THE REPORT OF THE
2018 SOUTHERN TRANS HEALTH FOCUS GROUP PROJECT

Southern LGBTQ Health Initiative
A Partnership of the Campaign for Southern Equality
& Western NC Community Health Services
Asheville, North Carolina

Introduction

In 2015, with over 27,000 trans and non-binary respondents from across the U.S., the National Center for Transgender Equality completed their U.S. Trans Survey. The results of this survey point to grave disparities in both physical and mental health, barriers to health care access, and patterns of mistreatment and discrimination across health care interactions. This research identified several barriers to trans and non-binary people’s health care access: 33 percent of trans people do not seek care due to cost, 23 percent do not seek care due to fear of mistreatment, and 33 percent of those who do seek treatment have a negative experience related to their gender identity. Barriers to health care inevitably lead to disparities in health outcomes. Disparate health outcomes are perhaps most visible in relation to rates of both HIV and psychological distress. According to the survey, 1.4 percent of trans and non-binary people are living with HIV, five times the rate of the U.S. population. Likewise, 39 percent of trans and non-binary people experience psychological distress, nearly eight times the rate of the U.S. population. These are but a few of the statistics that have been put forth by a number of agencies and researchers, all pointing to trans and non-binary people not getting the care that they need, resulting in increased morbidity rates within trans communities. While these statistics offer powerful markers of the health disparities that trans and non-binary people face across the U.S., our research team sought to better understand the lived experiences of these disparities for trans and non-binary people in communities across the South. According to the Williams Institute, the South is home to approximately 35 percent of LGBTQ people, including more than 500,000 transgender people. We wanted to know how trans and non-binary Southerners fare in relation to the national trans population and how these disparities manifest in daily life. We also wanted to explore what social and cultural interventions might look like to address these disparities and to create access to the highest standards of care.

This journey took us to Asheville, NC; Greenville, SC; Selma, AL; and Memphis, TN. While the stories we heard were punctuated by struggle and hardship, they were also stories of strength and resilience, of positive change happening in the South, and of the power of trans and non-binary communities working together to meet their needs. Across the South, we met trans and non-binary people embedded in strong community networks and working creatively to create and share resources to meet their community’s needs.

These grassroots initiatives should be applauded and supported, but they should not be positioned as the solution to the need for systems-level change. The South is, in most every way, a unique landscape; grafting national best practices into our communities does not necessarily create lasting change. Rather, we believe that transgender community leaders, providers, and health care systems based in the South will be the architects of the strategies and models that ultimately ensure that transgender Southerners have access to the highest standard of care.
Project Summary

The Southern Trans Health Focus Group Project (STHFGP) is a qualitative data collection project focused on the health care experiences of trans and non-binary people in the U.S. Southeast, with 48 participants from North Carolina, South Carolina, Alabama, Mississippi, Arkansas, and Tennessee. Conducted in the spring and summer of 2018 by the Campaign for Southern Equality (CSE) in partnership with community groups, the STHFGP consists of a series of focus group interviews with trans and non-binary adults in the South. The STHFGP serves as an exploratory study, designed to better understand the health care needs of trans and non-binary people, the challenges they face in meeting those needs, and the resilience they show in working together to do so. The STHFGP is part of the Southern LGBTQ Health Initiative, a collaboration between CSE and Western NC Community Health Services (WNCCHS) to increase access to LGBTQ-friendly primary care, HIV care and support services in the South.

Process

In 2018, we completed a total of four focus group interviews, with 48 trans and non-binary people from across North Carolina, South Carolina, Alabama, Arkansas, Mississippi and Tennessee. Each focus group interview lasted approximately two hours and included discussion prompts related to access to care, quality of care, and consistency in care. Focus groups were video/audio recorded for transcription. In exchange for participation, participants were given a $50 Prepaid Visa Gift Card. The interviews were held at locations known by and familiar to the trans and non-binary people we interviewed and easily accessible by foot or public transit. For two focus groups, transportation was provided from the bus stop to the focus group location. Space was reserved, with refreshments provided, prior to and following each focus group interview for members of the group to socialize and network with other trans and non-binary people in their local communities. We wanted this to be an opportunity for trans and non-binary people to begin conversations with each other about the challenges in and opportunities for health care in their local communities. This research was approved by the Institutional Review Board of Kenyon College.
Participants

We owe tremendous gratitude to the trans and non-binary people across the South who gave their time, expertise and energy to this project as well as to the community partners – Gender Benders, OUT Memphis, and The Knights & Orchids Society – who helped organize and host our focus groups. Our participants were diverse in nearly all aspects of their identities, including race, age, socioeconomic status, and gender identity. Below is an overview of the people who participated in our study.

