



# Some Kind of Strength

Findings on health care and economic wellbeing from a national needs assessment of transgender and gender non-conforming people living with HIV.





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# Introduction + Background

In August 2015, Positively Trans, a project of Transgender Law Center, held focus groups with transgender women of color living with HIV in Atlanta, Georgia and Miami, Florida. The purpose of the groups was to generate information to illustrate –with real experiences and stories–the resilience, challenges, and barriers our community faces. Meant to supplement and parallel our quantitative study, the focus groups produced deep and meaningful conversations that policymakers too often ignore or simply never hear.

One thing we heard repeated over and over was that the myopic vision of testing and condom distribution as the sole means of addressing health among transgender people falls infuriatingly short of providing meaningful support. Focus group participants pointed to the need for comprehensive, affordable, trauma-informed, culturally competent health care and a sustainable means for meeting basic needs – food and shelter. They clearly articulated that these social determinants of health are drivers of the epidemic that conventional prevention programs don't address. One Miami participant said, "The state thinks (HIV transmission) is solved by condoms, not by improving our lives or meeting our needs."

Transgender and gender non-conforming people living with HIV (TPLHIV) face barriers in every aspect of life, due to family rejection and rampant

discrimination in housing, health care, education, and employment.<sup>1,2,3,4</sup> As a result, TGNC people, especially transgender women of color, find themselves cut out of the formal economy without access to safe, respectful health care, which in turn leads to a cycle of trauma from which many transgender people struggle to exit.<sup>5,6,7</sup>

Transgender people face twice the rate of unemployment when compared to the general population, with trans people of color facing an unemployment rate at least four times higher.<sup>8</sup> Almost half of all trans people have reported under-employment at some point in their lives. Trans people in the state of California, a state with employment nondiscrimination laws inclusive of gender identity, are twice as likely to be living below the poverty line.<sup>10</sup> Nationwide, trans people are four times more likely to be living in "dire poverty," making less than \$10,000 per year.<sup>11</sup> Such dire economic situations lead trans people to be disproportionately (16%) involved in underground economies, including sex work.<sup>12</sup> Nearly one fifth of all transgender people have experienced homelessness, which increased their risk of violence, incarceration, HIV, and/or attempting suicide.<sup>13</sup> Trans women of color were worse off in all economic measures -- being more likely to experience homelessness, unemployment, and the underground economy.<sup>14</sup>

Nearly 60% of trans people have reported rejection from family members, which is correlated with much higher rates of homelessness, HIV, and suicide attempts.<sup>15</sup> Trans women are almost twice as likely to experience sexual violence than the general population.<sup>16</sup> Over 40% of trans people have reported physical violence due to the fact that they are transgender.<sup>17</sup> Transgender people of color report even higher rates of physical violence due to being transgender.<sup>18</sup> Other factors, such as participation in sex work, increase the risk of interpersonal violence for transgender people, with 65% of trans women participating in sex work in Washington, DC, reporting violence from both customers and police.<sup>19</sup>

While we know these heartbreaking statistics for the general transgender population, studies of transgender people living with HIV rarely go beyond transmission risk and surveillance data, hindering a holistic understanding of TPLHIV's lives that could identify the role of violence and discrimination in creating the conditions that result in the extreme HIV prevalence rates these studies do observe – with estimates as high as 27% for transgender women overall and above 50% for African American transgender women.<sup>20</sup>

Transgender Law Center launched Positively Trans as a project aimed 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. In order to identify community needs and advocacy priorities, we conducted a quantitative needs assessment in the summer of 2015, which was distributed online in Spanish and English. Responses were limited to adults living with HIV in the U.S. whose sex assigned 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.

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 experiences of TPLHIV, particularly trans women of color.

Our communities need substantive and dramatic change in the hearts and minds of people writing and enforcing public health policy, providing health care, and making hiring decisions. As one participant in the Miami focus group said, “It’s not only HIV testing, it’s not only giving out condoms. **Our community needs some kind of strength.** We need housing. Food. Healthcare.”

