"We Know Who We Are": Centering Queer and Trans Youth Narratives in the

## **Move Toward Affirmative Healthcare**

by

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# "We Know Who We Are": Centering Queer and Trans Youth Narratives in the Move Toward Affirmative Healthcare

#### Abstract

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Healthcare in the United States is not accessible to everyone due to the medicalization of certain socially situated identities such as sexual orientation, gender identity/expression, and age, and race. Each of these identities are all interconnected in how the medical system treats individuals with varieties of these identities. There is little in-depth exploration of the personal health narratives of queer and trans youth. Due to this lack of knowledge, queer and trans youth often experience discrimination from providers which affects their utilization of health services and long-term health. Resources that try to fill this gap are often based in the opinions of providers and parents, not in the opinions of the youth themselves. Utilizing nine interviews and three focus groups, this project seeks to provide a resource based on narratives from queer and trans youth on their relationships with healthcare providers to understand how to foster positive relationships between this community and their doctors. My findings indicate that the most prominent concerns of queer and trans young people are based in their negative experiences with doctors who either actively keep certain care inaccessible to them or ignore their pleas for help in navigating the various barriers and borders to get adequate sexual or gender-based healthcare. The specific ways in which care providers make care inaccessible or refuse to help these individuals seem to vary highly depending on the patients' racial or ethnic identities as well as their age. Future research should take these other identities into account when trying to understand the current state of LGBTQ youth healthcare and emphasize the role of doctors in making sexual and gender

healthcare inaccessible for this group of individuals. In order to create a more accessible and adequate healthcare system for queer and trans young people, health care providers need to take on the responsibility to confront their biases against this group through workshops and community events run by people who confront the barriers to getting LGBTQ youth healthcare.

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#### Preface

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#### **Key Terms**

Queer and trans: Queer is a term, in this paper, that describes a person's sexual or gender identity as not aligning with heterosexuality or their gender assigned at birth. Trans is specifically someone who does not identify with their gender assigned at birth, and includes people who identify with a binary identity such as girl or boy that is different than their own or people who identify as somewhere in between or outside of that binary gender spectrum. I purposely chose to not use the term "LGBTQ" to describe this population because the historical construction of each of these terms is based in medical and people outside of the queer, trans, and LGBTQ communities (Foucault 1979). The re-appropriation of the term "queer" as an identity encompassing people outside of heterosexuality and classical gender-sex constructs in part was a reaction to medical and governmental bodies attempting to define this community (Sedgwick 1990), and thus I use it to try to de-center those forces from my work.

**Youth:** In the case of this paper, I define youth as people between the ages of 14 and 26 years old. This is based on the extrapolation of various medical age definitions of adolescence & young adulthood, but is primarily based the American Pediatrics Association's definitions of middle to late adolescence (14-21) and the age limit on staying on parental insurance in America, which is 26 years old (American Pediatrics Association 2017, US Department of Health & Human Services, 2017). The reason for studying this age group for this research is because adolescence & young adulthood is usually when queer and trans young people begin seeking care for their gender and sexuality (WPATH 2011). I wanted participants who had ample experience in seeking healthcare on their own, thus this definition of youth makes the most sense.

**Non-normativity:** I use this word to describe the bodies, identities, and acts that medical researchers and clinicians have historically described as straying from "normal" human behaviors. Normative, in this case, would mean heterosexual, white, cisgender, and easily categorized as male or female. Non-normative bodies, identities, and acts in the case of this paper is anything that strays from the categories I just listed.

Gender non-conforming, gender variant, trans spectrum, non binary identities: I use all of these terms throughout this paper to reference people who do not identify with either end of the gender binary (male/female or man/woman). Gender variant is the term most often used to describe young people who are still figuring out the preferred term to describe their gender identity. Ultimately, the correct identifier for someone's gender is the one they provide, and I try to stick to this as much as possible throughout this paper.

**Cisgender:** Someone who still identifies with the gender they were assigned at birth.

Intersexuality and the faux sex-binary: Intersex people are those whose genitalia or hormone levels are considered to be out of the norm of medical constructions of sex characteristics. Intersexuality as a construct was created in the surgical centers of medical practitioners such as John Money and Richard Green, who decided what genitalia and hormone levels are "normal" (Gill-Peterson 2018, Fausto-Sterling 1993). However, the sex binary created by medicine is highly based on individual practitioner's ideas of normative sex characteristics and are also highly racialized, i.e. Black women's bodies & genitalia are more scrutinized for being non-normatively sexed than white women's bodies & genitalia (Somerville 1994, Fausto-Sterling 1993). Thus, the medical concept of a binary between male and female bodies is incredibly flawed and is not taken as fact in this research. **Sexual (re)assignment and gender affirmative surgery:** Whenever I use the term "sexual (re)assignment," I am referencing this history of doctors forcibly assigning a binary idea of sex onto people and children they deem intersex. The (re)assignment also refers to doctors performing surgeries and hormonal care that force individuals into the doctor's idea of the sex binary, whether they want that care or not. On the other hand, gender affirmative surgery is based on the patient's wishes and visions for the surgeries that they want to affirm their gender identity. This can mean having surgery on their genitals to create phalluses and vaginas, but it can also mean breast augmentation or breast removal, as well as facial reconstruction.

