



THE LINK

News About HIV Prevention, Care,
and Treatment for Key Populations

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TRANS-forming: DATA FOR DECISION MAKING

Throughout this edition of The LINK, our guest authors are brimming with optimism about the world’s increased attention to the human rights and health needs of transgender people—thanks to decades of advocacy by the trans community. Internationally, the transgender movement has been particularly strong in Asia and Latin America, where trans men and women are celebrating their identity and fighting for social change. In Bangladesh, hijras, who identify as neither male nor female, led Dhaka’s first pride parade in 2014. More than 1,000 Bangladeshi hijras marched to mark a year since their official recognition as a third gender. In 2012, Argentina’s government passed transgender rights regulations that are considered to be some of the world’s most progressive, and in 2013, Chile began to cover sex reassignment surgery under the government plan.

Certainly, we should celebrate these and other hard-won reforms. But the trans community and its allies also remember that trans men and women continue to face stigma, discrimination, violence, and, particularly for trans women, a disproportionate rate of HIV infection. Most of what we do know about trans women and HIV comes from studies in the United States and other western countries, though that has begun to change. (See Tonia Poteat’s article on page 4 for more information about trans women in the HIV cascade.) Even less is known about trans men, though according to a Lancet analysis,¹ those who have sex with men are likely to experience a “heightened vulnerability” to HIV.

This dearth of information is not surprising. Few countries issue identification documents in which a person’s self-identified gender differs from his or her assigned sex. Also, the way data are collected contributes to trans people’s relative invisibility. When trans women are diagnosed with HIV, they are often coded as “male,” which makes it difficult to gather reliable data on HIV in these communities. LINKAGES advisory board member JoAnne Keatley, in her article on page 3, provides a more in-depth look at the need to count trans people in public health measurements.

Beyond failure to officially recognize trans people, many countries criminalize “impersonations of the opposite sex,” effectively forcing the transgender community underground. And in 2014, only 39 percent of countries reported that their national AIDS strategies specifically addressed transgender people.

Though their need for health services is great, their experiences in the health system are not. In a 2010 survey of 7,000 transgender people in the United States, 19% reported being refused care because of their transgender or gender

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nonconforming status and 28% said they were subjected to harassment in medical settings.² Even trans-friendly health care providers often are not “trans-competent”; that is they lack training to address trans-specific medical issues. In this study, 50% of those surveyed reported having to teach their medical providers about transgender care.

Despite these often formidable obstacles, the trans community has shown resilience and strong leadership. Trans-led grassroots organizations are challenging the barriers that transgender people face, advocating for their rights, fighting stigma and discrimination, and demanding improved health care. For example, LINKAGES partner Sisters is a Thai organization run by and for trans women. Sisters employs community-based peer educators to help trans women navigate HIV treatment, care, and services. (Read more about Sisters on page 5.) Transgender constituency groups have been partners in the development of the *Transgender Implementation Tool* and the *Asia Pacific Trans Health Blueprint* which, as Darrin Adams discusses in his article on page 6, will be foundational guides

to improving health services for transgender people.

Until recently, the world’s response to HIV has largely overlooked trans people. But due to the hard work of the trans community and their partners, the tide has begun to turn. We must all continue to support these efforts, for trans people need and deserve to be counted. Health care providers must become trans-friendly *and* trans-competent. Researchers must study the needs of trans men and trans women specifically and collect data in a way that correctly captures gender identity. Governments and policymakers must codify the rights of trans people into law and then see that laws are enforced. For through combined efforts made at many levels, health care and social justice can really be transformative.

1. Baral SD, et al. Worldwide Burden of HIV In Transgender Women: A Systematic Review and Meta-Analysis. *Lancet Infect Dis* 2013;13(3):214–222.
2. Poteat T, et al. HIV Epidemics Among Transgender Women. *Curr Opin HIV AIDS* 2014;9(2):168–173.

PROMISING STRATEGIES FOR STIGMA REDUCTION

The *Transgender Implementation Tool (TRANSIT)* operationalizes the trans-specific recommendations in the WHO’s *Consolidated Guidelines on HIV Prevention, Diagnosis, Treatment and Care for Key Populations*. (For more information about the *TRANSIT*, see page 6). Among other topics, the tool discusses promising strategies for building empowerment in the trans community and preventing and responding to stigma, discrimination, and violence. Following is a sample of the recommendations.