# Findings

In all, over 400 people attempted the survey; 80% of complete responses came from the English version, and 20% from the Spanish version. Findings presented below represent analysis from 157 complete, valid responses. 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 (for example, 77% of respondents were virally suppressed). As a result, the responses may underrepresent the experiences of those who are more isolated. Significantly, the survey did not reach respondents who are currently incarcerated; we expect that including incarcerated people in the study would shift findings dramatically. 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.

The majority of respondents 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. Descriptive statistics of respondent demographics suggest that the survey oversampled whites and undersampled young people and people living in the Northeast.

## Health Care

The survey instrument asked about many aspects of health and health care. This report includes data on access to care, provider attitudes, and viral suppression. Overall, respondents of color, trans women of color in particular, low-income respondents, Spanish-language respondents, and respondents who

were not virally suppressed reported more difficulty accessing care and more negative experiences with health care providers.

Generally, respondents had a low rate of uninsurance, but the distribution of the 17% of respondents who lacked health insurance was striking. Southern

TABLE 1

# Health Care Items by Race and Gender

	GENDER			RACE			TRANS WOMEN OF COLOR	
	TRANS WOMEN (N=132)	P	TRANS MEN (N=18)	RESP. OF COLOR (N=107)	WHITE RESP. (N=50)	TWOC (N=96)	ALL OTHER (N=61)	P
Have had a gap in care of at least 6 months since HIV diagnosis	41%	0.550	28%	42%	67%	43%	39%	0.802
Currently uninsured	17%	0.209	6%	21%	6%	22%	8%	<b>0.028</b>
Accessing HIV care is somewhat or very difficult	17%	0.614	28%	15%	20%	16%	18%	0.692
Accessing hormone therapy is somewhat or very difficult	35%	<b>0.030</b>	24%	39%	26%	43%	23%	<b>0.011</b>
Accessing surgical care is somewhat or very difficult	61%	0.187	61%	62%	56%	66%	51%	0.065
Provider restricted access to hormones based on ART compliance	15%	0.475	11%	20%	6%	18%	11%	0.406
Provider refused to treat because TGNC	31%	0.301	44%	23%	48%	25%	41%	<b>0.004</b>
Provider refused to treat because LHIV	21%	<b>0.035</b>	33%	12%	38%	11%	34%	<b>&lt;0.001</b>
Provider for HIV care is neutral or hostile	22%	0.827	17%	22%	20%	23%	20%	0.631
Provider for transition-related care is neutral or hostile	20%	0.815	25%	28%	22%	27%	25%	0.729
Provider for primary care is neutral or hostile	28%	0.998	24%	27%	30%	27%	30	0.742
Not virally suppressed	23%	0.239	33%	23%	22%	22%	25	0.693

Note: P-values are presented for Pearson chi-square tests of difference across groups (e.g., respondents from Southern states vs. non-Southern states). A small number of respondents (7) were not classified as trans men or trans women; their responses are included in the analysis, but the small number prohibited meaningful statistical analysis as a group. P-values reported for trans women are compared to the combination of trans men and the seven other gender non-conforming respondents. Similarly, p-values reported for trans men are compared to the combination of trans women and the seven other gender non-conforming respondents. P-values less than 0.05 indicated in bold.

