

a vision for greater access to

# gender affirming healthcare

For a future where our communities can feel whole, safe and at home in their bodies.



**INGERSOLL GENDER CENTER**

[www.ingersollgendercenter.org](http://www.ingersollgendercenter.org)

## WHY THIS PROJECT AND WHY NOW:

We believe deeply in building a world where we can all access **our collective self determination**. Self determination is when we all have a full menu of choices to decide how to live our lives authentically and free from violence. For trans and gender nonconforming communities the right to control our own lives is something that is constantly being taken over, controlled, redirected, and in many cases completely taken away. For us, most of our lives are lived in a constant state of reactivity to the discrimination, fear, and uncertainty of being trans in America; especially in terms of healthcare access. With our Healthcare Access Visioning Project we wanted to be deliberate in highlighting the barriers that trans and gender non conforming folks come up against when just trying to be healthy, and feel at home in their bodies.



We are passionate about healthcare and this project because we know that for our communities these are life and death medical decisions. We know that accessing healthcare can be a traumatic experience and we hope this project can outline a future where all trans and gender nonconforming communities have equitable access to the life saving health care they need.

**Our goal** is to be proactive in our approach to envisioning a healthcare system that centers the collective self determination of our communities to be able to determine with their providers the type gender affirming care that is right for their health and their bodies, and to have healthcare systems and insurance companies support and honor those decisions instead of impeding them.

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# OUR PROCESS

We share our organizing process because we value transparency and we hope that other trans organizers can use this as a template for organizing similar projects in their communities.



1

## BRINGING TOGETHER OUR ADVISORY COMMITTEE

We believe deeply that there is no one way to be trans and every time we are building an organizing project we try to bring together a group of trans leaders with diverse experiences to ensure that we are building something that's truly reflective of the diversity of trans experiences.

2

## BUILDING AND LAUNCHING OUR SURVEY

Our advisory committee helped us build our survey while our community partners helped spread the word about our survey and focus group opportunities.

3

## HOSTING OUR FOCUS GROUPS

We hosted two focus groups that had 25 attendees in total that focused on asking more in depth questions about the barriers community members were facing than was possible in our survey format.

4

## REVIEWING OUR DATA

In total we received 87 survey responses and got feedback from 25 focus group attendees. We took a few months to review this data and compare it to trends we were seeing in our own direct services and data from other sources when possible.

5

## REPORTING BACK TO OUR COMMUNITIES

We hosted a retreat that brought together trans leaders from across Western Washington that are leading work focused on the health and wellness of our communities to report back on what we have learned and to get their feedback on advocacy strategies. We also hosted a retreat for the Coalition for Inclusive Healthcare - a group that has led the policy work to expand healthcare access to our communities - to report back on what we have learned and identify the best advocacy strategies based on community insight.

6

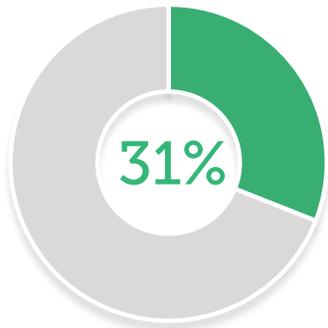
## BUILDING WITH OUR COMMUNITIES

After reporting back to our communities and identifying advocacy priorities and strategies we began putting what we have learned in to practice – with a clear focus on how we can make our community's vision for healthcare access a reality.

# WHO WE HEARD FROM

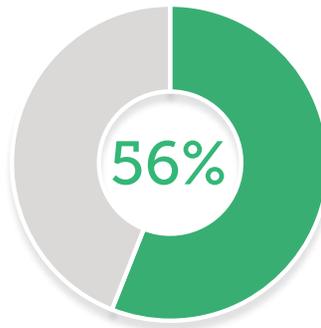
**87** people completed our Healthcare Access Vision Survey throughout the fall of 2018 that we crafted in collaboration with our advisory committee.

