

Positively Trans

Initial report of a national needs assessment of transgender and gender non-conforming people living with HIV.



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Positively Trans

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About Transgender Law Center

Founded in 2002, Transgender Law Center has grown into the largest trans-specific, trans-led organization in the U.S. changing law, policy and attitudes so that all people can live safely, authentically, and free from discrimination regardless of their gender identity or expression. As a multidisciplinary national organization, Transgender Law Center advances the movement for transgender and gender nonconforming people using an integrated set of approaches, including strategic litigation, policy advocacy, educational efforts, movement building, and the creation of programs that meet the needs of transgender and gender nonconforming people and communities.

www.transgenderlawcenter.org



Positively Trans

About Positively Trans

Positively Trans (T+), developed and directed by Transgender Law Center Senior Strategist Cecilia Chung, is a constituent-led project grounded in the principle that we are all capable of forming our own network, telling our own stories, and developing our own advocacy strategies in response to inequities, stigma, and discrimination over punitive laws and lack of legal protections in our local communities.

With the support of Elton John AIDS Foundation, TLC launched T+ as a response to the structural inequalities that drive the high rate of HIV/AIDS and poor health outcomes. By partnering with a National Advisory Board of community leaders, T+ seeks to mobilize and promote resilience of trans people most impacted by or living with HIV/AIDS, particularly trans women of color, through research, policy advocacy, legal advocacy, and leadership strengthening.

Introduction + Background

In 2015, Transgender Law Center launched Positively Trans as a project focused on to develop self-empowerment and advocacy by and for transgender people living with HIV. Positively Trans operates under the guidance of a National Advisory Board (NAB) of transgender people living with HIV from across the United States; the NAB is primarily composed of trans women of color who are already engaged in advocacy in leadership roles in their local communities.

Recent studies indicate that transgender people, especially transgender women of color (TWOC), experience disproportionate economic marginalizationⁱ, homelessness, and stigma and discrimination in healthcare access and provisionⁱⁱ; harassment and violence at schoolⁱⁱⁱ; and police abuse^{iv}, as well as physical, sexual and physical violence^v. In the face of these systemic threats and barriers to autonomy and wellbeing, the impact of HIV on the transgender

community cannot simply be addressed by programs that work to affect individual behaviors; we must address the systemic barriers our community members face—and the complex interactions of these systems—to reduce HIV risk and increase access to care and other resources for trans people living with HIV (TPLHIV). We believe that effective HIV responses for transgender people must include a combination of leadership development, community mobilization and strengthening, access to quality health care and services, and policy and legal advocacy aimed to advance the human rights of the community. Furthermore, we believe that an effective HIV response for trans people must center the leadership, voices, and experience of TPLHIV particularly trans women of color.

In order to identify community needs and advocacy priorities, we conducted a needs assessment in the summer of 2015. The

needs assessment was released online and made available across the U.S. Key questions focused on barriers to health and well-being for transgender people living with HIV and on their legal and health priorities. This report describes the responses to a small subset of those questions. We made the survey available online in English and Spanish; 80% of complete responses came from the English language instrument and the remaining 20% came from the Spanish language instrument. Recruitment took place through existing networks of transgender people and people living with HIV, and through clinics serving transgender people living with HIV. Responses were limited to people living with HIV in the U.S. whose sex at birth is different from their current gender identity. The project was reviewed and

given exempt status by the Eastern Michigan University Institutional Review Board.

Based on responses to several items on the survey instrument, we expect that the survey mostly attracted respondents who already have access to medical care. As a result, the responses may underrepresent the experiences of those who are more isolated. Because respondents were recruited through existing networks and not randomly selected, the results cannot be interpreted as representative of all transgender people living with HIV in the U.S. Instead, these results should be understood as illustrating the experiences and priorities of transgender people living with HIV and as providing a starting point for further engagement.