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Our conversations with trans and non-binary people across the South reveal patterns of mistreatment, discrimination, and disparities related to access to care, quality of care, and consistency of care. These findings confirm and build upon reports from the 2015 U.S. Transgender Survey (USTS) and the 2008-09 National Transgender Discrimination Survey (NTDS), offering a more in-depth look at the experiences of trans and non-binary people in the South. Trans and non-binary Southerners experience barriers to health care in areas of access, quality and consistency. In addition to identifying these barriers, our participants highlight the resilience within trans communities when it comes to coping with these barriers and emphasize the role of peer-to-peer and community support in filling the gap that the lack of a local resource infrastructure leaves.

The US Trans Survey offers a snapshot of the disparities in health care access for trans and non-binary people across the United States and the social factors that influence those disparities from mistreatment to insurance coverage. The USTS reports that one third of trans and non-binary people in the US who had seen a doctor in the last year had at least one negative experience, such as verbal harassment, refusal of treatment, or having to teach their health care provider in an effort to receive competent care. In addition, one quarter of trans and non-binary people were denied insurance coverage for transition-related care and fifty-five percent were denied coverage for surgeries. Our participants bring these statistics to life, illustrating the lived experiences of trans and non-binary people who struggle with institutional, interpersonal, and cultural barriers to getting their health needs met. Participants reported barriers to seeking and/or accessing care related to affordability of care, provider availability or willingness to provide care, intake and waiting room experiences, and the clinical encounter itself. On the following pages is an overview of the prominent themes in these interviews.
Accessing Care

Trans and non-binary Southerners are often denied care outright or dropped by their providers when they are honest about their gender identities. Participants live in fear of being mistreated or refused treatment when seeking care as a trans person in the South.

"And when I go my primary concern is not, at least for me, if my gender identity is going to be a problem...it is am I going to be helped regardless of it?"

Our participants are understandably frustrated at the inability to find willing providers that will take them on as patients. Care from providers who are not altogether supportive is preferred over outright refusal of treatment. Physicians regularly deny primary care to the trans and non-binary people we spoke with, often citing religious doctrine or personal disapproval for gender diverse experiences. Prior experience or knowledge of this kind of treatment causes most of our participants a great deal of stress and anxiety. Many of our participants experience stress or anxiety to such a degree that they would rather not seek treatment.

"It’s invalidating, and it makes me not want to come in. At least for me, I’m like, oh, they’re going to discriminate against me and use the wrong name and pronouns. Like, I just don’t go."

Trans and non-binary Southerners are delaying or avoiding care altogether in order to protect themselves against invalidating and discriminatory encounters. Delaying or avoiding care may exacerbate health issues or lead to negative health outcomes in the future.
Consistency in Care

When trans and non-binary participants are able to identify a friendly and supportive provider in their local communities, that provider often requires long waits. This is in large part due to providers being over-extended as the only known provider willing to treat trans and non-binary people in the area. Some of those providers understand the role they are playing in their community and will open spots for patients who are trans.

"I think most of the primary care providers are really over-extended. There are a few of them here, and two or three others around town that are recommended by folks, but it’s really hard to get into any of them. And, a lot of them, their practice isn’t accepting new patients unless you are trans. And it’s still a wait because there’s an enormously high percentage of trans people in this city. There are providers, but there are not enough providers to serve all the trans people who live here.”

In addition to long wait times, affirming providers are not always situated within affirming practices. When a primary physician is away or when participants have emergent or immediate care needs, they are often treated by providers that are not as educated or affirming as their primary provider, even within the same practice or urgent care facilities.

“You have a UTI and you can’t get in to see your PCP [primary care provider] so you have to go to urgent care and see whoever is working. You never know who is going to be on location. I came here not long after gender reassignment surgery, because I thought I had an infection. I kept trying to see my PCP, but they made me come to urgent care. When the guy who came to see me figured out what was going on, he started to sweat and really didn’t handle it well.”

Trans and non-binary Southerners experience inconsistency in care. As many of our participants are low-income and/or uninsured, they often seek care at urgent care facilities or local minute clinics that are unfamiliar with their personal health history and, more generally, with trans and non-binary experiences.
Mistreatment from Care Providers & Support Staff

Trans and non-binary Southerners’ barriers to care do not stop when they secure an appointment with a willing and affirming provider. Our participants report experiencing disrespect and mistreatment from the front desk to the pharmacy. Front desk and nursing staff are the first line of communication between patient and provider and have a significant impact on patients’ comfort in a care setting.