**25** people participated in our focus groups facilitated by Ingersoll Staff in October 2018.



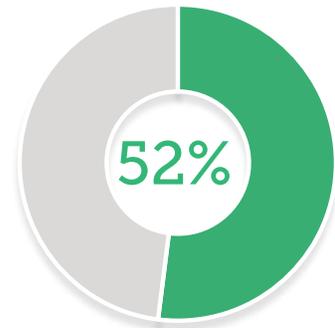
**of participants identified as people of color.**

Which is roughly similar to the percentage of King County residents that identify as people of color.



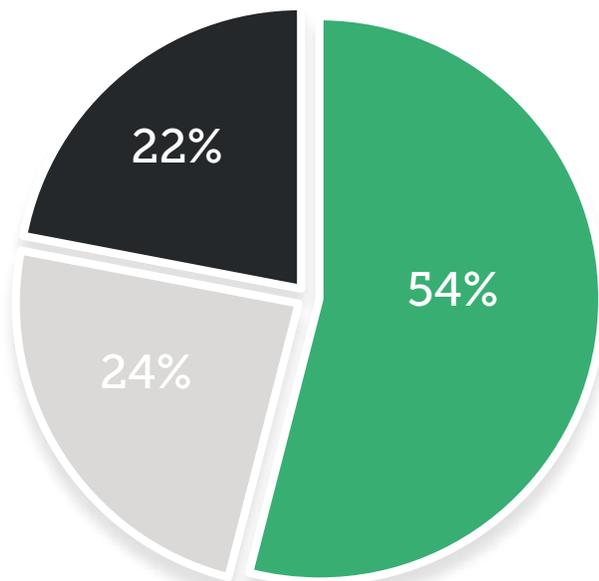
**of participants identified as disabled, sick, and/or chronically ill**

As opposed to the 12.9% of the general population in WA State that identify as disabled.



**of survey respondents made under \$24,000 a year**

A further 72.3% of respondents made under \$50,000 – well under the median average for the Seattle Metro area.



## GENDER IDENTITY BREAKDOWN BASED ON SURVEY PARTICIPANTS\*

- Trans Women/Trans Femme
- Trans Man/Trans Masc
- Non-Binary/Gender Non-Conforming

\*This is a roughly similar breakdown of those that attended our focus groups but we had a higher percentage trans women/trans femme community members participate in our focus groups.

# COMMUNITY STRENGTHS

There is a lack of trans led research efforts in to the experiences that our communities have in accessing healthcare due to institutional barriers our communities face. What research does exist, that is often not led by trans people, focuses on negative outcomes. We certainly found alarming negative outcomes and experiences in our conversations and work with community but we wanted foreground community strengths in our report. Our communities have been finding ways to access the care they need within and outside of the western healthcare system for decades.

## KNOWING THEIR PLAN



**71.1%** of survey participants know what kind of insurance coverage plan they have (examples: Employer Plan, a Insurance Marketplace Plan, a Private Plan, Tricare, Medicaid, Medicare etc) and a pretty good idea what that plan covers.

## ACCESSING CARE



**51%** of survey respondents and focus group participants said that they could find a medical provider within 30 mins of where they live.

## SHARING KNOWLEDGE ABOUT MEDICAL TRANSITIONS

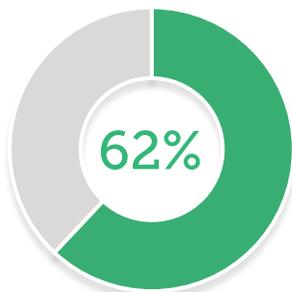
**Most trans folks noted that their number one source of information about medically transitioning was other trans people.**

This falls in line with what we see in community and what folks share with us when receiving services at Ingersoll. In the absence of more easily available information about medically transitioning or how to access gender affirming healthcare trans people have relied on each other to find affirming healthcare providers, answer questions and learn how to get access to the care they need.

