.

Stimulant drugs and alcohol have been demonstrated to have a particular effect on sexual risk behaviour and can create the conditions within which HIV and other sexually transmitted diseases may be shared. UNAIDS acknowledges the need to develop a greater understanding and more effective responses for people who use stimulant drugs in relation to HIV prevention, testing and treatment.

ADVOCACY – SEXUAL AND REPRODUCTIVE HEALTH AND RIGHTS OF IDUS LIVING WITH HIV, IN GENERAL

IDUs living with HIV urgently need advocacy support around decriminalisation of drug users. Advocacy should focus on influencing governments to understand and respond to drug use in public health terms rather than criminal ones, to provide suitable treatments; replace moral attitudes toward drugs with a pragmatic approach, and to ground clinical and therapeutic practice in scientific evidence. In drug treatment, there should be no "one-size-fits-all" approach.

Advocacy must be aware that the existence of formal patterns of service provision and the formal existence of rights, while necessary, may mean little on the ground. Consequently, in addition to pressing for policy changes at international, regional, national and local levels, advocacy should be *individually focused* to ensure that formal rights and entitlements to healthcare, security and social inclusion are not blocked by institutional cultures of prejudice in clinics, treatment centres, and prisons.

Finally, and importantly, IDUs living with HIV should be regarded as a resource whose unique experiences should be drawn upon by policy-makers, programme managers, researchers and non-governmental organisations. Advocacy should emphasise the value of this resource in all circumstances.

GENDER-RELATED SEXUAL AND REPRODUCTIVE HEALTH NEEDS AND RIGHTS OF IDUS LIVING WITH HIV

Sexual and reproductive needs of IDUs living with HIV naturally link to the specifics of gender: male, female and transgender. Gender inequalities therefore cut across numerous issues and problems that arise around these needs. Legal arrangements can mean women have no rights of property and inheritance when their husbands die, thus providing a route into poverty. Women generally have less social, political and economic power than men; for female IDUs living with HIV, these inequalities are aggravated by stigma around both HIV and illicit drugs.

In some parts of the world, women must obtain the permission of husbands to use health clinics and contraception; they fall victim to gender-based violence, rape, low self esteem, all of which impact their sexual and reproductive health. Sexual violence, including marital rape, should be prosecuted as criminal acts. Girls are often expected to abstain from sex, which makes them reluctant to use sexual and reproductive health (SRH) and sex education services. Women are placed in danger of severe stigmatisation and even physical violence if their drug use and/or HIV-positive status is disclosed, a major factor discouraging the use of SRH services.

Contraception is a very important issue for IDU women living with HIV; menstruation often ceases with regular use of opiates, which can make it difficult to detect pregnancy. It is vital that the full range of contraceptive options be made available, and that women are not forced to use a particular method in order to comply with ART contraception stipulated by service-providers. Family planning and abortion choices should be made with the same range of choices available to women who are not HIV-positive; pressured or forced sterilisation is diametrically opposed to the human rights of IDU women living with HIV and should be specifically outlawed.

Former IDU who benefited from an Harm reduction programme. Supported by an NGO, he created an income generating activity as a painter. Credits: UNAIDS

In our consultations, we found that perhaps the greatest fears of IDU women living with HIV focused not so much on having children but on the difficulties of keeping them, since discrimination against such parental choices by IDUs is very widespread in society and amongst health workers. IDU women living with HIV seek protection against the threat that their children will be removed by the state. The provision of peer led support and childcare services would provide a valuable resource to assist IDU HIV-positive parents through these circumstances.

The prevalence of HIV is higher than average amongst sex workers; some IDU men and women turn to sex work to support themselves and their dependent drug use, particularly where illness and marginalisation result in lack of alternative means of coping with poverty. Many programmes pressure IDUs living with HIV to end sex work, rather than offering empowerment through harm and risk reduction interventions. Sex workers obviously face the greatest problems where such work, as well as their drug use, is illegal.

The problem of gender equality has male dimensions, too; for example, men should be educated and supported to go beyond the traditional masculine roles.

Treatment for sexual dysfunction should be available. Opiates and stimulants (such as crack or methamphetamine) can impact adversely on sexual functions such as erection or ability to achieve orgasm. These can often be alleviated through adapting medication dosages, and so on, but it is important that treatment be available if IDUs living with HIV are to achieve their SRH rights.