Respondent Demographics

More than 400 people responded at least in part to the survey, with complete responses coming from 157 respondents. The analysis we provide in this report contains data only from the set of complete responses. The majority were female-identified U.S. citizens making less than \$23,000 per year. More than 40% had been incarcerated in their lifetime and 42% currently live in the South. The median length of time since identifying as transgender/gender non-conforming was 5 years greater than the median

length of time living with HIV, suggesting that transgender and gender non-conforming people face unique risk and vulnerability to the HIV/AIDS epidemic. Table 1 contains a summary of demographic information for respondents who submitted complete surveys. Descriptive statistics of respondent demographics suggest that the survey oversampled whites and undersampled young people and people living in the Northeast.

Table 1.

Summary of Respondent Demographics (N=157)

Item	%	Item	%		
Gender Identity	MTF/transfeminine spectrum	84%	Metropolitan Area	Urban	70%
	FTM/transmasculine spectrum	12%		Suburban	14%
	Other identity	4%		Rural	16%
Survey Language	English response	80%	Education	Less than HS diploma	15%
	Spanish response	20%		HS diploma or GED	22%
Race/Ethnicity	African American	26%		Some College	36%
	Latina/o	33%		College Graduate	20%
	White	32%		Graduate school	8%
	Asian	6%	Incarceration	Any incarceration history (Prison, Jail, Immigration detention)	41%
	Native	4%		None	59%
	Arab	3%		Current Annual Income	\$12,000 or less
	Native Hawaiian/Pacific Islander	3%	\$12,000 to \$23,000		22%
Race/Ethnicity	One race only	93%	\$23,000 to \$47,000		20%
	Multiracial	9%	\$47,000 to \$75,000		8%
Citizenship	U.S.	88%	More than \$75,000		8%
	Not U.S.	12%	Age	25 and under	9%
Region	Northeast	14%		26 to 40	40%
	South	42%		41 to 55	41%
	Midwest	13%		56 and over	11%
	West	29%			
	Alaska, Hawaii, Puerto Rico	2%			

Median length of time since identifying as transgender/gender non-conforming **17 years**

Median length of time living with HIV **12 years**

Findings

This initial report focuses on findings related to two key areas:

ADVOCACY PRIORITIES & BARRIERS TO HEALTH CARE

Subsequent reports will include findings on stigma, violence, substance abuse, law enforcement interaction, identity documents, and priorities for youth and elders.

Advocacy Priorities

Creating gender affirming and non-discriminatory healthcare facilities and addressing HIV-related discrimination were the top health and legal priorities for respondents. Many respondents expressed concerns about hormone replacement and antiretroviral therapies and their side effects for transgender people. Ensuring support for mental health and recovery from trauma and for personal (self) care were selected as top critical priorities for transgender people living with HIV.

Participants were asked to select their top five health concerns. Figure 1, above, shows the

items ranked by percentage of respondents who indicated each item was among their top 5 concerns. Not listed are: dental care (35%), interaction between hormone therapy and anti-retroviral therapy (35%), complications from silicone injections (26%), pre-exposure prophylaxis and post-exposure prophylaxis (16%), substance abuse (9%), and reproductive health (8%).

Respondents overwhelmingly selected discrimination as priorities for legal advocacy work. Addressing HIV-related discrimination and discrimination in employment, public accommodations, and housing, made up four of the top five priorities. The other top five priority focused on the critical need to access gender appropriate ID documents.

Not listed in Figure 2 are: dealing with law enforcement (including addressing a past criminal record) (38%), immigration (17%), and family law (including parental rights) (14%). We hypothesize that immigration issues rank higher among Asian/Pacific Islander and Latina/o respondents; further analysis will determine this.

The concerns about discrimination were coupled with the belief of many respondents that they were not knowledgeable enough about their legal rights. Together, these two sets of responses highlight a critical need for rights-based trainings and advocacy work specifically for transgender people living with HIV.

Barriers to Health Care and Well Being

To better understand the healthcare barriers that transgender people living with HIV face, respondents were asked if they had ever gone six months or longer without medical care since their HIV diagnosis. 41% of respondents (n=65) indicated that they had.

