People who inject drugs continue to be disproportionately affected by HIV because of limited investment in — and access to — proven interventions. Even when effective services are available, severe stigma and punitive laws create barriers to their use, compounding people’s risk of acquiring HIV and hepatitis infection through unsterile injection equipment.

Discrimination against drug users and criminalization of drug use also make it difficult to collect accurate data about people who inject drugs. Estimates of HIV prevalence among people who inject drugs; the size of drug-using populations; and their use of HIV prevention, care, and treatment services are incomplete, as is understanding of their needs and risk behaviors, because many people are unwilling to identify themselves as users of illicit drugs.

All over the world, successful responses to the HIV epidemic have been driven in large part by two key factors: political commitment and agency of the constituency group. For people who inject drugs, neither of these pillars has been given sufficient attention and dedicated focus. In this issue of The Link, our guest authors write about innovative efforts to strengthen both.

On page 4, Judy Chang writes about Afghani women who use drugs—a group who, traditionally, has had about as little agency as it’s possible to have. Chang explains how gaps in the data on these particular women—but also for all women who inject drugs—are particularly pronounced. National and international research and surveillance of people who inject drugs are often gender-neutral or heavily skewed toward the men. Although women who inject drugs are even more hidden than their male counterparts, they account for about one-third of all people who inject drugs.1

Estimates of those receiving evidence-informed and rights-based HIV and harm reduction services are

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**Personal experiences inspired Amran Ismail to establish the first community-based organization in Kuala on the east coast of Malaysia, CAKNA, which supports people who inject drugs.**

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**ARTICLE CONTINUED ON PAGE 2**
also problematic, but coverage is undoubtedly poor. Fewer than eight in 100 people who inject drugs have access to opioid substitution therapy (OST), and only an average of two sterile needles are distributed per month per person who injects drugs. HIV-positive people who inject drugs appear to have lower rates of HIV treatment and viral suppression compared to other key populations, in part because many people do not report their drug use when they seek these services.

Estimating coverage may be challenging, but the evidence base for comprehensive HIV and harm reduction services for people who inject drugs is strong. Distributing free or low-cost sterile needles reduces HIV transmission among people who inject drugs without increasing drug use, and it is most effective when combined with access to OST and HIV counseling and treatment. OST reduces high-risk injection behaviors and drug-related deaths while improving adherence to antiretroviral regimens among HIV-positive people who inject drugs.

Despite the strength of this evidence, most countries continue to emphasize criminalization over harm reduction. Drug use is illegal in all but a handful of countries, and few offer harm reduction services in prisons. In many countries, people who inject drugs experience involuntary drug testing and compulsory detention, or “rehabilitation,” which rarely includes OST.

Lack of commitment is one cause of the failure to heed evidence, as Ralf Jürgens notes in his article on page 5. This, rather than the scarcity or quality of data, is the main reason why people who inject drugs are left behind in the response to HIV. In addition to more comprehensive data, he writes, we need a better understanding of how to promote application of the data we have.

However, a number of promising developments suggest a potential trend toward more evidence-based policies and greater political commitment. In April 2016, The UN General Assembly will hold a Special Session (UNGASS) on drugs. This Special Session will offer member states the opportunity to deliberate on the thorny issues related to drug law reform. For over a year, organizations led by people who inject drugs as well as other stakeholders have been participating in pre-UNGASS consultations to share their practical expertise and experiences.

Most recently, the U.S. Congress effectively lifted a decades-long ban on needle and syringe programs. Malaysia has transformed eight compulsory detention centers into voluntary care clinics and has expanded OST provision in prisons. Tanzania has established the first community-based OST program in East Africa.

Such community action has been instrumental in the development of harm reduction, writes Andy Guise on page 3. His call for research on how to support community action and a study exploring how to support integrated OST and HIV care in Kenya (see page 6) are examples of a much-needed implementation science approach to adapting proven interventions for people who inject drugs in different settings.