“Disrespect and misgendering is an issue. We just did a training with the organization that provides care to trans folks because misgendering was an issue. There was a transgender lady trying to get in and called the office. They did not respect her pronouns, and she corrected them multiple times. It was horrible, but then when she got back to the exam room, this is just the front desk, when she got to the back, there were conversations about her being held on the other side of the door that she could overhear.”

Whether communicating over the phone or completing intake face-to-face, trans and non-binary people experience mistreatment and disrespect at intake, in waiting rooms, and during clinical interactions with their provider. There is still a significant amount of stigma attached to trans and non-binary experiences, and our participants feel the effects of that stigma as they are stared at, whispered about, misgendered (i.e., referred to using incorrect pronouns and other gendered language), and at times harassed by other patients and administrative and clinical staff. Some of these experiences result in the mismanagement of care, leading to complications.

“When I first came out I was gender fluid and I used he/they pronouns. I broke my foot and I went to physical therapy and they wouldn’t respect my pronouns at all […] They would change me a lot [to new/different physical therapists]. They would switch me around because they were tired of me telling them to use the right pronouns. They would change me to different people because they didn’t want to deal with respecting my pronouns. So, I stopped and now my foot is hurt really badly. Walking hurts. My full body hurts from adverse reactions to that. All because I didn’t complete physical therapy, because I was too nervous to go because of that.”
Some of the people we spoke with said that they accept this mistreatment, fearing they will lose access to care if they stand up for themselves.

“A lot of transgender people are afraid to speak up or be direct. And, you know, if you want to correct people or stand up for yourself, you always have that fear... oh God, that could risk me getting my hormones, what if she refused to treat me or refused to help me with this. So, you just sit in it and then you try to go on.”

During the interviews, our participants shared their worry that standing up for themselves might compromise their access to and quality of care.

“I just didn’t have that [respect] with my provider. I just didn’t have that with my primary care [provider]. [I would experience] things like misgendering, [...] wanting [him] to use the correct pronoun, wanting [him] to use the correct name. And then just not being able to [ask for that], [...] not having the courage to correct [him].”

Our participants are consistently misgendered, called the incorrect name, and treated with disrespect while seeking and receiving care. Rather than stand up for themselves and demand to be treated with respect, some participants accept this mistreatment to maintain their access to care.
A majority of the trans and non-binary Southerners we interviewed are treated by providers who lack a general education related to trans and non-binary identities, experiences, and health needs. While a few of the providers treating our participants have sought education to support their treatment of trans and non-binary patients, ongoing education for trans and non-binary health is not easily accessible, and even motivated providers may not have all of the information that they need to provide the highest standards of care and patient-provider interaction for trans and non-binary patients. This lack of education among providers extends to their clinical staff and administrative staff. Medical training for trans and non-binary health is nonexistent in most medical schools’ curriculum. Physicians who treat trans and non-binary patients must educate themselves in both interacting with and treating trans and non-binary people. This lack of education and awareness resulted in a particularly negative experience for one participant when they came out to their physician during an exam for a broken finger.

“As soon as I walked in, they didn’t respect pronouns at all. I took my husband with me because I like him there, and they are more likely to listen. They looked at him the whole time and talked directly to him. They didn’t use my name or pronouns. Then they referred me to psych because I kept insisting they use them [as my pronoun]. There was a lot of “Yeah, okay. We will see.” It was ridiculous. I was there for my broken fingers that had not healed and they did not look at them at all.”

Our participants’ experiences suggest that most providers are not taking additional steps to educate themselves, leaving the burden on their trans and non-binary patients to educate their providers on their health care needs and the standard protocol for meeting those needs. This often results in trans and non-binary people receiving incorrect, negligent, and sometimes harmful care. For one trans Southerner, the result was fatal.

“We had a sister that died of a blood clot in her lungs. She was trans, and because she was trans they didn’t know how to deal with her, how to approach her. She actually probably could have lived, but she was in the emergency room for so long she ended up dying in the emergency room.”

While not every negative encounter ends tragically, one tragedy should be enough to warrant a swift and meaningful correction from the medical community.
Normative Medicine

Due to lack of medical education, providers sometimes approach trans and non-binary health from a place of uncertainty. Uncertainty leads providers to fall back on widespread cultural stereotypes and incorrect understandings of what it means to be trans or non-binary. These cultural stereotypes rely on binary and medicalized models of gender that overemphasize medicalized interventions and discount non-binary and non-interventionist trans experiences.

"My experience with the affirming family practitioners is that there’s still some learning about non-binary identities and flexibility and fluidity around gender changing from day to month to year. And I took T for a long time, and it wasn’t right for me to take T. And I don’t want to take T. I don’t know that it challenged my access to care, but there was this push that yes, this was right for me. And I don’t have to take T to be a trans person. I think there is just still very binary thinking even from the medical community where it’s like – I actually know what’s right for me, and I would like for you to trust me."