TABLE 2

# Health Care items by Region, Income, and Language

	ALL		REGION		INCOME		LANGUAGE				
	(N=157)		SOUTH (N=66)	OTHER (N=91)	P	<\$12,000 ANN. (N=67)	>\$12,000 ANN. (N=90)	P	SPANISH RESP. (N=31)	ENGLISH RESP. (N=126)	P
Have had a gap in care of at least 6 months since HIV diagnosis	41%		45%	38%	0.475	43%	40%	0.680	35%	43%	0.455
Currently uninsured	17%		30%	7%	<0.001	24%	11%	0.033	32%	13%	0.009
Accessing HIV care is somewhat or very difficult	17%		23%	12%	0.121	18%	16%	0.695	23%	15%	0.314
Accessing hormone therapy is somewhat or very difficult	35%		53%	22%	<0.001	45%	28%	0.027	65%	28%	<0.001
Accessing surgical care is somewhat or very difficult	61%		65%	57%	0.325	66%	56%	0.201	77%	56%	0.026
Provider restricted access to hormones based on ART compliance	15%		15%	15%	1.000	15%	16%	0.914	29%	12%	0.018
Provider refused to treat because TGNC	31%		28%	34%	0.464	27%	34%	0.311	32%	31%	0.888
Provider refused to treat because LHV	21%		16%	25%	0.236	16%	23%	0.287	13%	22%	0.249
Provider for HIV care is neutral or hostile	22%		32%	14%	0.015	22%	21%	0.848	42%	17%	0.002
Provider for transition-related care is neutral or hostile	20%		32%	22%	0.230	27%	26%	0.853	42%	22%	0.025
Provider for primary care is neutral or hostile	28%		35%	23%	0.150	28%	37%	0.936	39%	25%	0.139
Not virally suppressed	23%		29%	19%	0.137	27%	20%	0.312	32%	21%	0.168

Note: P-values are presented for Pearson chi-square tests of difference across groups (e.g., respondents from Southern states vs. non-Southern states). P-values less than 0.05 indicated in bold.



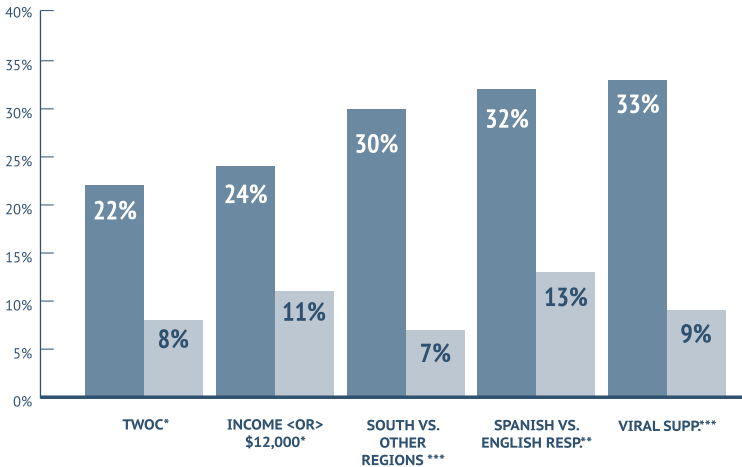
TABLE 3

# Health Care items by Viral Suppression

	ALL (N=157)	VIRAL SUPPRESSION		P
		NOT VIR. SUPP. (N=36)	VIR. SUPP. (N=121)	
Have had a gap in care of at least 6 months since HIV diagnosis	<b>41%</b>	56%	37%	<b>0.050</b>
Currently uninsured	<b>17%</b>	33%	9%	<b>&lt;0.001</b>
Accessing HIV care is somewhat or very difficult	<b>17%</b>	36%	11%	<b>0.001</b>
Accessing hormone therapy is somewhat or very difficult	<b>35%</b>	42%	33%	0.452
Accessing surgical care is somewhat or very difficult	<b>61%</b>	64%	59%	0.576
Provider restricted access to hormones based on ART compliance	<b>15%</b>	28%	12%	<b>0.035</b>
Provider refused to treat because TGNC	<b>31%</b>	42%	28%	0.181
Provider refused to treat because LHIV	<b>21%</b>	25%	19%	0.434
Provider for HIV care is neutral or hostile	<b>22%</b>	42%	16%	<b>0.002</b>
Provider for transition-related care is neutral or hostile	<b>20%</b>	42%	21%	<b>0.028</b>
Provider for primary care is neutral or hostile	<b>28%</b>	47%	22%	<b>0.007</b>