- Foster and support programs and advocacy led by the trans community. Areas that have a history of trans people organizing to advocate for their own rights tend also to have the highest standards of care and the most community-based organizations meeting transgender people’s needs.
- Reform laws so that trans people are allowed a legal identity, and all associated identity documents, based on the gender of their choosing.
- Increase the use of information and communication technologies, especially in languages other than English, to reach global trans audiences.
- Develop and improve strategies for measuring, documenting, and monitoring stigmatizing and discriminating events and experiences.
- Implement trans-specific trainings of health care workers on a systematic basis, with buy-in and participation by the ministries of health and in-country educational systems.



Photo Credit: © Ian Taylor

Ms. Popy is a hijra community leader in Bangladesh.

COUNT ME IN!

It is an amazing time in transgender (trans) health. Never before has there been this level of interest and attention being paid to my community. Steadily there is progress being made toward health policy and human rights inclusion. Yet, for all the progress we've made, there remains a challenge in adequately addressing our health and wellness needs. Trans people cannot be fully accounted for in health policy if we are not counted in surveillance and public health measurements. Data used by governments and global health organizations to describe epidemics and allocate funds to steer public health responses do not consistently include measures that capture gender identity. As a result, trans people continue to be included in data describing gay men and other men who have sex with men. This practice leads to erroneous equating of gender identity with sexual orientation and a serious undermining of trans peoples' ability to take leadership of our own public health approaches. In spite of the lack of standardized measures capturing gender identity, studies that have intentionally sampled

trans women have consistently shown them to have among the highest HIV prevalence rates of any population. In some instances, public health data reflect that in addition to high HIV rates, trans women have to deal with a lack of trained, culturally aware providers. As a result trans women who are disproportionately affected by HIV also reflect lower percentages of being linked to and retained in ARV therapy.

Even when public health officials have good intentions and make attempts at inclusion, they often get it wrong. The use of inappropriate measures forces trans people to choose among male, female, and transgender options as if trans people do not have male and female identities. In the best case scenario, this practice captures the existence of a trans identity but does not distinguish between trans male and female identities. In fact many of the issues we deal with have to do with societal views of gender. For example, trans women face problems common to non-trans women, such as gender-based violence, lower pay for equal

work, and more. In order to adequately describe the public health status of all trans people one must distinguish between trans men, trans women, and people who are non-binary. Public health approaches cannot simply be reduced to a "one size fits all" model. We must tailor our efforts to account for the specificities within our community in order to be able to make an impact that is sustainable and that respects our bodies, minds, and identities.

At the Center of Excellence for Transgender Health (www.transhealth.ucsf.edu) we advocate the use of a two-step model to capture both gender identity and sex assigned at birth. We believe that this approach is the most efficient way to delineate differences in identity and anatomy, both crucial for making health care decisions. The model can be used in surveillance as well and will more accurately describe not only issues affecting trans people but also distinguish them from non-trans people such as MSM. If this model is used consistently, we believe it will lead to greater clarity and understanding of the issues we have in common and the differences that make us distinct. At the end of the day, when you are not counted, you don't count.

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Photo Credit: © Cameron Wolf

allianceindia.org

Members of Swing Thailand pose outside the transgender networking zone at the International AIDS conference, wearing costumes they made of condoms.

HIV CARE AND TRANSGENDER WOMEN: WHERE DO WE LOSE THEM ALONG THE CONTINUUM?

With the goal of ending the AIDS pandemic by 2030, UNAIDS has set ambitious intermediate targets: by 2020, 90% of people living with HIV will know their status, 90% of people diagnosed with HIV will be on treatment, and 90% of people on treatment will have a suppressed viral load. Ultimately, the ability to end AIDS depends on reaching key populations—the people who bear a disproportionate burden of HIV.

Transgender women are a highly vulnerable group among key populations; they have a global HIV prevalence of 19% and 49 times the odds of HIV infection compared to the general population.¹ Since these data suggest that about one in five transgender women worldwide may be living with HIV, it's critical to understand what the HIV care continuum looks like for them. The data to answer this question are limited, but what we do know tells us we have much work to do.²

One study among a probability-based sample of transgender women in San Francisco found that while 95% were previously aware of their HIV status and 87% had accessed care in the prior

6 months, only 65% of those living with HIV were on antiretroviral therapy (ART) and only 44% had suppressed viral loads.³

However, a nationally representative sample of people in HIV care in the United States suggests that the news may not be all bad. In this study of more than 36,000 people in HIV care, 80% of the 285 transgender participants were retained in care, 76% received ART, and 68% achieved viral suppression, and their outcomes were not significantly different from nontransgender men and women.