The emphasis on gender stereotypes privileges gender normativity for binary trans people while eclipsing the experiences of non-binary trans people. These experiences suggest that providers who have experience with trans and non-binary health should also be educated about trans and non-binary experiences of gender and identity.

When I got my breasts, I wanted to listen to my surgeon. I went in wanting small breasts because I was thinking about my parents, thinking about everybody else instead of thinking about me because I would have gotten bigger. But I end up getting them a whole lot bigger because my doctor is like no you need 600 CCs, he just kept saying it. And when he was saying it, it kind of made me mad. When I left there I was like why did he do that? But my friends are like you need to listen to your doctor. I did, but it made me uncomfortable. I felt like he was trying to give me a look that I didn’t want.”

These normative assumptions of trans experience cause providers to overemphasize medical interventions, including hormones and/or surgery, that emphasize stereotypical ideals of masculinity and femininity.
Trust

Trans and non-binary people in the South experience a well of mistrust when it comes to their health care interactions. Patients’ past experiences of mistreatment, discrimination, and lack of proper health care lead them to practice caution when seeking care.

“Going to the doctor is completely anxiety-producing and scary... not a lot of hope that it is going to turn out okay. Kind of expecting the worst. So, every time I would call or whatever, I would expect not to have my pronouns respected or not understand issues. Going in, I know I am going to have to explain things... I’d rather not take that chance.”

Trust plays an important role in the health behaviors, symptom management, quality of life, and treatment satisfaction of patients. Past experiences of mistreatment result in trans and non-binary people experiencing a lack of trust in their medical providers. This contributes to trans and non-binary people delaying or avoiding treatment, receiving less effective treatment, and potentially exacerbating or creating additional health issues as a result.
Intersections

Socioeconomic Status

Trans and non-binary people in the South live multidimensional lives that are affected not only by their gender identities but also by their socioeconomic status, race, age, coexisting health issues, and whether they live in rural or urban environments. With each of the intersecting social experiences, accessing consistent quality care becomes more difficult.

Socioeconomic status, according to the USTS, has a significant impact on the quality and consistency of care that trans and non-binary people receive. Trans and non-binary people who face financial hardship are more likely to face difficulties maintaining a care relationship with a provider and may delay care to avoid the financial burden that comes with being under- or uninsured. One participant deals with their financial barriers on a case-by-case basis:

“My only two options now are going to the ER or going to the clinic. So, I have to decide: Do I have a cold? I could go to the doctor or just get some medicine that may help. So, I won’t go. But... if I am having chest pains, or really bad back pains, or need bloodwork done, I’ll be like, okay, I have to go. [When I go], I go to the free clinic, but still I have to be there very early and I have to wait all day while they work everyone in [because I am not a regular patient].”

When lower-income participants do seek care, they often do so at emergency rooms, urgent care facilities, and other retail clinics where there is little consistency in patient-provider relationships. This inconsistency may lead to worse health outcomes, as trans and non-binary patients’ health is not contextualized in personal medical history, family medical history, and provider familiarity with patients’ sociomedical resources.
Intersections

Institutionalized and Interpersonal Racism

Institutionalized and interpersonal racism impacts the care experiences of trans and non-binary people of color (POC) in the South in similar ways to those that have been documented for Black, Latino/a, American Indian and Alaska Native, and Asian, Native Hawaiian, and Pacific Islander POC across the U.S. These experiences include disproportionate rates of refusal of care, out-of-date or remedial care, verbal harassment, physical and sexual assault, morbidity, and mortality. While reporting the same barriers to care as white participants, participants of color shared experiences of mistreatment and exclusion that were much more pronounced.

“When I was in the hospital, I watched a bunch of other white people coming in after me and get treated. Like, there’s a difference. Also, my placement... Where I was, I didn’t have a room or any curtains or anything. I had to watch white people come in and get taken to rooms and areas with curtains and watch doctors go by and get medicine for folks. I could watch doctors go by [and address another patient] with a very enthusiastic voice, ‘How are you doing today, sir?’”

Participants of color across the South report being passed over for treatment at emergency centers, being forced to wait until white patients had been cared for, being denied rooms and forced to wait on gurneys in hallways of care facilities, and being accused of medication seeking when trying to receive care for pain.