GENDER-RELATED ADVOCACY

Advocacy should be centred on countering the assumption that the HIV-positive IDU community cannot, does not and should not want to bear and raise children. Support is urgently required to empower reproductive rights in the face of prejudice, and to enact legal, healthcare and social mechanisms to facilitate it.

AGE-SPECIFIC SEXUAL AND REPRODUCTIVE HEALTH NEEDS AND RIGHTS OF IDUS LIVING WITH HIV

Young people share with women a general disadvantage when compared to adult men; they have less access to political, social and economic power. Young drug users living with HIV, in particular, face multiple barriers in accessing SRH rights and services.

All young people should have access to accurate and comprehensive sexual health education.

Confidentiality is a critical issue for young people living with HIV, especially when they are also IDUs. It is likely to deter them from seeking an HIV test, for example, if they fear that the fact may be known to their parents and their community. Again, stigmatisation is the overarching issue here. Fears and prejudices around sexuality are prevalent in many communities, and are often included in countries' legal frameworks. Where this is the case, and laws compel the parent or guardian to provide consent for a young person to approach SRH services, legal change is imperative, as such laws can prevent young people accessing information and support that are integral to their right to health. In the case of young people below the age of sexual consent, adolescents should be permitted to access services at an earlier age should they choose to. They should be able to obtain the contraceptive method of their choice, when supplied with full information.

Young people who are IDUs and HIV-positive face multiple exclusions, which radically endanger both their general health and their sexual and reproductive health and rights. The same harm reduction ethos outlined above with respect to confidentiality and access to healthcare should apply to IDU adolescents living with HIV, who are likely to be exposed to a diverse set of risks for which guidance and support are essential. This is a controversial area, even in a field riven with differences of opinion; but if young people are IDUs and living with HIV, the case for life-saving OST and harm reduction services becomes all the more compelling.

It is also essential to avoid criminalising young people and to direct them into evidence-informed drug and health treatment, and services offering psychological and social support. In almost all countries, the prevalence of HIV is greater in prisons than outside. The gender-specific needs and desires of young people should be taken into account, in addition to the different problems that may be faced.

The same principle applies to the question of age more broadly: we must not fail to recognise the existence of an ageing population of IDUs living with HIV, with their own needs and rights, many of which are severely under-researched. Older people are prone to the frailties of ageing, and may have long careers of injecting drug use, criminalisation, stress and isolation behind them. They may be in sore need of shelter, housing, physical and psychological security, and advice around benefit entitlements. The specific set of needs will vary by culture and region, but elderly people around the world are often believed to lack erotic needs and desires, especially if they are IDU and living with HIV. This must be addressed.

AGE-SPECIFIC ADVOCACY

Advocacy should focus on the application of SRH rights across the age range, recognising the specific issues related to each age group. For young people, confidentiality is a critical right to be established and defended. Where laws preclude confidentiality by insisting on parental consent, these laws need to be changed as they are in conflict with fundamental health and human rights. Older people should not be forgotten in advocacy work. With drugs often linked to youth in the popular imagination, it is important to recall that many drug users are actually people of mature years, with needs that change as they grow older. This social invisibility should not be reproduced by healthcare providers.

RECOMMENDATIONS FOR SEXUAL AND REPRODUCTIVE HEALTH AND HIV PROGRAMME MANAGERS AND POLICY MAKERS

Sexual and reproductive health (SRH) services must be delivered to all people living with HIV, regardless of their gender, sexuality or other social and cultural identity. This includes injecting drug users and non-injecting drug users such as users of crack cocaine.