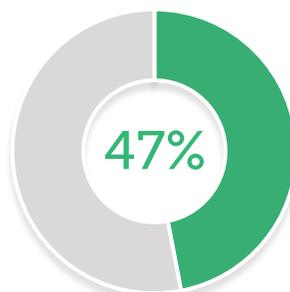
While this is a powerful source of community knowledge we have also seen how this can often lead to community members operating off of old information. The most common place we see this is when community members are operating off of older standards of care that are often more restrictive than current practices.

# COMMUNITY CHALLENGES

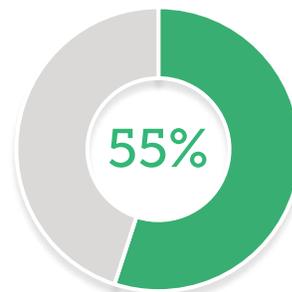
Every year Ingersoll helps hundreds of transgender and gender diverse Washingtonians connect with the life saving gender affirming healthcare they need. Through connecting with community members and providing services we felt like we had a solid sense of our communities challenges; even we were surprised to see some of our results. Below we have provided an overall overview of the challenges faced by survey respondents and focus group attendees and in subsequent pages have provided further information on the challenges specific parts of our community face.



of survey respondents say they sometimes to always have difficulty paying for healthcare costs



of survey respondents couldn't find a gender affirming surgeon that would work with their insurance



of survey respondents have been misgendered in a healthcare setting

**“ I am afraid to share too much about my gender identity, including pronouns. I know that having this info will lead to negative bias in my treatment. So the choice I have to make is between being my authentic self or being treated with respect. Additionally I rarely go to a doctor. Maybe once a year when it is required for my medication to be re-upped at pharmacy. –Survey Respondent**

## GENERAL TAKEAWAYS

- » Community members overwhelmingly distrust healthcare providers and healthcare institutions. That distrust has resulted in community members not seeking preventative care and care when they needed it. Often times this leads to poorer health outcomes and increased complications.
- » Community members cited confusing standards of care and insurance practices as the largest barriers outside of cost that prevented them from accessing the gender affirming care they needed.
- » Community members sited confusion, lack of support and time as the biggest reasons they do not report mistreatment they experience in healthcare settings.

**55%** of survey respondents reported having to lie to their healthcare provider in order to get the care they needed

## CONFUSION IN NAVIGATING CHANGING POLICIES AND PRACTICES

 **56%** of survey respondents and focus group participants said they are not aware or inconsistently aware of the gender affirming care that they are entitled to.

 **66%** of survey respondents and focus group participants either did not know or weren't sure if they understood Washington State & Federal laws and rulings that guaranteed their rights and access to medical care.

Many focus group participants commented that due to constantly changing rules, uncertain federal law, broad plan language around gender affirming care/trans health, that many times they were uncertain or did not know what services they were entitled to nor did they have a firm grasp on ever changing Washington State & Federal laws and rulings, and interpretations of such by state and federal agencies - meaning they often times delayed life saving gender affirming healthcare.

 **56%** of survey respondents and focus group participants were *sometimes comfortable* or *almost never comfortable* asking about what their rights are in their medical providers office when unsure or unclear as to what their rights are.

Focus group participants commented that they often feel as if they do not trust their providers; some even have a level of fear around their doctors and other medical professionals due to current or past negative experiences. These fears and lack of trust often prevent community members from seeking clarity when they do not understand what their rights are.

## UNDERSTANDING TREATMENTS AND PROCEDURES

**53%** of survey respondents and focus group participants have *sometimes* or *frequently* been in situations where they have not fully understood a treatment or medical procedure before having the treatment or procedure performed

Focus group participants stated that there have been times where they have felt "coerced" into procedures that they did not want. A few participants had stated that they had been given blood tests; specifically pregnancy tests after telling medical staff that they 1) were not having penetrative sex that could lead to pregnancy 2) had a partner who was not able impregnate them or 3) had no partners. They were administered and charged for pregnancy tests and other such testing that they did not need or ask for.