“The ER person threatened to call security on me. He was like “nothing is wrong with you, you’re trying to get meds, blah blah blah.” I couldn’t move [my leg]. I kept trying to get someone’s attention, to let them know that I needed to use the bathroom. They sent two people over, and every time someone came over they were like, “Get up and go to the bathroom.” I’m like, “If I could go to the bathroom, I wouldn’t be talking to you.” Finally, they helped me to the bathroom [and when we were in there] they had to help me take off my clothes, and [then they were] wigging out and it was just weird. I’m just like trying to get the whole thing over with. I’m in pain, I’m crying, they still haven’t given me anything for pain.”

The treatment that trans and non-binary people of color experience when seeking and receiving care has a visible effect on their health outcomes. National studies of trans and non-binary experiences indicate disproportionate rates of illness for trans and non-binary people of color related to both physical and mental health.
According to the 2015 U.S. Trans Survey, these disparities include a 19 percent HIV rate among Black trans women and a 4.4 percent HIV rate among Latinx trans women. As a point of comparison, the HIV rate of the general U.S. population is .03 percent, and 1.4 percent for trans and non-binary people overall. The rate of HIV transmission is especially high among trans and non-binary Southerners. The Centers for Disease Control and Prevention (CDC) report that between 2009-2014, 43 percent of all HIV diagnoses for trans women and 54 percent of all HIV diagnoses for trans men were in the U.S. South.

Trans and non-binary people color also experience elevated rates of psychological distress and suicidality. Across the U.S., 41 percent of Black trans women and 45 percent of Latinx trans women experience serious psychological distress. These rates occur alongside equally high rates of suicidality, with 47 percent of Black trans women and 45 percent of Latinx trans women having attempted suicide at least once in their lifetimes. If we situate these statistics next to the murder rates for trans people of color, over half of the victims being trans women of color from the South, we gain a more nuanced understanding of the ways that race intersects with region to create disproportionate disadvantages for trans people of color.

Beyond individual experiences in specific health care settings, trans and non-binary people of color in the South live in communities where the legacies of slavery and the Jim Crow era are entangled with modern manifestations of institutional racism and white supremacy. Health researchers have even argued for racism to be understood as a social determinant of health due to its negative impact on both physical and mental health. Structural and interpersonal racism comes to bear on individual health outcomes through various channels, including interational displays of prejudice within the patient-provider relationship or the biochemical response to minority stress within bodies of color. Researchers have documented the consequences of race and racism on various health outcomes for people of color, including infant mortality, maternal mortality, cardiovascular disease, kidney disease, and cancer death. Three of these health outcomes, cancer, cardiovascular disease, and kidney disease are in the top ten leading causes of death for Americans. The adverse health outcomes of institutional and interpersonal racism cannot be overstated.
Intersections

Age

Age also plays a significant role in the care experiences of trans and non-binary Southerners. We spoke to an intergenerational group of trans and non-binary people throughout the South who identified unique health care needs and experiences that were age-specific. Trans and non-binary young adults are experiencing high levels of physician mistrust, disrespect, and paternalism. Young trans and non-binary people are struggling with being taken seriously when expressing concerns about their health and are treated as if they are not old enough to make decisions about their bodies. A non-binary participant experienced this form of invalidation with their therapist.

“Adults don’t trust young people with their own experiences: You’re young, you’re naïve, you don’t know, it’s just a phase. I had a therapist who was more literate and competent in gender, but not so much with trans and non-binary identities. He wouldn’t say it outright, but he would say I wanted to be a boy because I was treated so poorly as a woman by society, and I was running away from my identity.”

As trans and non-binary people age and their provider networks increase to include more specialists, unique obstacles arise related to health and health care. These obstacles include a lack of training and awareness among specialty care providers, lack of social support, and lack of legal support for gender-affirming elder care housing and transition-related treatment. Research suggests that these obstacles arise from non-conscious biases held by providers, requiring widespread cultural as well as institutional shifts to address them.
Mental Health care is also largely inaccessible for trans and non-binary Southerners. The bulk of the trans and non-binary people in this study were lacking in access to mental health care and resources as much as they were to primary care. Existing research points to several reasons for this limited access including cost of treatment, previous bad experiences and fear of mistreatment.

One community leader we spoke with witnessed the effects of this lack of resources among the people he and his organization served:

“We have one guy now who just reached out to us recently, who’s really dealing with mental health issues. Like, damn... And that’s an [area of health] that he doesn’t even know how to talk about. [...] Living trans in the South, facing racism, facing heteronormativity, transphobia... these are things that are impacting people daily. [People] who are just trying to cope. [I want to] see us not necessarily thriving, but just existing, you know?”