- Donor governments should increase funding to meet need, mixing general budget support with politically sensitive areas such as those involving HIV-positive IDU populations.
- Public funds or insurance schemes should fund health care, not fees from the end user.
- Donor governments should fund coverage of shortages in healthcare workers where necessary.
- Drug treatment, HIV care and treatment and comprehensive SRH services should be thoroughly integrated.
- A continuum of care should be established, covering all the stages of human life and linking HIV prevention, care and treatment.
- All those who are tested for HIV (including pregnant women) should also be able to access appropriate HIV treatment, care and support.
- IDUs should have meaningful involvement in decisions made about their care, with formal and informal mechanisms of input into decision-making processes and structures.
- Voluntary and confidential testing and counselling should be available to all, including multiply excluded groups such as IDUs.
- All those living with HIV, including IDUs, should have access to the full range of sexual and reproductive health services.
- HIV status and drug use, as such, should not form the basis of decisions regarding child custody.
- As and when HIV testing is scaled up, treatment, care and support systems must be expanded to ensure full availability of services to meet increased demand.
- Healthcare workers should receive training in human rights and their relation to health, and which addresses the mythologies which underlie popularly held prejudices regarding drugs and drug use, including the ways that these impact on sexual health and reproduction.

RECOMMENDATIONS FOR HEALTH CARE WORKERS IN SRH AND HIV SETTINGS

Staff in these healthcare settings should receive education and training in human rights and relation to health. They should be trained in the management of drug use, and in the linkages between drug use and sexual and reproductive health rights.

The SRH needs and rights of IDUs living with HIV must be fully recognised. The HIV-positive IDU community should be fully engaged in providing this training to healthcare staff.

Staff should be monitored in order to ensure compliance with SRH and human rights regulations, and that "cultures of abstinence" are replaced by therapeutic alliance and genuine patient choice (the latter may, of course, include abstinence.)

The full range of drug treatment and harm reduction modalities should be made available, including OST and needle exchange, and clients should participate

meaningfully in all decisions related to the management of their drug use.

All available contraceptive methods should be offered, and no coercion used to direct clients toward a particular one.

- Access to abortion should be offered where legal, along with post-abortion care.
- Counselling and support should be offered around pregnancy needs.
- Counselling and support for infant feeding should be available.
- Diagnosis and treatment for STIs should be available.
- Diagnosis and treatment for Hepatitis B and C should be available.
- Diagnosis and treatment for TB should be available.
- Counselling related to violence should be available.
- Counselling and treatment related to sexual dysfunction should be available.

Support and counselling, and if necessary legal expertise, should be made available as resources to assist IDUs living with HIV to maintain custody of their children, in cases where drug use and HIV are used as the reasons to remove children from their HIV-positive IDU parents.

Outreach services should be set up in order to extend service provision to hard-to-reach communities such as IDUs, and should make full use of peer workers to help achieve this objective.
The essential medicines lists should be kept under review, and services should ensure that they include sexual health and reproduction commodities, as well as those used for drug treatment.

RECOMMENDATIONS FOR COMMUNITY AND CIVIL SOCIETY ORGANIZATIONS AND NETWORKS OF PEOPLE LIVING WITH HIV

There are a number of key implications stemming from these considerations for advocacy and support from civil society and activist groups. Again, many of these will apply to the whole population of people living with hiv; we concentrate here on those that impact especially on the hiv-positive IDU community.

Perhaps the first thing that advocates must do is to disseminate the simple fact that people who inject drugs and live with hiv *do in fact have sexual and reproductive needs*. There is, as discussed above, a widespread perception that this particular population does not share these needs, and the rights that go with them, with the remainder of humanity. This perception is present amongst healthcare workers too, and must be countered with the facts.

The most effective way of opposing this culture of prejudice is for the networks of people living with hiv to take the lead role in advocating for change. However, IDUs living with hiv are multiply disadvantaged, and will require energetic assistance and considerable resources from civil society groups in order to advocate effectively. Nonetheless, their meaningful involvement remains the key resource for change.

The criminalisation of drug use is incompatible with health and human rights. This legal prohibition runs counter to the imperatives of health and human rights, and the criminalisation of the HIV-positive IDU population remains one of the leading obstacles to social inclusion and to accessing healthcare and drug treatment services. Where IDUs are imprisoned, they are made especially vulnerable to infection with HIV, HCV and other conditions. The lack of harm reduction services is also a major barrier to healthcare participation and infection control. Advocacy must continue to press for decriminalisation and/or depenalisation of drug use, for the availability of scientifically evidenced drug

treatments and harm reduction interventions. Advocates should work against all those laws that effectively criminalise people living with HIV, such as laws against stigmatised sexualities and practices, laws against transmission of HIV, against people with HIV marrying, and so on. Where laws restricting discrimination are already in place, advocates must monitor to ensure that the reality gap between formal rights and actual rights is closed. In the case of IDUs living with HIV, this may entail one-on-one advocacy at clinics and treatment centres to prevent cultures of prejudice being maintained at the expense of the health needs and rights of clients.