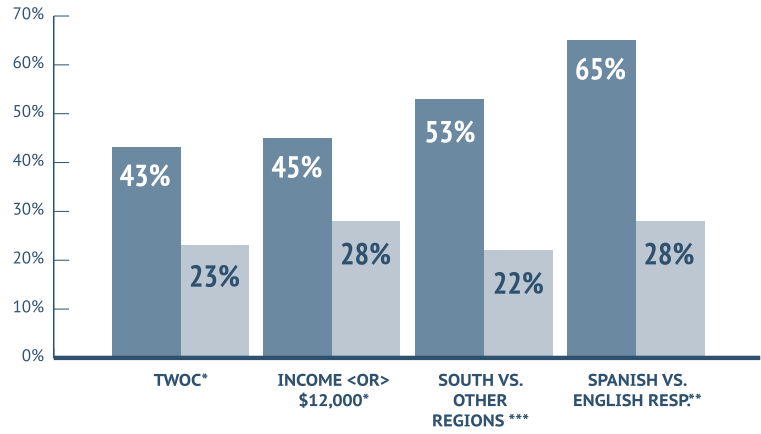
Note: P-values are presented for Pearson chi-square tests of difference across groups (e.g., respondents from Southern states vs. non-Southern states). P-values less than 0.05 indicated in bold.

**Fig. 1**  
Respondent Uninsured Rates by Key Characteristics



\*indicates p<0.05 \*\*indicates p<0.01 \*\*\*indicates p<0.001

**Fig. 2**  
Differences in Difficulty in Accessing Hormone Therapy, by Key Characteristics



\*indicates p<0.05 \*\*\*indicates p<0.001

TABLE 4

## Economic health items by Race and Gender

	GENDER		RACE		TRANS WOMEN OF COLOR	
	TRANS WOMEN (N=132)	TRANS MEN (N=18)	RESP. OF COLOR (N=107)	WHITE RESP. (N=50)	TWOC (N=96)	ALL OTHER (N=61)
	P	P	P	P	P	P
Have experienced workplace discrimination because TGNC	<b>50%</b>	50%	47%	52%	49%	64%
	0.631	0.886	0.538	0.863		
Have experienced workplace discrimination because LHIV	<b>17%</b>	11%	16%	16%	17%	15%
	0.991	0.553	0.986	0.750		
Have experienced housing discrimination because TGNC	<b>35%</b>	39%	33%	36%	35%	31%
	0.551	0.625	0.230	0.097		
Have experienced housing discrimination because LHIV	<b>20%</b>	18%	21%	16%	20%	18%
	0.753	0.959	0.271	0.189		
Currently unemployed and not working at all	<b>31%</b>	17%	35%	36%	30%	33%
	0.073	0.157	0.376	0.734		
Do not have any ID that matches name and gender*	<b>32%</b>	29%	32	34	29%	47%
	0.260	0.752	0.766	0.333		

Note: P-values are presented for Pearson chi-square tests of difference across groups (e.g., respondents from Southern states vs. non-Southern states). P-values less than 0.05 indicated in bold. \* This item has N=130.

TABLE 5

## Economic Health Items by Region, Income, and Language

	ALL (N=157)		REGION		INCOME		LANGUAGE		
	SOUTH (N=66)	OTHER (N=91)	P	<\$12,000 ANN. (N=67)	>\$12,000 ANN. (N=90)	P	SPANISH RESP. (N=31)	ENGLISH RESP. (N=126)	P
Have experienced workplace discrimination because TGNC	59%	44%	0.251	49%	48%	0.855	45%	49%	0.686
Have experienced workplace discrimination because LHIV	19%	16%	1.000	15%	17%	0.768	19%	15%	0.560
Have experienced housing discrimination because TGNC	39%	32%	0.076	40%	22%	<b>0.006</b>	39%	33%	<b>0.007</b>
Have experienced housing discrimination because LHIV	23%	18%	0.228	25%	9%	<b>0.012</b>	19%	19%	<b>0.001</b>
Currently unemployed and not working at all	32%	31%	0.889	55%	13%	<b>&lt;0.001</b>	26%	33%	0.469
Do not have any ID that matches name and gender*	41%	25%	<b>0.047</b>	36%	29%	0.397	32%	32%	0.995