When trans and non-binary people are able to access mental health resources, they face the same level of institutional and informational erasure as in primary care interactions. Participants report being misgendered, called by former names, being treated as if their gender was a delusion, and interacting with providers with limited knowledge of trans and non-binary health. Recurring and acute stress is an important predictor of both mental and physical health outcomes, and as such these experiences may be detrimental to trans and non-binary people in and after the clinical encounter.
Intersections

The South

The South presents its own unique challenges to trans and non-binary people’s access to health care. Accounting for over 33 percent of the U.S. population, the South is home to the highest rates of chronic disease and poor health outcomes in the country. According to the Williams Institute at UCLA, the South is also home to 35 percent of all LGBTQ Americans, a significantly higher percentage than any other region of the United States. Factors like higher poverty rates, lack of structural resources, and high religiosity are some of the additional barriers that trans and non-binary people face when trying to access care in the South.

"It’s so dated down here. We also have to take in the fact that, you know, Alabama prides itself on being this Christian state. And, we’re still having to fight with the church to get the resources that queer and trans folk need, you know? The resources that they have, you know? We were on a call where [the other organizers] kept pushing [for us to connect with the church]. You know, we need to use the church, we need to use the church... And, I’m like, but what if you’re not welcomed in those [spaces]? Like, how are we supposed to have access to stuff like that when we’re not even welcome or invited in?"

In many communities throughout the rural South, churches and other religious organizations lead ministry work to address inequalities in their local communities by providing food, shelter, and emergency funds to community members in need. Trans and non-binary Southerners, however, are often excluded from those ministries as their identities are not reliably respected or welcomed by churches and other faith-based institutions. Additionally, transgender Southerners lack basic state-level legal protections related to discrimination in public accommodations, housing and employment settings.
Rurality

Rurality is a backdrop to the lives of many trans and non-binary Southerners, erecting unique barriers to care. Many of the trans and non-binary Southerners we spoke with are unable to find a primary care provider in their local community who is willing to treat them. Our participants are often limited to one provider treating trans and non-binary people across several counties and are further limited by their ability to pay for that provider’s care. One participant spoke of the unique treatment seeking experience that arises for trans and non-binary people at the intersection of rurality and socioeconomic status:

“...So, like in my job [as a health insurance navigator], I cover a lot of rural areas. Some of these people that I meet with don’t even know they qualify for health care, or that there are certain places they can go to [receive health care]. Since [the government] did cuts to Medicaid, a lot of rural clinics have been closing [...] We’re seeing more and more of our people having to come out and come into the city to do stuff. So, with that in mind, you gotta think about [queer and trans] people that we run into [in] these rural areas, you know. Now I’m already trying to find a doctor to go to, now I gotta figure out, is it even worth me mentioning, “Hey, I’m interested in maybe, you know, hormones.”

The lack of affordable, affirming providers also makes it difficult for trans and non-binary people to discontinue care relationships with providers who are uneducated, disrespectful, and invalidating. Participants who are able to afford the travel and/or out-of-network costs of seeking higher quality care often travel to Atlanta, for some up to four hours away, to receive care for their basic health needs.
Coping with Barriers

The experiences that trans and non-binary Southerners shared with us are instructive. As we listened to their stories of accessing health care, we heard that trans and non-binary people in the South are struggling to get their basic needs met related to health and health care. In those same stories, we heard testimonies of peer-to-peer support and the role of community in filling the gaps that formal and traditional health care institutions leave behind.

Peer-to-Peer Support

Connecting with peers is an important resource for trans and non-binary people to guard against the distress that results from transphobic mistreatment. Peer-to-peer support offers trans and non-binary people a way to normalize their identities and experiences, receive support from someone with similar experiences, and feel empowered to take control of their social interactions and identity development. Trans and non-binary people are building peer-to-peer support networks through community organizations, activist groups, and online networks. One participant refers to this support as the most important resource available to trans and non-binary Southerners seeking health care.

“If we don’t talk to each other and let each other know who is doing what, who is doing it appropriately, and who is doing it inappropriately, we won’t know. If you’re trans [...], you’re an important resource for us and we are an important resource for you [...] We are the most important resource.”

Our participants’ experiences suggest that these support networks are playing a large role in the resilience of trans and non-binary people in the South and should be fostered alongside enhancing practices and providers. It is important to note, however, that all trans and non-binary Southerners may not have equal access to these networks, dependent on geographic location, language barriers, and cultural and political differences that arise outside of a shared gender experience.
Both in-person and online support networks appear effective in helping people overcome feelings of isolation and hopelessness that can be overwhelming as a Southern trans or non-binary person. Most of our participants are connected to a community of trans and non-binary people organized in large part by local community organizations. These organizations are run by and for trans and non-binary people. Leaders in these organizations volunteer their time to meet the needs of their community and fill the gaps that a formal resource infrastructure leaves behind. The leaders we interviewed shared stories of finding ways to pay for medical care, find housing, and provide HIV testing and self-defense trainings for the trans and non-binary people in their local communities.