Another population-based study from the Medical Monitoring Project in the United States and Puerto Rico compared transgender women in HIV care to nontransgender people in care. The authors found no difference in the proportion receiving a prescription for ART; however, transgender women were less likely to report 100% adherence and less likely to have durable viral suppression than nontransgender men.⁴ These differences took place in the context of significant structural disparities. The same study found that

transgender women had a greater need for supportive services ranging from mental health and domestic violence services to meals, transportation, and housing.⁴ The need for meals and housing services were significantly less likely to be met for transgender women compared to nontransgender men.

All of these studies took place in the United States, a high-income country with some of the best health care resources in the world. While we don't yet have data about the HIV care continuum for transgender women from other countries, it is likely that transgender women living in countries with greater resource constraints will have more difficulty accessing HIV testing, care, and treatment services. When developing programs to better engage transgender women along the HIV care continuum, it will be important to keep in mind lessons learned from data. We know that it is possible to engage transgender women in HIV testing and care. However, once they are in care, we must address housing instability, food insecurity, and other structural barriers to ART adherence and viral suppression.

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1. Baral SD, et al. Worldwide Burden of HIV In Transgender Women: A Systematic Review and Meta-Analysis. *Lancet Infect Dis* 2013;13(3):214–222.
2. Poteat T, et al. HIV Epidemics Among Transgender Women. *Curr Opin HIV AIDS* 2014;9(2):168–173.
3. Santos G-M, et al. HIV Treatment Cascade Among Transgender Women in a San Francisco Respondent Driven Sampling Study. *Sex Transm Infect* 2014;90(5):430–3.
4. Mizuno Y, et al. Characteristics of Transgender Women Living with HIV Receiving Medical Care in the United States. *LGBT H* 2015;2(00).



Photo Credit: © Ian Taylor

IN FOCUS: TRANSGENDER RESPONSE IN THAILAND

The government of Thailand recently endorsed a “test and treat” policy allowing people living with HIV to access antiretroviral therapy without having to meet a CD4 cutoff. In support of this progressive new policy, LINKAGES is partnering with the local nongovernmental organization Sisters, using an enhanced peer mobilizer approach to increase HIV testing and linkage to care among transgender women.

Although many transgender individuals identify as women, their HIV-related needs have typically been discussed alongside those of men who have sex with men. Established in 2005 and registered as a foundation in 2014, Sisters is the only organization in Thailand that is run by and works for trans women specifically. Supported by the U.S. Agency for International Development (USAID), Sisters focuses on improving the social acceptance, legal rights, and health care of this important key population, focusing on HIV and AIDS.

“The enhanced peer mobilizer model we are implementing with LINKAGES is really elevating the work of our outreach staff to be more comprehensive,”

says Thitiyanun “Doi” Nakpor, the director of the Sisters Foundation.

The model focuses outreach on a small, core team of community-based peer educators who are given a salary and an expanded role in identifying and managing HIV-positive trans women across the HIV cascade. Once an outreach worker identifies an HIV-positive client, the worker helps the client navigate and access clinical services, works to ensure that she remains in care, and offers support and encouragement to initiate and adhere to antiretroviral therapy.

These salaried workers are partnered with a wider, informal network of trans volunteers who identify and refer members of their social and sexual networks for testing. For each trans woman who is successfully tested, the volunteer who referred her is given a small payment.

“In the near future, all of these outreach workers will use smartphones installed with an application called CommCare to collect data and monitor performance in real time,” says Nakpor. “CommCare will also serve as a job aid to standardize the outreach approach and to aid in client follow-up and retention,” she says.

Using the smartphones during outreach, workers will be able to pull up easy-to-use forms for entering information about clients and their referrals. Once the data are entered, they will be immediately sent to a central database that can be accessed through smartphones in participating clinics. When a client comes to one of those clinics, a clinic worker can easily access her records. If the client does not show up for her referred appointment, the system is also capable of sending her a personal reminder via text message.