respondents (30%), low-income respondents (24%), Spanish-language respondents (32%), respondents who were not virally suppressed (32%), and trans women of color (22%) all had significantly higher rates of uninsurance ( $p < 0.05$ ). While respondents from every other region reported having had at least one viral load test done since their diagnosis, 8% of Southern respondents had never had a viral load test. An additional 8% of Southern respondents to the same question did not know the result of their most recent viral load test, compared to 2% of respondents from all other regions; these findings point to a high need for further study and support for TGNC people living with HIV in the South. While the direction of association cannot be determined, the connection between access to care and viral suppression is clear – overall, 77% of respondents were virally suppressed. However, among those who were uninsured, only 42% were virally suppressed ( $p < 0.0001$ ). Respondents who were not virally suppressed were more than twice as likely to report that their provider had a “neutral or hostile” attitude towards them, for all types of providers we asked about -- HIV care (42% vs 16%,  $p = 0.002$ ), transition-related care (42% vs 21%,  $p = 0.028$ ), and primary care (47% vs 22%,  $p < 0.01$ )—and were more than three times as likely to say that accessing HIV services is “somewhat or very difficult” (36% vs 11%,  $p = 0.001$ ). This group was also more than twice as likely to report that a provider had restricted their access

to hormone therapy based on compliance with anti-retroviral therapy (28% vs 12%,  $p = 0.035$ )—a dangerous practice that clearly does not yield the intended results.

Almost one in three respondents reported that a provider had previously refused to treat them because they were transgender, and more than one in five reported a provider had refused to treat them because they were living with HIV. White respondents were more likely to report the provider refusal than respondents of color ( $p < 0.005$  for both types of refusal), but respondents of color were more likely to report that they weren’t sure whether this kind of discrimination had occurred.

Access to transition-related care remains a high barrier, with more than a third of the sample reporting that accessing hormone therapy is “somewhat or very difficult.” Trans women (39%,  $p < 0.05$ ), trans women of color (43%,  $p = 0.011$ ), respondents from the South (53%,  $p < 0.001$ ), low-income respondents (45%,  $p = 0.027$ ), and Spanish-language respondents (65%,  $p < 0.001$ ) all reported significantly higher rates of difficulty accessing hormone therapy. However, access to surgical care was almost uniform across all groups, with 61% of respondents reporting that access is “somewhat or very difficult”; among Spanish-language respondents, the rate was significantly higher, at 77% ( $p = 0.026$ ).

## Economic Wellbeing

Measures of economic wellbeing focused on discrimination on the job and in housing, unemployment, income, and identity documents. Trans women, Southern respondents, and trans women of color were much more likely to report earning less than \$12,000 annually than their counterparts ( $p < 0.01$ ). Trans women, trans women of color, respondents of color overall, and Spanish-language respondents were significantly less likely to have received a college degree ( $p < 0.005$ ),

but education level was not associated with geographic region.

For transgender people, not having ID that matches your name and gender identity is more than an inconvenience—it can be a barrier to accessing social services (including health care), can prevent you from getting a job, and can escalate routine traffic stops into violent confrontations and even incarceration. Almost one in three respondents

in our sample reported that they didn't have any form of identification that matches their name and gender—this statistic was stable across almost all groups, including low-income respondents. However, significantly more Southern respondents (41%, compared to 25% of non-Southern respondents,  $p < 0.05$ ) reported having no ID that matched their name and gender. Many states in the South require a person to have gender reassignment surgery in order to change the gender marker on state ID; since almost two thirds of respondents reported difficulty accessing surgical care, the increased proportion of people lacking ID makes sense.