We heard stories that are nothing short of heroic about trans and non-binary community leaders volunteering their time to support and organize for trans and non-binary people in their communities while managing paid employment and family obligations and facing public and interpersonal opposition to their work. We heard dreams of and concrete plans for community centers with wraparound services where trans and non-binary Southerners can get health, economic, and legal resources. These dreams were borne of frustration with the resource desert that is harming the physical and mental health of trans and non-binary people in the South. Southern trans and non-binary leaders are changing the landscape for their communities one step at a time.

Community Organizations
Our participants shared their roadblocks and their resilience with our research team and with each other, offering support by sharing resources both during and after the focus group interviews. The interaction among participants points to how deeply the trans and non-binary community cares for itself when systems fail. Participants from every state we visited communicated the same thing: the system is failing and trans and non-binary people are creating a new system. This new system is not one that mirrors the existing system of health management and care delivery in the U.S. Rather, this new system mirrors those that have been formed by minoritized groups throughout history, focused on enhancing a more holistic understanding of health, centering their unique needs, and supporting each other with social, emotional, and financial resources that traditional systems either cannot or will not provide.

These emergent systems have been studied among Black communities where fictive kin networks have been necessary to fill the gaps created by laws, policies, and cultural norms that work to separate, destabilize, and disrupt Black people, families, and communities. In the early decades of the AIDS epidemic in the U.S., we saw similar processes among LGBTQ people who formed community groups and organizations, in a context of governmental and institutional neglect, aimed at caring for those dying from AIDS related illnesses, forming support groups to share resources and strategies, and organizing “buyer’s clubs” to acquire and distribute yet-to-be FDA approved treatments for those battling the effects of the virus.

Minoritized communities have always found imaginative and resilient ways to care for themselves. Trans and non-binary people in the South are experiencing crises of health and health care. While local leaders are stepping up to support their communities where and when they can, not all of the existing needs can be met by grassroots organizations. Trans and non-binary people in the South need health providers, practices, and care systems to deliver affirming, consistent and quality clinical treatment, emergency care, preventative care, and medication.
An Open Letter to Providers, Practices, and Health Care Systems

Thank you for taking the time to gain a better understanding of the health care needs of trans and non-binary Southerners.

By doing so, you have demonstrated your commitment to providing quality care to trans and non-binary patients. As you know from reading this report, community leaders across the South are stepping in to address the resource desert that is created and maintained by a widespread lack of education, understanding, and acceptance of trans and non-binary people. These leaders work with other volunteers to provide peer-to-peer support, HIV-testing, blood-pressure monitoring, smoking cessation support, daily activity tracking, group counseling sessions with local providers, intra-organization helplines for those in crisis, food pantries, self-defense courses, and trainings for providers, practices and health care systems. Beyond providing these resources, trans and non-binary leaders are recruiting and training new leaders that will develop strategies and programs to serve some of the health care needs of Southern trans and non-binary people in the future.

The level of bias faced by trans and non-binary people in the South is so profound that it limits their access to even the most basic and emergent health care. While local grassroots leaders are doing critical work and deserve respect and admiration for serving their communities, trans and non-binary people need access to providers, practices, and health care systems in their local communities that are educated in how to treat trans and non-binary people with dignity and respect while delivering high quality health care.

Based on the interviews, observations, and community gatherings that our research team carried out, we offer some recommendations for best practices and a list of resources for providers, practices, and health care systems joining or continuing in the fight for trans and non-binary health in the South.

“I feel like we need to be more radical in our thinking because it’s our life, it’s our health. Our lives and our health matter, regardless of what anybody thinks about it.”
Recommendations for Southern Providers, Practices, and Health Care Systems

Streamline the Intake Process

- Ask for and consistently use the patient's correct name and pronouns when referring to them.
- Avoid using terms like mister, miss, misses, ma'am, and sir based on a patient's voice or appearance.
- Provide the opportunity for trans and non-binary patients to communicate the following necessary information during intake:
  - Name and gender to be filed for insurance
  - Name to be called in the waiting room, with their doctor and clinical staff, and with their family
  - Pronouns to be used in the waiting room, with their doctor and clinical staff, and with their family
- Consider making pronoun pins or stickers available at check-in.
- Provide funding for trans-led training for this process for administrative and clinical staff.