A central theme of this issue of The Link is the importance of engaging people who inject drugs in research to guide the programs that serve them. Implementing Comprehensive HIV and STI Programmes with People Who Inject Drugs: Practical Guidance for Collaborative Interventions, to be published in 2016, will be a welcome resource for improving programs.

It’s true that more information is needed to better understand the most effective way to provide services for people who inject drugs and to retain them in the HIV care cascade. But, put into perspective, data are just one part of a bigger picture. In the absence of perfect data, governments must be determined to move from deliberation to action. The history of response to the AIDS epidemic was built through this combination of data and resolve and based on the fundamental principles of people-centered approaches.

LEARNING FROM HISTORIES OF COMMUNITY ACTION

In New York in the late 1970s and early 1980s, before the public health and medical authorities had recognized HIV and taken action, people who were injecting drugs responded to the new challenge facing them. Even hostile policing couldn’t stop the emergence of a market in sterile needles and syringes among thedrug using community to replace the home-made and frequently shared injecting equipment that was being linked to HIV.1

This is just one vignette, from a specific time and place, but stories like this one have occurred many, many times around the world. People who use drugs have been central to the development of HIV and harm reduction services, in settings from Africa and Asia to Europe and America.1,2 Networks in countries across the world, and globally in partnership through the International Network of People who Use Drugs, push for wide-ranging policy reform.

However, community action and mobilization is often marginalized in research. Our evidence and understanding of community organization and action by people who use drugs is limited,3 reflecting an overall gap in research of the grounded experience of those who must confront HIV.4

The context for this gap is an HIV research agenda focused on biomedical interventions. About $1.25 billion is spent on research and development of biomedical methods of HIV prevention, and just 1% of that is oriented toward their social and behavioral dimensions.5 New HIV research priorities from within the NIH’s Office of AIDS Research also focus almost exclusively on cure and treatment efforts.6

Biomedical interventions for people who use drugs are, of course, essential. PrEP, vaccines, and microbicides should all form part of a comprehensive HIV strategy, alongside ART, opioid substitution therapies, and needle and syringe programs. Community mobilization is in turn essential to ensure the relevance of these interventions and their accessibility.7

And yet, community mobilization, especially among people who use drugs, is little understood.8 The cause of this lack of knowledge is partly methodological: community mobilization deals with complex relationships and shifting norms, which are not easily identified and monitored (a randomized controlled trial of organic processes like network formation is not easy, or necessarily desirable).8 But a neglect of community action by people who use drugs in research is also partly political and economic: criminalization and hostility toward people who use drugs flow from all sectors of society, and public health structures are often more interested in top down, biomedical interventions.

Community action, and how to support it, is then a key priority for global health research in the response to HIV for, and with, people who use drugs. Among the many issues to learn about:

- The various roles people who use drugs can play in facilitating access to care within clinics
- How community action can foster new norms that support preventive action and that allow for the uptake of new biomedical interventions
- How people who use drugs, and their networks, are instrumental in altering the structural environment and overcoming barriers, such as police brutality, that create vulnerability to HIV

Self-organized community action in the 1970s and 1980s in New York likely stopped HIV prevalence among people who inject drugs from reaching 70%.1 We need to learn more from these experiences and the ongoing work of drug user networks to foster communities’ ability to protect human rights, and prevent, treat, and care for HIV.

By Andy Guise, IAS-NIDA Research Fellow, University of California San Diego aguise@ucsd.edu

Many thanks to Professor Steffanie Strathdee for comments and support.

Photo Credit: © Nell Freeman for the Alliance

An outreach worker talks with injecting drug users ‘Niko’ and ‘Omar’ in Mombasa, Kenya.
Critical gaps in data and strategic information, which threaten to hamper effective HIV responses, are severely pronounced when it comes to women who use drugs. National and international research and surveillance of people who inject drugs are often gender-neutral or heavily skewed toward the male population. This means that the specific challenges and needs of women in this key population remain unaccounted for. Coupled with the lack of reliable population size estimates of women who use drugs, significant hurdles are present in designing appropriate, tailored, and effective HIV prevention, care, and treatment responses.