Almost a third (31%) of respondents reported that they were unemployed at the time they took the survey – this rate is dramatically higher than the overall US unemployment rate, which was 5.1% in the same time period.<sup>21</sup> The unemployment

rate was, as expected, higher among low-income respondents (55%,  $p < 0.001$ ), but reverse of this statistic should cause alarm as well – 45% of low-income respondents, or almost a quarter of the total sample, were working and still not able to earn more than \$12,000 annually. More than a third of respondents reported having experienced housing discrimination because they were transgender and 20% reported housing discrimination because they are living with HIV. Low-income respondents and Spanish-language respondents were more likely to report both types of discrimination ( $p < 0.01$ ). Overall, fully half of our sample reported experiencing workplace discrimination because they are transgender, and more than one in six reported workplace discrimination because of their HIV status—regardless of region, income, language, race, and gender, transgender people living with HIV report the same level of workplace discrimination.

Fig. 3

### TPLHIV Face Hurdles to Economic Health

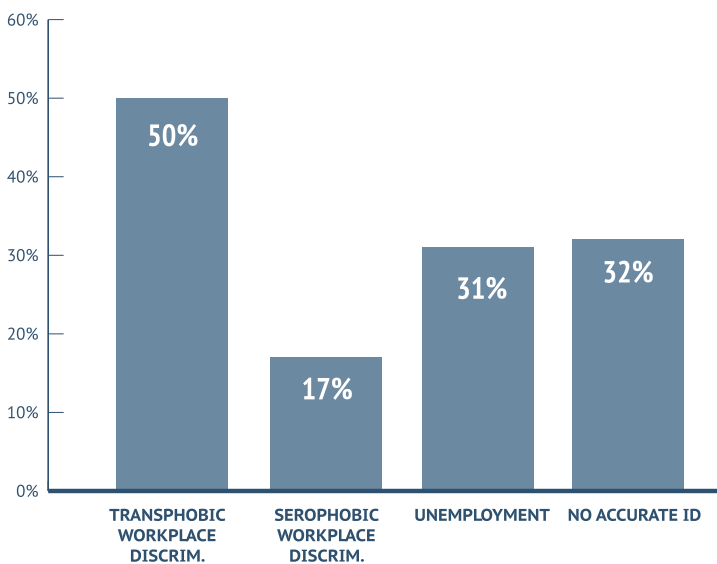
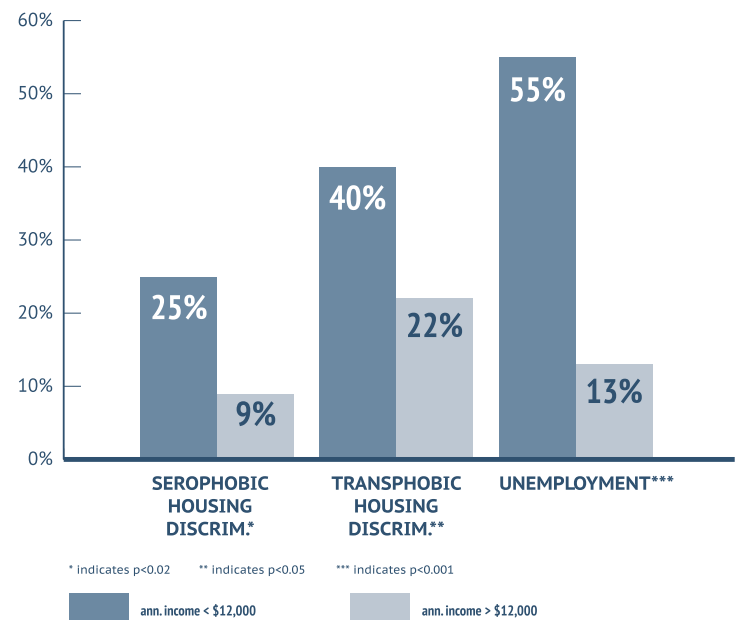