In addition to using the enhanced peer mobilizer model with CommCare, Sisters is offering rapid HIV testing for transgender women and other key populations in its drop-in center. The organization will also implement oral HIV testing once it is available through LINKAGES. “Ultimately, the goal of all of these interventions is to have no cases of trans women being sick or dying because of AIDS,” says Nakpor.

*By Kerry Aradhya, MS
FHI 360*



Photo Credit: © Sisters Foundation

Staff of the Sisters Foundation, the only transgender-led, community-based organization in Thailand. From left to right: Suriya Rattanayan, Supasin Raksachon, Chayothon Kansae, Chomchaba Sangphon, Pannui Thatpaiboon, Thitiyanun Nakpor, Phonpiphat Potasin, Suma Simla, Chatchaya Wuthijirakarn, Keerati Pollap, Amphon Chailae, and Aris Sangkharom.

THE WHAT, WHERE, AND HOW: MAPPING THE HIV AND COMPREHENSIVE HEALTH IMPLEMENTATION STRATEGY FOR TRANS PEOPLE GLOBALLY

"This is the year for trans," said a donor representative at the kick-off consultation for the *Asia and the Pacific Trans Health Blueprint* (or *AP Blueprint*) in October 2014. In many respects, this was a reading of the tea leaves about what would indeed transpire in the months following—what many trans advocates and their allies have been working toward for years. As trans people have generally become more visible and some have achieved mainstream fame (read: Lavern Cox and Caitlyn Jenner), trans people have become a part of the public discourse.

Now, a collection of global and regional documents (see text box) is emerging that, together, will shift discourse into action to improve the health and human rights of trans people and their communities. Two of these documents are the *AP Blueprint* and the *Trans Implementation Tool (TRANSIT)*.

The *AP Blueprint* is being developed through a collaboration of the Asia Pacific Transgender Network, United Nations Development Programme, and the United States Agency for International Development (USAID)-

funded Health Policy Project. The purpose of the document is to provide a contextual map about where the gaps and points of intervention lie for the realization of comprehensive trans health. The document is grounded in the World Health Organization (WHO) *Consolidated Guidelines for Key Populations* and developed with regional input from trans people, trans health medical providers, WHO, and other stakeholders.

The *TRANSIT* is one of a series of global implementation tools for key populations—sex workers, men who have sex with men, transgender people, and people who use drugs. The *TRANSIT* is a programming guidance document that demonstrates *how* to implement the trans-related recommendations from the WHO *Consolidated Guidelines*. With chapters written by trans people who are members of regional and country-level initiatives, the *TRANSIT* compiles promising practices and evidence-based approaches in five key areas: community empowerment; stigma, discrimination, violence, and human rights; services; service delivery approaches; and program management.

On its own, the *AP Blueprint* could serve as an advocacy tool to demonstrate what is needed for comprehensive health services for trans people and their communities. This demonstration could be further highlighted in technical briefs that feature chapters or sections of interest in a particular region or country. Furthermore, the blueprint could be adapted to

A FAMILY OF DOCUMENTS FOR TRANS HEALTH

A core set of documents has emerged to advocate for the implementation of HIV-specific and comprehensive trans health. They include, but are not limited to:

- The PAHO 2011 Latin America and 2014 English-speaking Caribbean Trans Health Blueprints
- WHO's 2014 HIV Consolidated Guidelines for Key Populations and a policy brief on trans people and HIV
- The forthcoming Trans Implementation Tool and the Asia and the Pacific Trans Health Blueprint

develop modular health provider trainings that might be instituted as part of a national curriculum and other pre-service training points of entry. Used together, the *TRANSIT* and the *AP Blueprint* could make an even larger impact in the region. The *Blueprint* could complement the *TRANSIT* by showing *where* to implement the *how*. Additionally, the *TRANSIT* is a global document that has been synthesized from regional approaches. The *AP Blueprint* could provide the cultural context needed to begin localizing the *TRANSIT* into implementation and adoption at the national and sub-national levels in the Asia-Pacific region.

The *AP Blueprint* and the *TRANSIT*—developed through the hard work of so many people passionate about these issues—will pave the way for trans health and human rights in the Asia-Pacific region and around the world.

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Photo Credit: © Rose Wilcher, FHI 360

Beyonce Karungi, founder and executive director of Transgender Equality Uganda, participated in a TRANSIT consultation in Bangkok earlier this month.