It is also vital to work for more and better research, addressing the needs of marginalised populations in ways that are relevant to policy. This can be achieved by forging and developing relationships with established research institutions and driving such research on to their agendas. In addition, networks of people living with HIV can themselves be trained and educated to conduct systematic scientific research and analysis. As the Guidance Package puts it: *"Advocacy's greatest ally is evidence"*.[6]

MAIN POLICY AND PROGRAMMATIC CONSIDERATIONS

The first step toward improving the SRH situation of all people living with HIV would be the enactment and enforcement of legislation against discrimination against people on grounds of HIV status.

For IDUs living with HIV, the decriminalisation of drug use represents an equally fundamental necessity; it is difficult to confront social prejudice when it is seen to be supported by the law. Moreover, criminalisation is often in conflict with the fulfilment of health and human rights imperatives, since it tends to drive people underground, into social exclusion and marginalization and away from healthcare and social inclusivity. At the same time, all countries should make OST available. Treatment programmes based on scientifically tested modalities supplemented by the full spectrum of harm reduction services are the best way to reduce risky injecting conduct and HIV transmission.

The transmission of HIV should not be criminalised except in the most exceptional cases. Criminalisation is counter-productive, and, as in the case of drugs, makes risk-reducing training and behaviours that much more difficult to disseminate, since people are unwilling to risk the harsh consequences of disclosing their status. The criminalisation of behaviours such as anal sex is similarly counter-productive; consenting acts between adults in private should not be a matter for the law.

CONCLUDING REMARKS

Confronting the legal, social and cultural obstacles to the enjoyment of full rights to sexual, reproductive and human rights of IDUs living with HIV requires the coordinated actions, energies and wills of HIV networks, non-governmental organisations, scientists, medical professionals, UN agencies and supportive governments around the world.

KEY RESOURCES

GNP+ The Global Network of People living with HIV
www.gnpplus.net

International Network of People Who Use Drugs
www.druguserpeaceinitiative.org

Asian Network of People who Use Drugs
www.anpud.info

International HIV/AIDS Alliance
www.aidsalliance.org

International Harm Reduction Network
www.ihra.net

UNAIDS
www.unaidstoday.org

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[4] For a guide to the UN position, see Office of the UN High Commissioner for Human Rights/World Health Organization: The Right to Health- Factsheet No. 31. Available at: *www.ohchr.org/Documents/Publications/Factsheet31.pdf*

[5] Information provided by the INPUD Interim Standing Expert Group on HIV and AIDS

[6] GNP+, ICW, EngenderHealth, IPPF, UNAIDS. (2009). p. 47.

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About the International Network of People who Use Drugs (INPUD):
The International Network of People who Use Drugs (INPUD) is a movement of people who use drugs (current and former) who support the Vancouver Declaration, which sets out the demand that the human rights of people who use drugs should be respected and for harm reduction measures to be put in place to protect individual and public health. INPUD is a global network that seeks to represent people who use drugs in international agencies such as the United Nations and with those undertaking international development work. INPUD believes that people who use drugs must be meaningfully represented in decision-making processes that affect their lives.

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About the Global Network of People living with HIV (GNP+):
GNP+ is the global network for and by people living with HIV. GNP+ advocates to improve the quality of life of people living with HIV (PLHIV). As a network of networks, GNP+ is driven by the needs of PLHIV worldwide and its work is guided by the Global Advocacy Agenda, determined by and for PLHIV, through the implementation of the GNP+ platforms of action: Positive Health, Dignity and Prevention; Human Rights; Sexual and Reproductive Health and Rights of people living with HIV; and Empowerment.

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Ira, 29, an HIV-positive former heroin user, holds her two-month-old son Kiril in her apartment in St. Petersburg, Russia. It won't be clear whether Kiril has HIV until he is a year and a half old. Credits: Brendan Hoffman/Corbis


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