Respondents who had been incarcerated or detained were significantly more likely to have gone without medical care for more than 6 months (51% of those detained versus 35% of those never detained, p<0.03).

TOP 5 HEALTH CONCERNS

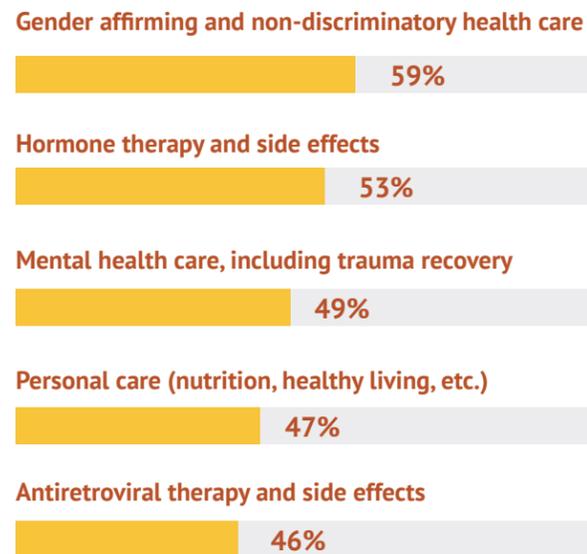


Figure 1 respondent-identified legal priorities

TOP 5 LEGAL PRIORITIES

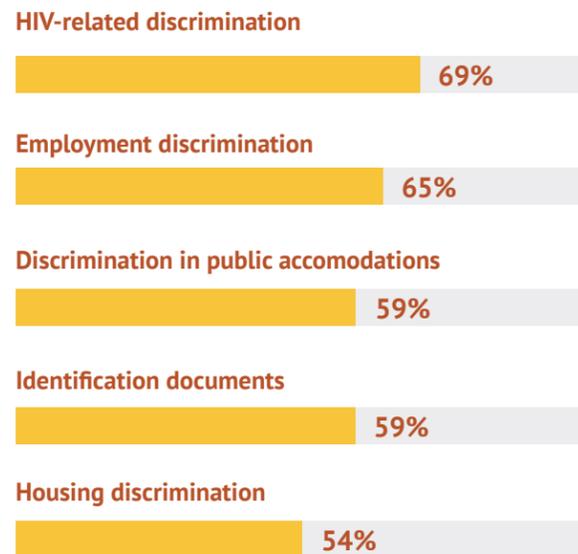


Figure 2: respondent-identified health concerns

How confident are you that you know your rights...

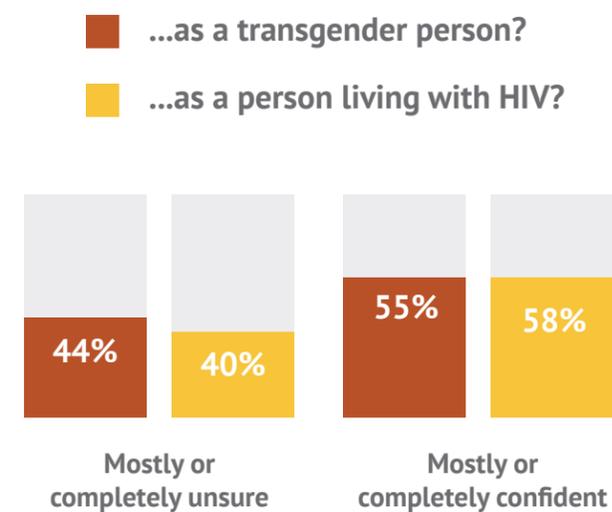


Figure 3: respondent confidence with legal rights

Have you ever gone more than six months without medical care since your HIV diagnosis?