In August 2015, Coact and Bridge Hope and Health Organisation worked together with the Afghan National AIDS Control Program (NACP) to collect strategic information on women who use drugs. Afghanistan is one of the lowest ranking countries on the Human Development Index and a country of chronic instability and conflict. Gender inequality is deep-rooted and profound. Afghani women have few legal rights, and they experience low literacy rates—21% among women compared to 51% among men—low participation rates in public life, and a high prevalence of gender-based violence. The last Bio-Behavioural Surveillance study that included women was conducted in 2009 and estimated there to be 110,000 women who use drugs in Afghanistan.

The challenge that presented itself was how to mount an effective HIV response in such a highly complex and high-risk setting, and among one of the most marginalized and vulnerable populations in the world.

Coact was commissioned by the NACP to carry out a community consultation, as part of its mission to involve and consult people who use drugs in the national HIV response. This three-way innovative partnership among Bridge, NACP, and Coact combined community know-how and expertise, national government planning, and international technical support grounded in community-based principles to bridge the gaps in HIV and harm reduction responses.

To ensure that women who use drugs were not left behind, the community consultation had a specific component on women who use drugs and other at-risk women, who were sex workers and wives of PWID. Our community-based approach capitalized on community connectedness and trust among people who use drugs to engage peers, and we were able to include 36 women in our consultation, including hard-to-reach women from the open air drug scene of Kabul. Focus group discussions were structured to collect information on levels of HIV knowledge; access to services related to HIV, harm reduction, and women’s health; and the barriers and challenges to this access.

Our findings revealed that:

• Many women were not aware of available services.
• Some important information gaps are best bridged by peer-based interventions.
• Participants feel a strong need to attract and retain female clients through the provision of child care facilities, gender-segregated services, and vocational training.
• Barriers and challenges include lack of investment in services, extreme levels of stigma and discrimination compounded by gender inequality, lack of personal resources, and gender-based violence.

Finally, the women were asked to identify the most important factor in successfully reaching women who use drugs. They all agreed that the best way to gather data and information and to promote essential HIV, harm reduction, and health services among the community is through other drug users. Peer-led, community-based HIV responses provide a vital link among government, services, and community. These lessons will prove valuable to work among women who use drugs all over the world, not just in Afghanistan. By bringing women who use drugs out of the shadows, hidden populations become visible; easier to engage, count, and account for; and empowered through appropriately designed HIV, health, and social interventions.

By Judy Chang, MIntDev, Coact judychang@co-act.info

Coact training session for women.
Most importantly, perhaps, there is a need to shift from simply calling for more data and for undertaking more research, to developing a better understanding of when data are most useful for decision making and how we can increase uptake of data. This will require a different way of working, across disciplines and communities of researchers, involving activists and people who use drugs. It won’t be easy because there are many vested interests and also a lot of mistrust, but it is a challenge we all need to live up to if we are truly committed to ending the epidemics for everyone.

By Ralf Jürgens, Senior Human Rights Coordinator in the Community, Rights and Gender Department of the Global Fund to Fight AIDS, Tuberculosis and Malaria ralf.jurgens@theglobalfund.org

...while there is no doubt we need more data to be able to provide better services... lack of data is rarely, if ever, the main reason people who inject drugs are left behind in the response to HIV and TB.
WHAT WORKS FOR WHOM AND WHERE: THE VALUE OF IMPLEMENTATION SCIENCE FOR PWID PROGRAMS

In addition to its well established role for the treatment of opiate dependence, medication-assisted treatment (MAT) such as methadone has been shown to support people who inject drugs in accessing and adhering to antiretroviral treatment (ART), leading to positive HIV-related outcomes.1-3 Debates on whether methadone should be available reflect politics and ideology, not human rights and public health.