THE PEOPLE @ LINKAGES: STEVE MILLS

In the early days of the HIV epidemic, Thailand's "Condom King" Mechai Viravaidya asked a young intern named Steve Mills to take on an interesting assignment. With the enthusiasm he now brings to his work as a regional advisor to LINKAGES in Asia, Steve, six feet tall, gamely donned a superhero's costume and headed to Bangkok's brothels to distribute condoms to sex workers and their clients. "I must say it was a once-in-a-lifetime experience playing Captain Condom," he remembers with a grin.



Photo Credit: FHI 360

Steve Mills, FHI 360, technical director, health, population, and nutrition portfolio in the Asia-Pacific Region

Steve's 21-year career with FHI 360's programs in the Asia-Pacific region includes serving for eight years as country director in Vietnam. He is currently technical director for FHI 360's health, population, and nutrition portfolio in the Asia-Pacific Region.

What is LINKAGES doing in the Asia region with key populations?

LINKAGES works with local partners in Thailand, Laos, and Indonesia to improve each step of the HIV cascade to ensure that members of key populations receive the services they need and don't fall through the cracks.

How will LINKAGES and its partners reach key populations?

Traditional peer outreach is no longer enough. For example, men who have

sex with men are meeting each other on the Internet, so outreach needs to be there too. We also want to make traditional peer outreach more effective, cost-efficient, and nimble so that outreach cadres can find HIV-positive individuals and those at highest risk in sexual and drug-using networks that may have been previously ignored. This enhanced peer mobilizer approach will link members of key populations with case managers who will expedite access to HIV testing and ART.

We're also using real-time communications technologies and unique identifier codes to confidentially monitor clients so that we can tell when individuals are falling out of the cascade and need higher levels of case management to keep them in the system.

What are some of those strategies?

In Asia, we're helping ministries and NGOs roll out PrEP [pre-exposure prophylaxis] for people who are engaging in high-risk behaviors, particularly men who have sex with men. We'll also pilot test oral HIV testing in several countries.

What is your one wish for key populations?

My wish is that members of key populations are treated like every other member of society — that we would have no need in the future for interventions to reduce stigma and discrimination.

What do you think will be the biggest challenge we'll face toward meeting the project's objectives?

One of our biggest challenges is that governments still are not owning and financially supporting work with key populations. Programs that serve key populations need to be prioritized by the governments that serve them.

Another challenge is that as we put more people who are HIV positive on ART, there's a tendency for the epidemic to become invisible, particularly to young people. They believe that HIV is not an issue for their cohort. Changing that perception will take much more creative communications and outreach

LIFE FACTS

Expertise: Applications of global HIV evidence to local programming; bio-behavioral disease surveillance

Number of years working on HIV programs in the Asia-Pacific Region: 22

Professional achievements: Managed a gifted team that scaled-up integrated ARV treatment and methadone programming in Vietnam; collaborated on the evolution of global guidelines on HIV bio-behavioral surveillance guidelines for key populations; co-authored numerous peer-review articles with country nationals; currently serving on the Global Fund's Technical Review Panel

Family: Single with one son (age 9 years) with an extended family and invaluable global support network

Family activities: Running, skiing, biking, piano — all with the goal of reducing consumption of the internet

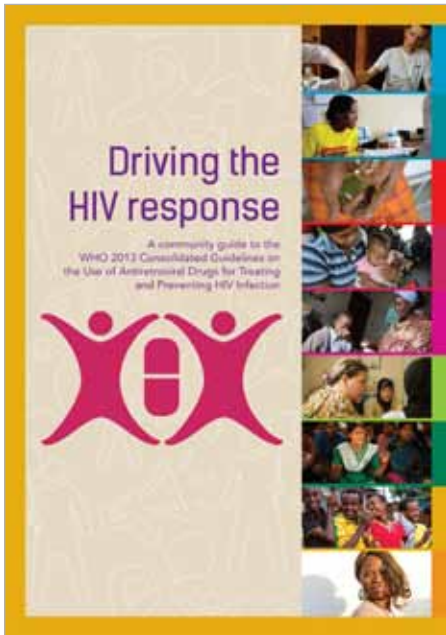
and a multigenerational approach, since younger and older cohorts are always intermingling in sexual networks.

What excites you most about your work?