Seek & Share Resources

- Educate yourself about trans and non-binary experiences and identities.
- Educate yourself about trans and non-binary health care needs and standards including primary care and transition-related care.
- Provide trainings focused on trans and non-binary identities, experiences, and health care within your practice and community.
- Share resources and information with other providers and/or practices in your local community.
- Engage more experienced providers, through telemedicine or specific consultations.
- Familiarize yourself with the ICD-10 codes commonly used for trans and non-binary health care.
Communicate Clearly & Openly

- Ask patients their preferred terminology when referring to primary and secondary sex characteristics.
- Ask for patients’ permission before touching them, explain why touch is a part of the clinical encounter.
- Explain clinical processes to patients in detail before asking them to remove any clothing.
- Practice caution when asking patients about their medical transition process unless it is related to the clinical encounter.
- Reflect on the boundary between clinically necessary medical information and information that is a result of provider curiosity about gender identity and transition.
- Avoid giving advice or probing for explanations related to a patient’s transition process unless medically necessary.
- Trust your patients to know what medical interventions are best for their unique transition experience.

Engage With & Support Trans & Non-Binary People and Community

- Listen to trans and non-binary people regarding their health care needs.
- Promote positive health behaviors among trans and non-binary people.
- Promote health awareness and education in trans and non-binary communities.
- Attend local community events to get to know the trans and non-binary people in your community.
- Partner with community leaders to provide screenings and resources to trans and non-binary people.
- Find ways to support and promote the health and wellness work being done by local leaders.
- Hire community leaders for education work with your complete care team.
- Structures like Community Advisory Boards and Patient Advisory Boards create ways for individuals to have direct input and leadership into how care is delivered.
Additional Resources for Southern Providers, Practices, and Health Care Systems

Resources Available from National Organizations

- The Transgender Health Learning Center at the Center of Excellence for Transgender Health
- The National LGBT Health Education Center at the Fenway Institute
- The Transgender Health ECHO Project through the Fenway Institute
- The Healthcare Action Center at The National Center for Transgender Equality
- Guide to Best Practices for Front-Line Health Care Staff
- Guide to Providing Health Care to Non-Binary People
- Guide to Making Health Care Forms More LGBT-Inclusive
- The Patient Services and Support Guide for Hospitals & Administrators from Human Rights Campaign
- The Transgender-Affirming Hospital Policies guide from Lambda Legal and the Human Rights Campaign
- The Guide for Community Clinic Organizing and Advocacy from The Transgender Law Center
- The Professional Organization Statements Supporting Trans People in Health Care from Lambda Legal
- The Standards of Care (7th edition) from the World Professional Association for Transgender Health
- The Clinical Guidelines for Hormone Replacement Therapy from The Endocrine Society
- The Guidelines for Psychological Practice with Transgender and Gender Nonconforming People from the American Psychological Association
- The Know Your Rights: Healthcare guide from The National Center for Transgender Equality
- The Know Your Rights: Medicare guide from The National Center for Transgender Equality
Resources Available from Campaign for Southern Equality and Western NC Community Health Services

- The Trans in the South Resource Guide in English
- The Trans in the South Resource Guide in Spanish
- Organizational or Institutional Trainings on Transgender Issues
- The Southern Equality Fund for Grassroots Groups and Leaders
- The ICD-10 Insurance Codes for Transgender Health
- “Trans Voices for Health Care” by filmmaker Polly Schattel (a training video for health care providers); available on Vimeo

Peer-Reviewed Professional Journals

- Transgender Health
- LGBT Health
- International Journal of Transgenderism

Reports from National Trans and Non-Binary Research

- The 2015 U.S. Trans Survey
  - Executive Summary
  - Full Report
  - Reports on the Experiences of Black, Latinx, American Indian and Alaska Native, and Asian, Native Hawaiian, and Pacific Islander Respondents
We owe a debt of gratitude to the trans and non-binary people who shared their experiences and time with us. We also want to thank our community partners who promoted and provided space for the focus group interviews and community gatherings. These partners include OUT Memphis, The Knights & Orchids Society, and Gender Benders. This research would not be possible without these community leaders who are building a strong network of trans and non-binary people across the South. The Southern Trans Health Focus Group Project was also made possible by the collaborative efforts of a dedicated research and support team and this report would not have been possible without the talent and skill of Graphic Designer and CSE Communications Director Adam Polaski.

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Southern LGBTQ Health Initiative

This project is part of the Southern LGBTQ Health Initiative, a collaboration between CSE and Western NC Community Health Services (WNCCHS) to increase access to LGBTQ-friendly primary care, HIV care and support services in the South. Learn more about CSE at www.southernequality.org and WNCCHS at www.wncchs.org.

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