Methadone works, and there is long experience of its delivery in North America, Europe and, increasingly, Asia. Methadone is now being introduced in settings across Africa in response to the rising role of injecting drug use in HIV epidemics, like in Kenya. But there is little understanding on how to best deliver MAT and integrate it with HIV care in ways that are acceptable for people using these services.

Findings from Tanzania show that an integrated hospital-focused model is feasible and acceptable, although women find access to be difficult.4-6 Integrated care can, and is now being introduced in settings across Europe and, increasingly, Asia. Methadone works, and there is long experience of its delivery in North America, Europe and, increasingly, Asia. Methadone is now being introduced in settings across Africa in response to the rising role of injecting drug use in HIV epidemics, like in Kenya. But there is little understanding on how to best deliver MAT and integrate it with HIV care in ways that are acceptable for people using these services.

Research ongoing in Kenya through the University of Nairobi, Kenya AIDS NGOs Consortium, University of California San Diego, and London School of Hygiene and Tropical Medicine is adopting an implementation science approach to understand community experiences of MAT and HIV care.

In Nairobi, the model of care focuses on hospital-focused delivery and integrated MAT and HIV care. Clients are often euphoric in their praise for the program, with the initiation of methadone equated to feeling “reborn.” The ease of getting ART at the same site is welcomed.

However, lingering concerns remain for some about the visibility of taking HIV medication. Stigma is persistent. For others, travel time to access the methadone clinic—which can take several hours—limits the potential for integrated care. If a daily visit to the clinic can’t be managed, then both daily doses of methadone and HIV care are missed unless carry-home doses can be permitted. Women in particular seem to face disadvantages in accessing methadone.

What is the best role for community outreach workers and nongovernmental programs, who often have developed relationships of several years with their clients? How will communities react to and use methadone?

The need to understand how an evidence-based intervention works in particular contexts represents our growing recognition of the value of an “implementation science” approach.4 As interventions are introduced in particular settings they respond and evolve in response to political, economic, social, and cultural contexts. The era of evidence-based policy is evolving from “what works,” to focus on “what works for whom and where.”5 What works in one social, political, economic, and cultural context may be very different from what works in another.

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What works for whom and where? The challenge for integrated methadone and HIV care in settings like Kenya is likely to focus on developing multiple entry points to respond to varying needs. A fixed site clinic with comprehensive support will suit the needs of many. For others, travel, family commitments, and fear will prevent this, and more community-focused models of delivery may be optimal.6 Our broader challenge is then also in developing a more local, client-centered evidence base for what works.

By Andy Guise, Frederick Owiti, Steffanie Strathdee, Tim Rhodes, James Ndimbii, Emmy Iganyo

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We thank the National AIDS and STIs Control Programme and National AIDS Control Council in Kenya for their support and guidance in the research. The research is funded by the Centre for AIDS Research at the University of California.

In India, the HIV prevalence among people who inject drugs is 10.9%. Targeted interventions for people who inject drugs include needle and syringe programs, free condoms, peer outreach, abscess management and STI services provided by nongovernmental and community-based organizations (NGOs and CBOs); and referrals to government hospitals for opioid substitution therapy (OST), HIV testing services and antiretroviral therapy (ART) for those found positive.

LINKAGES will be providing technical assistance to NGOs and CBOs implementing targeted interventions such as these in five districts of two high-HIV-prevalence states—Guntur, Krishna, and East Godavari in Andhra Pradesh and Mumbai and Pune in Maharashtra. The estimated number of key population members in the districts is 108,234 of whom 2,732 are people who inject drugs.