What excites me most is when I'm working with local researchers or key population representatives and they're brainstorming about how to solve problems for their own communities or to confront their own health systems and governments for more respect, attention, and funding.

*By Kathleen Shears, MS
FHI 360*

NEW RESOURCES: GUIDES AND TOOLKITS



DRIVING THE RESPONSE TO HIV: A COMMUNITY GUIDE TO THE WHO 2013 CONSOLIDATED GUIDELINES ON THE USE OF ANTIRETROVIRAL DRUGS FOR TREATING AND PREVENTING HIV INFECTION

<http://www.gnpplus.net/assets/Community-Guide-final1-copy.pdf>

The Global Network of People Living with HIV (GNP+), the International HIV/AIDS Alliance, and STOP AIDS NOW! developed this community guide in response to the World Health Organization (WHO) 2013 *Consolidated Guidelines on the Use of Antiretroviral Drugs for Treating and Preventing HIV*. The guide aims to help community leaders and civil society organizations:

- Better understand the WHO recommendations and guide country-level discussions on priorities (within civil society and between civil society and government)
- Ensure the meaningful participation of communities most affected by HIV in national decision making and planning
- Advocate for any changes or further research necessary to adapt recommendations to suit their country context
- Mobilize and prepare communities to implement the recommendations

While the guide covers the use of antiretroviral drugs for prevention and treatment among HIV-affected populations in general, this module (<http://www.gnpplus.net/resources/community-guide-i-hiv-and-key-populations/>) specifically addresses key populations and WHO's 2014 *Consolidated Guidelines*.



IMPLEMENTING COMPREHENSIVE HIV/STI PROGRAMMES WITH SEX WORKERS—NOW AVAILABLE IN MULTIPLE LANGUAGES

<http://www.unfpa.org/publications/implementing-comprehensive-hivsti-programmes-sex-workers-practical-approaches>

This tool, now available in Russian, French, Spanish, and English, offers practical advice on implementing HIV and STI programs for and with sex workers. Topics covered include approaches to developing programs that are led by the sex worker community, addressing violence against sex workers, and implementing condom and lubricant programming and other crucial health care interventions for HIV prevention, treatment, and care. The tool also contains examples of good practice from around the world. It is designed for use by public health officials and managers of HIV and STI programs; NGOs, including community and civil society organizations; health workers; international funding agencies; and health policymakers and advocates.

NEW RESOURCES: GUIDES AND TOOLKITS *continued*



ATENCIÓN DE LA SALUD INTEGRAL DE PERSONAS TRANS: GUÍA PARA EQUIPOS DE SALUD

<http://www.msal.gov.ar/images/stories/bes/graficos/0000000696cnt-guia-equipos-atencion-Salud%20integral-personas-trans.pdf>

Esta guía, publicada por el Programa Nacional de Salud Sexual y Procreación Responsable en Argentina, contiene recomendaciones para la atención integral en salud de personas trans en el marco de la Ley de Identidad de Género (26.743). La guía introduce las cuestiones centrales de la Ley de Identidad de Género, presenta conceptos de expresiones e identidades de género, describe la situación actual de las personas trans en Argentina, propone lineamientos para la atención de la salud integral de personas trans desde un modelo de atención centrado en la despatologización, y ofrece información sobre diversas técnicas y estrategias para mejorar la calidad de la atención en relación con procesos de modificación corporal. Esta guía está disponible en español en: <http://www.msal.gov.ar/images/stories/bes/graficos/0000000696cnt-guia-equipos-atencion-Salud%20integral-personas-trans.pdf>

COMPREHENSIVE HEALTH CARE FOR TRANS PEOPLE: GUIDE FOR HEALTH TEAMS

This guide, published by the National Program for Sexual Health and Responsible Parenthood in Argentina, contains recommendations for comprehensive health care for trans people in the context of the Gender Identity Law (26.743). The guide introduces the central components of the Gender Identity Law, presents concepts of gender expressions and identities, describes the current situation of trans people in Argentina, proposes guidelines for comprehensive health care for trans people from a depathologization-centered model of care, and provides information on various techniques and strategies to improve quality of care in relation to hormone therapy and surgical interventions. This guide is available in Spanish at: <http://www.msal.gov.ar/images/stories/bes/graficos/0000000696cnt-guia-equipos-atencion-Salud%20integral-personas-trans.pdf>

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