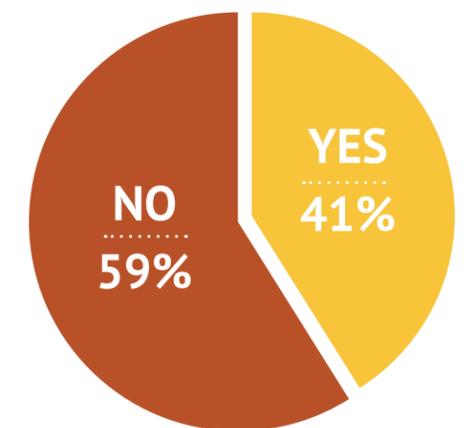


Figure 4: respondents with long gaps in health care since HIV diagnosis (N=157)

The respondents who had gone without care for more than six months were asked a further question about why this happened. The most common reason respondents reported for going without healthcare for more than 6 months was previous or anticipated discrimination by a healthcare provider (29%). Other reasons included having too many other things to deal with (20%), economic barriers (health care costs, transportation) (17%), not having a health care provider (12%), and fear that someone they knew would see them (8%),

Respondents who had gone without healthcare for more than six months highlighted costs as a barrier to health coverage. All respondents were asked about health insurance and only 80% of respondents indicated that they had health coverage. The percentage of respondents with

insurance coverage dropped dramatically for Hispanic and Latino/a respondents (67%) and African American respondents (75%) when compared with White respondents (94%). Differences for Latina/o and White respondents were significant at the $p < 0.02$ level. When stratified by income, insured rates also showed expected disparity – 100% of respondents earning more than \$75,000 annually reported having health insurance, while only 70% of those earning less than \$12,000 did. As a group, 87% those earning more than \$12,000 overall reported being insured, underscoring the particular vulnerability low-income people face in attaining health coverage as well as the increased likelihood that people of color experience extreme poverty.

Many respondents indicated the previous experience or expectation of mistreatment by providers. The distance that can occur between many transgender people living with HIV and their providers is at least partially demonstrated by the low number of respondents (9% to 17%) who indicated that they had providers who shared their experiences as transgender or gender non-conforming people. The clearest barrier to health and well-being reported in the survey was the outright denial of health services. Respondents indicated that they had been denied health care because they were transgender or gender non-conforming (31% had this experience) and because they were HIV-positive (20% had this experience). These high numbers reflect violations of respondents' human right to health care.

Transphobic provider discrimination as predictor of gap in care

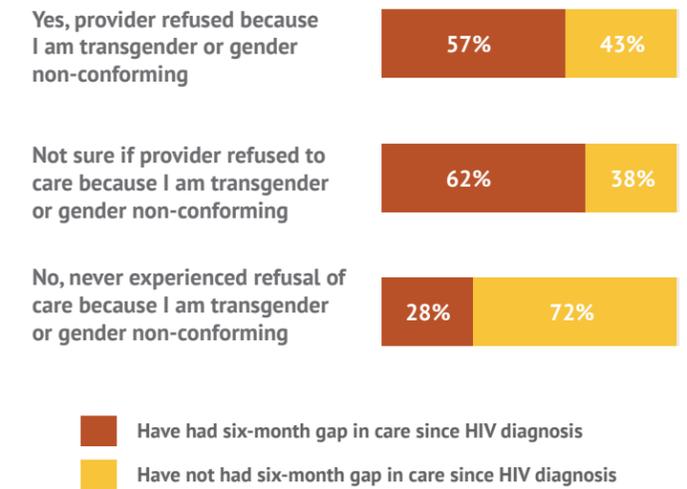


Figure 8: transphobic provider discrimination associated with gap in health care access ($p < 0.0001$, $N = 156$)

Are any of your health providers transgender or gender non-conforming?

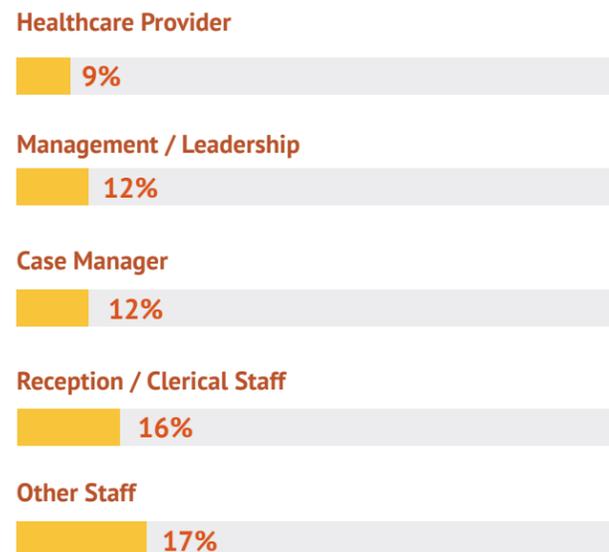


Figure 5: Percentage of respondents answering "yes" for each type of provider

Has a health care provider ever refused you care because you are...