LINKAGES’ technical assistance will focus on the following:

- **Addressing dual risk.** LINKAGES will conduct an exercise to revalidate key population estimates and map new sites and unreach populations. Female sex workers, men who have sex with men, and transgender people who are also people who inject drugs will be identified and provided appropriate services to address their dual risks.
- **Assessing the feasibility for secondary distribution of needles and syringes.** To improve access to and coverage of needle and syringe programs, LINKAGES will explore the feasibility of secondary distribution through preferred health care providers, government primary health care centers, nontraditional outlets, and peer volunteers.
- **Improving OST coverage.** To improve coverage of OST services, LINKAGES will explore lower threshold strategies such as take-home dosing and task shifting of OST program management to nurses once a patient’s dose has been stabilized.
- **Mobilizing the community and generating demand.** Engaging and working with both the community of people who inject drugs and other community organizations that support them will strengthen linkages to services and increase the probability of retention and outcome success along the cascade.  
  
  LINKAGES will form support groups for young people who inject drugs and for family members to help enhance access to OST and other harm reduction services. Peer navigators will be trained and placed in the HIV testing and ART centers to facilitate referrals and provide adherence support to HIV-positive people who inject drugs.
- **Strengthening links to testing and treatment.** Community-based HIV screening services will be established at sites where HIV testing coverage is low. LINKAGES will strengthen referral services to government HIV testing centers for confirmation of diagnosis and to ART centers for treatment.
- **Develop referrals for hepatitis B/C and tuberculosis (TB).** Referral linkages will be established with government hospitals for screening of hepatitis B and C. All people who inject drugs, regardless of HIV status, will be verbally screened for TB at regular intervals. Those suspected of having TB will be referred to diagnostic centers, and confirmed TB cases will be linked to the nearest provider of directly observed treatment short course for treatment.

HIV prevalence among people who inject drugs in India is high with previously unknown pockets of infection emerging from new areas. However interventions are currently available to only a small proportion of people who inject drugs in India. Particularly because of stigma and discrimination, greater attention will be needed to avoid losses at every step of the HIV cascade. LINKAGES India will be working to identify the cause of these losses and address these issues to help achieve the UNAIDS goal of 90:90:90.

By Anjana Das, FHI 360

Gregorio Soriano Urbaez moved to Honduras in September 2015 to serve as the country representative for LINKAGES. The move coincided with the launch of LINKAGES Honduras last November and was closely followed in December by the birth of Gregorio’s son, Sebastián Elías. The new country representative (and father) finds himself with the exciting challenges of “parenting” two very different newborns. He recently took time from his new roles to answer some questions about the first few months of life for LINKAGES in Honduras.

**What is LINKAGES doing in Honduras with key populations?**

We are working with the Honduran Ministry of Health, plus local and international partners, to improve the delivery of HIV services to key populations, specifically men who have sex with men, transgender people, sex workers, and those key populations among the Garifuna population. We assist these organizations with the use of evidence-based interventions, the collection and use of strategic information, and the documentation of best practices. Our objective is to save (and prolong) lives by increasing HIV detection, reducing transmission, and retaining individuals in treatment.

**What are your responsibilities for LINKAGES Honduras?**

I provide overall vision and leadership for the project in Honduras and manage its implementation and monitoring. Among other tasks, I oversee work plans, budgets, technical assistance in program operations, project reports, quality control, and the efforts of the project’s staff. I also act as liaison between LINKAGES, USAID Honduras, the Government of Honduras, stakeholders, donors, and all other relevant players and client country partners.

**What challenges have you encountered?**

There is still a lot of stigma associated with HIV testing and HIV-positive diagnoses in Honduras, even among health care workers. As a result, key populations do not seek HIV testing and treatment services. Hard-to-reach populations are also not accessing these services, so very few new HIV-positive individuals are being identified.

**What is your wish for key populations?**

My greatest desire is to integrate key populations into a strong health care network that will provide access to high-quality, stigma-free HIV treatment and prevention services. This will ensure that key populations groups have a better quality of life and, for those members who are HIV positive, attain an undetectable viral load by being retained in the HIV cascade.

**What excites you most about your work?**

I am absolutely thrilled to be part of a community of change agents working to ensure that our key population groups have the scientifically based information and practices needed to reduce spread of HIV and the stigma that surrounds it.