Fig. 4

### Low-Income Respondents Face Higher Rates of Discrimination and Unemployment



# Recommendations

A cascade of economic effects including family rejection, discrimination and push-out in schools, and workplace discrimination, result in many TPLHIV working high-risk, low-wage jobs with increased exposure to police intervention. However, smart, compassionate public policy with strong enforcement mechanisms can make a difference if decision-makers commit to improving conditions on the ground for transgender people living with HIV.

**In particular, we recommend:**

**Medicaid expansion should be adopted in all states immediately, and Medicaid programs in all states must expand eligibility to undocumented immigrants and non-permanent residents**

.....

**Hospitals, clinics, and AIDS Services Organizations (ASOs) must bring their staff and programming into compliance with Section 1557 of the Affordable Care Act, which prohibits discrimination in health settings, including discrimination based on gender identity or expression**

.....

**Health care providers working with transgender people should follow informed consent and harm-reduction guidelines with administering hormone therapy, instead of punitive or restrictive approaches**

.....

**All health care providers should receive training in the basics of transgender medicine, and all workers in health settings should receive cultural competence training..**

.....

**Funded campaigns to educate employers about the benefits of hiring transgender employees**

.....

**Given high rates of conviction and incarceration as drivers of high unemployment, employers should remove screening questions for prior convictions from job applications**

.....

**Financial support for trans-led organizations, particularly service organizations, to improve health in the trans community as well as providing gainful employment**

.....

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## In Addition

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TABLE 6

## Appendix - Demographic Summary, Health Care and Economic Health Items, Transgender Men Respondents

	ALL (N=157)	TRANS MEN (N=66)	P
<b>DEMOGRAPHICS</b>			
% of total sample	100%	11%	
Respondents of color	68%	33%	<0.001
Annual Income <\$12,000	43%	6%	0.002
Education Level			0.002
No formal education	3%	0%	
Less than HS/GED	12%	0%	
HS diploma/GED	22%	0%	
Some college	36%	50%	
College Degree	20%	22%	
Graduate degree	8%	28%	
<b>HEALTH CARE</b>			
Have had a gap in care of at least 6 months since HIV diagnosis	41%	28%	0.321
Currently uninsured	17%	6%	0.318
Accessing HIV care is somewhat or very difficult	17%	28%	0.306
Accessing hormone therapy is somewhat or very difficult	35%	24%	0.343
Accessing surgical care is somewhat or very difficult	61%	61%	0.909
Provider restricted access to hormones based on ART compliance	15%	11%	0.601
Provider refused to treat because TGNC	31%	44%	0.309
Provider refused to treat because LHIV	21%	33%	0.147
Provider for HIV care is neutral or hostile	22%	17%	0.585
Provider for transition-related care is neutral or hostile	20%	25%	0.690
Provider for primary care is neutral or hostile	28%	24%	0.560
Not virally suppressed	23%	33%	0.265

	ALL (N=157)	TRANS MEN (N=66)	P
<b>ECONOMIC HEALTH</b>			
Have experienced workplace discrimination because TGNC	50%	50%	0.886
Have experienced workplace discrimination because LHIV	17%	11%	0.553
Have experienced housing discrimination because TGNC	35%	39%	0.625
Have experienced housing discrimination because LHIV	20%	18%	0.959
Currently unemployed and not working at all	31%	17%	0.157
Do not have any ID that matches name and gender*	32%	29%	0.752

There is a paucity of medical research on transgender men generally, and almost no published research on transgender men living with HIV. Our sample novel findings among trans men living with HIV; however, their small number inhibited showing statistically significant differences on many items. P-values are presented for Pearson chi-square tests of difference between trans men and all other respondents. \* This item has N=130.



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