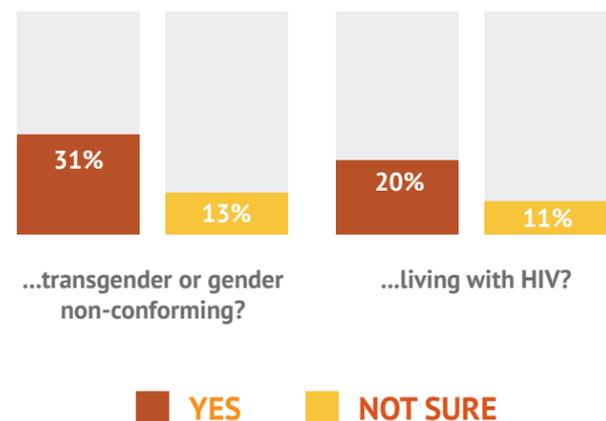


Figure 6: Respondents reporting provider refusal to treatment ($N = 157$)

Has a health care provider ever refused you care because you are...

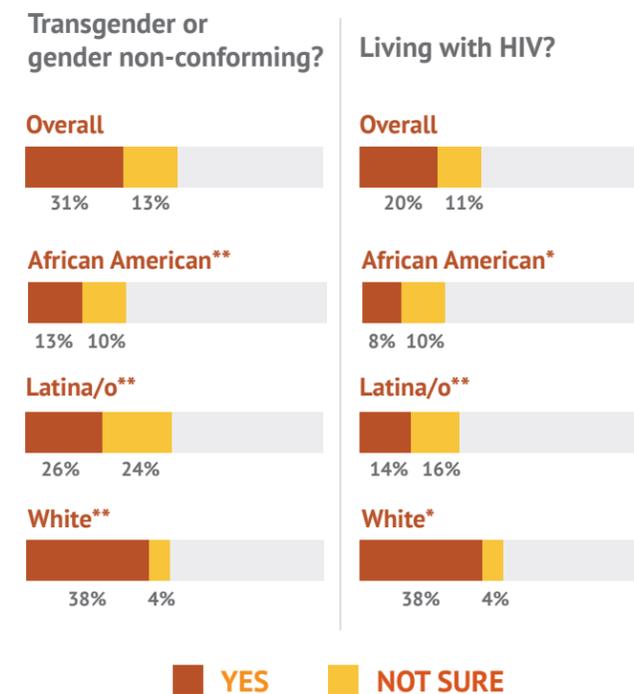


Figure 7: provider refusals broken down by race; * $p < 0.10$, ** $p < 0.01$

Serophobic provider discrimination as predictor of gap in care

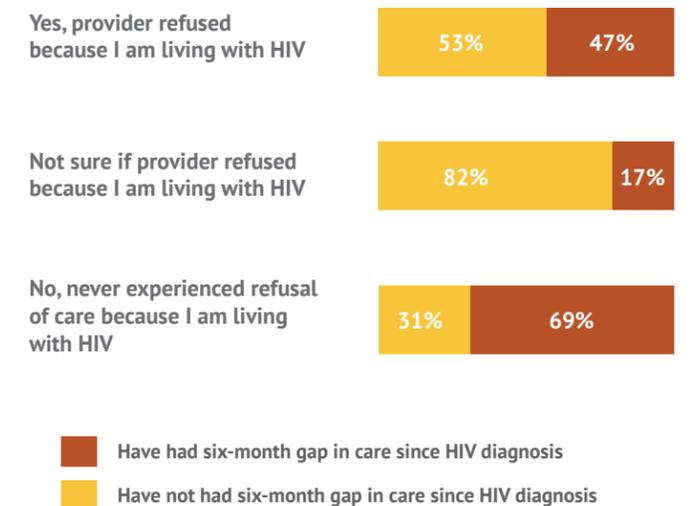


Figure 9: Serophobic provider discrimination associated with gap in health care access ($p < 0.0001$, $N = 155$)