**42%** of survey respondents and focus group participants said that they sometimes or often do not feel comfortable asking for explanations of treatments and procedures when they do not understand them. Focus group participants concluded that being coerced into treatments or procedures or not being listened to, contribute to anxieties around asking providers and medical staff for clarification around treatments and procedures when they do not fully understand them.

## BUILDING TRUST WITH AND ACCESSING PROVIDERS



**67%** of survey participants said that they are not or not completely comfortable speaking with their medical providers about their trauma.

For focus group participants of color it was mentioned that the fear of being pathologized by trauma, when already being pathologized by racial identity, sexuality, and gender identity was one of the reasons why trauma was difficult to discuss with medical providers. Focus group participants also mentioned that medical providers don't seem to take their trauma as seriously as they might for a cis person and feel a double standard present.

**Focus group participants also mentioned that in addition to having to lie to a provider to get the medical care that they need, that providers have also had to present their needs in creative ways in order to get trans and gender non conforming patients the care that they need. Participants mentioned that it can sometimes challenge their personal values to have to be dishonest and to have others unable to be completely honest on their behalf just to get medical care.**



**46.5%** of survey respondents and focus group participants said that they could not access a mental health provider on a regular basis.

An inability to find a mental health provider that accepted their insurance was a common barrier.

# CHALLENGES FACED BY TRANS FOLKS OF COLOR

We found that the trans folks of color who responded to our survey were more likely than the white respondents to be:

- » Experiencing homelessness or unstable housing
- » Making under \$25,000.00
- » On Apple Health Insurance

	Trans People of Color*	White Trans People**
Making Under \$25,000/year	65%	49%
Unstably Housed or Experiencing Homelessness	15.6%	11.7%
On Apple Health	46.9%	31.3%
Disabled Trans Folks	43.8%	61.5%
Trans Women	18.8%	21.6%
Trans Men	15.6%	25.5%
Non-binary	59.3%	50%

**66%**

of respondents did not know or were unsure of how to find a gender affirming healthcare provider, as opposed to 43% of white respondents

*The data in this chart is representative of our survey respondents – not those that attended our focus groups. \*n=32 \*\*n=51*

**“ Do I deserve to live? (because many signs point towards no).  
–Survey Respondent**

## GENERAL TAKEAWAYS

- » Transgender and gender diverse folks of color both in our survey and in our focus group noted how difficult it was to find a culturally competent healthcare provider. This is reflected in the 66% of respondents being unsure or not knowing how to find a provider. In particular, focus group participants noted that finding a gender affirming mental health provider that billed their insurance was difficult enough—finding one that was also able to support them as a person of color seemed nearly impossible.
- » Transgender and gender diverse folks of color reported a slightly lower rate (5% less than white respondents) of receiving support from a social worker or case manager to aid in their transition.
- » Transgender and gender diverse folks of color both in our survey and in our focus group noted that accessible transportation to and from healthcare appointments at clinics that provide gender affirming care was a major barrier - often times taking more than an hour to reach.

# CHALLENGES FACED BY UNSTABLY HOUSED TRANS FOLKS

We found that the trans folks who are experiencing unstable housing who responded to our survey are more likely than those stably housed to be:

- » People of color
- » Making under \$25,000.00
- » Disabled
- » On Apple Health Insurance

	Unstably Housed or Experiencing Homelessness*	Stably Housed**
Trans Person of Color	41.6%	36.8%
White Trans Person	58.4%	63.2%
Making Under \$25,000/year	91.6%	45.3%
On Apple Health	75%	32%
Disabled Trans Folks	75%	53.3%
Trans Women	33%	20%
Trans Men	8.3%	22.6%
Non-binary	50%	50.6%

The data in this chart is representative of our survey respondents – not those that attended our focus groups. \*n=12 \*\*n=75

**75%** of respondents did not have a social worker or case manager to help them in their medical transition or with accessing gender affirming healthcare

“ Who ultimately gets to **MAKE** decisions about ‘appropriate care’, my doctor or insurance companies? **–Survey Respondent** ”