I am also pleased to help local and national constituent-led organizations become empowered so they can secure, promote, and defend their rights within the public sphere through peer-support networks and public policies. When key populations achieve full inclusion and equality, the entire nation will benefit as we’ll become a more just and understanding society.

*By Michael Szpir, FHI 360*
NEW RESOURCES: RESEARCH, REPORTS, AND WEBSITES

TRANSGENDER WOMEN AND PRE-EXPOSURE PROPHYLAXIS: WHAT WE KNOW AND WHAT WE STILL NEED TO KNOW

Published by the National Center for Innovation in HIV Care, this report includes a discussion of the research on the safety of pre-exposure prophylaxis (PrEP) use among transgender women, guidance for clinicians on prescribing PrEP to trans women, and recommendations for more research on HIV prevention technologies for this population.

SERVICES UNDER SIEGE: THE IMPACT OF ANTI-LGBT VIOLENCE ON HIV PROGRAMS

This new report from the Global Forum on MSM and HIV (MSMGF) examines levels of violence against lesbian, gay, bisexual, and transgender (LGBT) people around the world. The report indicates that activists and HIV service providers are especially vulnerable, with attacks against community leaders resulting in interruptions to life-saving HIV services. The report underscores the urgent need for real, institutionalized protections for marginalized communities.

RESPECT, PROTECT, FULFILL: BEST PRACTICES GUIDANCE IN CONDUCTING HIV RESEARCH WITH GAY, BISEXUAL, AND OTHER MEN WHO HAVE SEX WITH MEN (MSM) IN RIGHTS-CONSTRAINED ENVIRONMENTS

These recently revised guidelines were developed for researchers, community-based organizations, and governmental agencies that engage in research in rights-constrained environments. The guidance is intended to help these stakeholders to better design and conduct meaningful research on HIV among MSM in challenging social, political, and human rights contexts; to help protect the rights and safety of MSM participants and communities involved in research; and to offer lessons learned through case studies of research and community partnerships.
SEX WORKERS WHO USE DRUGS: ENSURING A JOINT APPROACH

http://www.clac.cab/portfolio-item/sex-workers-who-use-drugs

This briefing paper by The Global Network of Sex Projects and The International Network of People who Use Drugs addresses the lack of recognition of the intersections between two key population communities. The document provides an overview of some of the most endemic and substantive ways in which sex workers who use drugs face double criminalization, compounded marginalization and social exclusion, and heightened harassment from health care workers and other service providers. Case studies highlight efforts to meet the needs, and advocate for the rights, of sex workers who use drugs.

COMMUNITY LEADERSHIP AND ACTION COLLABORATIVE (CLAC)

http://www.clac.cab/

The MSMGF and LINKAGES recently announced the launch of a redesigned website for the CLAC, which features a resource library for key-population-related policy and research. The site will serve as an online hub for information and resources on HIV among sex workers, men who have sex with men, people who inject drugs, and transgender people. The library serves a range of audiences including policymakers, advocates, program planners and implementers, health care workers, and peer educators. The site links beneficiaries with tools and resources that build and strengthen communities with a focus on organizational and technical capacity.

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LINKAGES, a five-year cooperative agreement funded by the U.S. President’s Emergency Plan for AIDS Relief (PEPFAR) and the U.S. Agency for International Development (USAID), is the largest global project dedicated to key populations. The project is led by FHI 360 in partnership with IntraHealth International, Pact, and the University of North Carolina at Chapel Hill.

The contents of The LINK do not necessarily reflect the views of PEPFAR, USAID, or the United States Government.

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Send feedback to LINKAGES@fhi360.org

Thank you to the following for submitting photos for the LINKAGES banner: FHI 360’s Asia-Pacific Regional Office (Ian Taylor and Mr. Naysokhim); Global Forum on MSM & HIV; Global Network of Sex Work Projects; and the International Network of People who Use Drugs.