Future Reports

In addition to descriptive statistics of areas of the needs assessment not covered in this initial report, future reports will include statistical inference to determine what, if any, relationships exist between variables measuring health outcomes, stigma, experiences of violence, viral load suppression, immigration, and participation in social change activism.

Recommendations

The work of the National Advisory Board of the Positively Trans and the responses to the survey by transgender people living with HIV across the U.S. demonstrate immediate and critical needs to protect transgender health and access to legal rights.

The following recommendations are not listed in priority order as each will be required to be put into place if ending barriers to care and access to legal rights are to be a reality for transgender people living with HIV.

The following programs and initiatives are required:

Legal and rights-based advocacy training programs designed specifically by and for transgender people living with HIV

Support systems for transgender people living with HIV who have experienced discrimination, and for those who anticipate discrimination, to be able to access care and services without fear of mistreatment

Identification and development of economic initiatives to relieve the financial barriers and stresses that limit access to care, for all transgender people living with HIV with particular attention to the needs of transgender people of color.

Focused anti-discrimination interventions and training in gender-affirming care in healthcare facilities, combined with on-going accountability processes to correct discriminatory actions

Healthcare and service provider education and support to address the mental health needs, including the effects of trauma, for transgender people living with HIV

Contact Us

For more information, visit www.transgenderlawcenter.org

Acknowledgments

Transgender Law Center is grateful to the many people who have contributed their time and energy to Positively Trans. Without them, this work would not be possible.

POSITIVELY TRANS TRANSGENDER LAW CENTER STAFF



Cecilia Chung
Senior Strategist, Transgender Law Center

Cecilia Chung is nationally recognized as an advocate for human rights, social justice, health equity, and LGBT equality. She was the former Chair of the San Francisco Human Rights Commission and is currently serving on the Health Commission. Cecilia has been working tirelessly on the local, national and international levels to improve access to treatment for transgender people and people living with HIV, and to erase stigma and discrimination through education, policy, advocacy, and visibility.



Anand Kalra
Health Programs Manager, Transgender Law Center

As Health Programs Manager at Transgender Law Center, Anand Kalra translates wins in law and policy into practice at the level of user experience. Coming from a background in library & information science, Anand applies systems analysis to identify breakdowns in the administration of health care in the private and public sectors, and uses this knowledge to create understandable educational materials and trainings for transgender community members and service providers. Prior to joining Transgender Law Center, Anand worked in public schools, private museums, academic libraries, and a pediatric clinic. He has ten years' experience as an activist in trans and LGB communities and holds a master's degree in Information Science from the University of Michigan.

POSITIVELY TRANS NATIONAL ADVISORY BOARD



Arianna Lint
Fort Lauderdale, FL

Arianna Lint is a "refugee" Latina Transgender Woman who started her own organization, Translatina Florida Chapter. Previously, she served as the Director of Transgender Advocacy at SunServe, a South Florida not-for-profit social service and mental health agency serving the Lesbian, Gay, Bisexual, Transgender, and Questioning Community.



Channing-Celeste Wayne
San Francisco, CA

Channing-Celeste is a transgender woman who tirelessly advocates for improved health outcomes among people living with HIV/AIDS, especially trans women of color. Diagnosed with HIV in 1989, her first advocacy was for herself, which naturally branched outwards. She is Assistant Program Manager at Larkin Street Youth Services.