## GENERAL TAKEAWAYS

- » Transgender and gender diverse folks experiencing unstable housing were twice as likely in our small sample size to have reported accessing prescribed medications and/or treatments that were not prescribed to them and/or performed outside of a clinic setting than those who were stably housed.
- » 66% of unstably housed survey respondents reported feeling unsafe in healthcare settings and at appointments with their providers. For many this led to not seeking care and/or not being fully honest with their provider.
- » An overwhelming majority of survey respondents and focus group participants that identified as unstably housed reported inconsistent access to gender affirming healthcare due to financial barriers treatment from providers because they did not ‘pass.’

# CHALLENGES FACED BY DISABLED TRANS FOLKS

We found that the trans folks who are disabled who responded to our survey are more likely than non-disabled trans folks to be:

- » Experiencing homelessness or unstable housing
- » Making under \$25,000.00
- » On Apple Health Insurance

	Disabled Trans Folks*	Non-Disabled Trans Folks**
Trans Person of Color	32.6%	47.3%
White Trans Person	67.4%	52.7%
Making Under \$25,000/year	53%	50%
Unstably Housed or Experiencing Homelessness	18.36%	7.9%
On Apple Health	40.8%	31.6%
Trans Women	24.49%	21%
Trans Men	20.4%	21%
Non-binary	48.9%	52.6%

*The data in this chart is representative of our survey respondents – not those that attended our focus groups.*  
\*n=49 \*\*n=38

**50%**  
of respondents reported concealing part of their medical history to providers to avoid outing themselves

**“ When I got my top surgery and started asking questions about hormones and such, my doctors didn’t understand why I wanted to start T or really know anything about being trans. I had to explain a lot to them. I also really struggled to have my correct pronouns used by nurses and doctors. I haven’t gone back to ask about hormones because I just felt frustrated and intimidated after my first experience. –Survey Respondent**

## GENERAL TAKEAWAYS

- » For the 50% of disabled trans folks that reported concealing parts of their medical history to avoid outing themselves in healthcare settings many also reported that this had negative impacts on both their mental health and self esteem but also prevented them from accessing the care they needed or meant that they didn’t receive preventive healthcare that they should have.
- » Further, 65% of disabled transgender or gender diverse survey respondents reported lying to their healthcare providers in order to get access to the care they needed.
- » The most common barrier to accessing mental healthcare for disabled survey respondents and focus group participants was cost. So much so that many have been unable to access care at all or had to interrupt their care because they could not afford to continue.

# CHALLENGES FACED BY TRANS FOLKS ON APPLE HEALTH

We found that the trans folks on apple health insurance who responded to our survey are more likely than those on other types of insurance plans to be:

- » Experiencing homelessness or unstable housing
- » A person of color
- » Making under \$25,000.00
- » Disabled

	Trans folks on Apple Health*	Trans folks on other insurance plans**
Trans Person of Color	46.8%	31.4%
White Trans Person	53.2%	68.6%
Making Under \$25,000/year	84.3%	33%
Unstably Housed or Experiencing Homelessness	25%	7.4%
Disabled Trans Folks	62.5%	53%
Trans Women	56.25%	20.3%
Trans Men	28.1%	24.07%
Non-binary	15.6%	46.29%

The data in this chart is representative of our survey respondents – not those that attended our focus groups. \*n=32 \*\*n=54

**33%** of survey respondents on Apple Health reported that their therapist did not bill insurance

**“ I feel like doctors do not trust patients about their own bodies. –Survey Respondent**

## GENERAL TAKEAWAYS

- » Different from other groups, transgender and gender diverse people on Apple Health reported that a major barrier to getting the care they needed - specifically surgeries - was the burdensome qualifications around needing letter written by providers.
- » 59% of transgender and gender diverse people on Apple Health reported that they either could not or were unsure of their ability to find a gender affirming medical healthcare provider within 30 minutes of where they live.

# RESULTS FROM OUR PROVIDER SURVEY

We host a healthcare provider consult group for over 500 providers who are committed to learning best practices from each other and expanding access to gender affirming care. As a part of building our vision we surveyed that group to learn more about their strengths and barriers.

## KEY LEARNINGS



43.5% of respondents are in private practice vs. 56.5% of respondents practice in hospitals and public institutions



44.9% of respondents do not accept Medicaid



Only 9.9% of respondents have doctorate level mental health credentials.

### Strengths:

» There are more providers actively providing gender affirming care today than ever before.

### Barriers:

» Providers reported inadequate educational and professional support that was available on an on-going basis.

» Similarly, providers reported inadequate opportunities to learn, expand knowledge continued learning opportunities like CMEs that focus on gender affirming care.

» As more gender affirming care is covered by health insurance providers reported an increasing amount of inexperienced providers misrepresenting their experience or competence in providing gender affirming care. This has led to many patients getting inaccurate information and providers having to do more work to address misconceptions.

» Ever changing and difficult to navigate insurance requirements force providers to spend more time advocating for their patients – many providers specifically noted numerous problems with the Apple Health system.

### Major Needs:

» Providers noted a need for increased support around building patient advocacy skills like letter writing and communicating with insurances that would improve their ability to provide care.

» Providers noted the urgent need to address systemic barriers in the Apple Health system - like the need to access doctorate level mental health credentials for surgical referral letters.

» Providers noted a need for more CMEs and other educational opportunities to grow their skills and knowledge to provide better gender affirming healthcare.

# HOW WE MOVE FORWARD

**It is vital that solutions to increasing access to gender affirming care are identified by transgender and gender diverse communities.**

While our communities face significant barriers in accessing care we also reaffirmed that our community has vast amounts of untapped brilliance and strategies to caring for themselves and each other.



**We envision a healthcare system that allows every transgender or gender diverse person to access culturally relevant gender affirming healthcare that makes them feel safe, whole and at home in their bodies regardless of their race, income, gender identity or zip code.**

## AS WE WORK TO MAKE THIS VISION A REALITY IN 2019 WE HAVE THE FOLLOWING FOUR PRIORITIES:



**Increasing community access to healthcare knowledge**



**Increasing access to culturally relevant care for trans folks of color**



**Increasing access to gender affirming care where folks live**



**Address the broken Apple Health System**

# GRATITUDE

## WE'D LIKE TO THANK:

- » Everyone who shared their experiences with us via our survey & focus groups
- » The trans leaders (pictured on pg. 12) who attended our retreat and gave us valuable feedback
- » The Coalition for Inclusive Healthcare

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### » Our Advisory Committee:



**Lucia Leandro Gimeno** is an Afro-Latinx, gnc femme, counselor/brujx/organizer based in Seattle. Born and raised by loud mouth working class dykes in Boston, Lucia Leandro was taught that love is most definitely a verb. For nearly 20 years they organized with queer, trans and gnc communities of color in NYC (The Audre Lorde Project & FIERCE!). Currently, the Director of The Queer & Trans People Of Color Birthwerq Project, an organization dedicated to mending the disconnect between Trans and Reproductive Justice through birthwerqer trainings and community organizing.



**Adrian Tunney** is a former member of the King County HIV/STD Program's Community Advisory Board. She is currently studying Social Work and was a Program Management Intern at Ingersoll Gender Center. Adrian brings a wealth of personal experience and knowledge to Ingersoll Gender Center's Healthcare Access Advisory Board.



In 2000, **Vanessa Grandberry** began working as a Health Educator on a project focusing on African American and Latina Transwomen for People of Color Against AIDS Network. Noticing a lack in diversity of voices within the trans-community, Vanessa, through POCAAN created a bi-monthly newsletter called T-TIME. By 2004, T-Time became a monthly magazine and a tool used for outreach and recruitment focused on HIV/STI prevention, health & beauty and social issues, but most importantly, it gave transwomen of color an opportunity to share their stories.

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