Dee Dee Chamblee
Eastpoint, GA

Dee Dee Chamblee has over 25 years of grassroots organizing experience, and is Executive Director of LaGender Inc and Co-Director of SnapCo Solutions Not Punishment Coalition. As Founder of LaGender Inc, she helps transform the environment in Atlanta, GA around trans issues such as HIV/AIDS, homelessness, mental health, incarceration, and police profiling.



Milan Sherry
New Orleans, LA

Milan Nicole Sherry is a Black Trans Revolutionist from New Orleans, Louisiana, and co-director of her own organization, Trans Dignity And Pride. As a Founding Member of the organization BreakOUT, she has been integral to her community development and campaign victories since 2010. Milan graduated from the Center for Third World Organizing's Movement Activist Apprenticeship Program in 2013, received the 2013 NOLA Unity Award for her work in the New Orleans LGBTQ community, received the POC Leader award in 2014 and the 2015 Equality Louisiana Rising Star Award. In response to the numerous killings of Black transgender women in the United States, Milan started the media campaign, #BlackTransLivesMatter and organized the first New Orleans Trans March, led by transgender and gender non-conforming youth of color.



Octavia Lewis
Bronx, NY

Octavia Y. Lewis, MPA leads all transgender-related programming and services at The Hetrick-Martin Institute. She provides youth with transferrable skills needed to navigate the systems which are in place to assist them while teaching them to find their voices to advocate for themselves, educating allies on what it means to be an ally, and leading through exemplary leadership skills on living one's authentic life unapologetically.



Ruby Corado
Washington, DC

Ruby was born in San Salvador, El Salvador. She fled a civil war when she was 16 years old. Now 43 years old, she has lived in Washington, D.C. for the past 27 years where she has devoted the last 20 years as an advocate for the inclusion of transgender, genderqueer and gender non conforming gay, lesbian, and bisexual people in mainstream society. Ruby is the founder of Casa Ruby, the only Bilingual Multicultural LGBT Organization providing life-saving services and programs to the most vulnerable in the LGBT community.

POSITIVELY TRANS NATIONAL ADVISORY BOARD (CONTINUED)



Tela Love
New Orleans, LA

Tela LaRaine Love is a trans advocate from New Orleans, Louisiana. She is co-founder of New Legacy Ministries, a grassroots organization striving to raise the voices of marginalized communities, including transgender women of color.



Tiommi J. Lockett
Little Rock, AR

Tiommi J. Lockett is an African-American Trans*woman, born and raised in Helena, Arkansas. She advocates for those living with HIV/AIDS, and has attended the 53rd annual Presidential Advisory Council on HIV/AIDS meeting, participated in a five-speaker panel discussing Medicaid expansion and the private option, and served as the Arkansas State Coordinator for AIDSWatch 2014.



Teo Drake
Greenfield, MA

Teo Drake is a spiritual activist, an educator, a practicing Buddhist and yogi, and an artisan who works in wood and steel. When this blue collar, queer-identified trans man living with AIDS isn't helping spiritual spaces be more welcoming and inclusive of queer and transgender people or helping queer and trans folks find authentic spiritual paths, he can be found teaching martial arts, yoga, and woodworking to children or blogging at www.rootsgrowthetree.com

In Addition

We would like to express our thanks to Laurel Sprague, Bré Campbell, Jenna Rapues, Chris Roebuck, Erin Armstrong, Collette Carter, *Poz Magazine*, *thebody.com*, *HIV Plus Magazine*, Positive Women's Network USA, the SERO Project, AIDS United, and AIDS Foundation of Chicago.

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Endnotes

ⁱ Baral, S.D., Poteat, T., Strömdahl, S., Wirtz, A.L., Guadamuz, T.E. and Beyrer, C., 2013. Worldwide burden of HIV in transgender women: a systematic review and meta-analysis. *The Lancet infectious diseases*, 13(3), pp.214-222.

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^v Bradford, J., Reisner, S.L., Honnold, J.A. and Xavier, J., 2013. Experiences of transgender-related discrimination and implications for health: results from the Virginia Transgender Health Initiative Study. *American Journal of Public Health*, 103(10), pp.1820-1829.