**Optimizing Cis-heteronormativity:** This phrase describes the actions that practitioners may take in treating queer and trans people, where they may attempt to use therapeutic and surgical techniques to force people with non-normative bodies and identities to be cisgender or heterosexual. Examples of this are the forced sex assignment surgeries on intersex children, conversion therapy for non-heterosexual people, and using hormones to try to force a person's gender performance to match their sex assigned at birth.

**Eugenics, Neo-Eugenics and Scientific Racism:** Eugenics refers to the 20th century popular pseudoscience that proposed that humans could and should direct their own evolution through selective breeding (Ordover 2003). In America and in many other Western societies, this meant creating a white Anglo-Saxon future, full of white Anglo-Saxon beliefs such as monogamous heterosexual reproduction and a clear sex and gender binary (Ordover 2003). Another pseudoscience that fueled the eugenic movement was scientific racism, which claimed that racial categories were biologically-based and that through these biologies, scientists could rank which races were the most civilized and intellectual; of course, White Anglo-Saxons were at the top of this list. Neo-eugenics refers to the resurgence of eugenic belief in American society

starting with the 1990's onward, which refers to the new technologies in screening fetuses for mutations and the implications of being able to then legally abort children with genetic mutations (Leroi 2006). Neo-eugenics has been an important concern for disability rights activists, who question what exactly is considered a significant mutation, but is also significant to the continuous popularity of find a "gay gene" or a biological indicator for a future person's sexual or gender choices (Ordover 2003).

Affirmative and Patient-Centered Healthcare: These terms refer to healthcare that is based in affirming the identities and medical wishes of their patients. Affirmative healthcare is generally used when referring to gender identity healthcare, indicating that this healthcare is based in affirming whatever needs patients have regarding their gender identities.

**Non-affirmative, and reparative healthcare:** These terms I use to refer to healthcare that do not support their patient's sexual or gender identity medical needs. I define non-affirmative healthcare as not offering services for these medical needs and not guiding patients to places where they can fulfill these needs. Reparative healthcare is when providers actively work against a patient's sexual or gender identity, attempting to use gatekeeping or medicalization techniques (see below) to reinforce cis-heteronormativity in their patients.

**Pathologization and medicalization:** When medical providers force people with nonnormative bodies and identities into psychiatric, therapeutic, or surgical medical care through coercion or forcibly against their will.

**Gatekeeping Care:** When medical providers refuse to provide services to patients despite requests from their patients for a certain type of care based on assumptions and stereotypes.

**Protectionism & Childhood Innocence:** Protectionism is the praxis of keeping children and other groups (such as non-Western people, poor people, people of color, etc.) away from harm

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through policies and practices. Childhood Innocence is the idea that children need protection because they are new and easily malleable as they grow up in the world. Protectionism is a paradox because while people believe they are protecting an innocent and marginalized population, this practice often removes the agency of the protected groups by having the power of decision-making be in the hands of the people outside of those groups.

Intersectionality & Intersecting Social Identities: This research looks at the ways different social identities affect queer and trans youth healthcare experiences and opinions. I call these different demographics, such as non-white people or people of color, intersecting social identities to reference Kimberle Crenshaw's pinnacle work on intersectionality. Intersectionality is the ways in which different social groups experience different forms of oppression based on the different ways social institutions treat them based on certain characteristics such as their perceived race, gender, sexuality, etc. Thus, intersecting social identities reference the different attributes that affect how people are treated in society.

#### **1.0 Introduction**

According to the primary medical guides for gender variant children's healthcare, "gender affirmative" health care is the best practice for transgender and gender variant young people. The two most prominent guides, the Human Rights Campaign's "Supporting & Caring for Transgender Children (2016)" and World Professional Association for Transgender Health (WPATH)'s "Standards of Care for the Health of Transsexual, Transgender, and Gender Nonconforming People (2011)", both define the role of care provider as one who provides resources for gender non-conforming and transgender children and their families and guides them all in the process of affirming the gender of that child. Affirmative in this instance can mean many things, such as: "patience, support, and careful listening" from therapists and mental health workers (Human Rights Campaign 2016, WPATH 2011); medical professionals supporting a "social" or "legal" transition of a child, without medical intervention; initiating "reversible" medical therapies to affirm a child's gender identity such as puberty blockers or voice therapy (Human Rights Campaign 2016, WPATH 2011); and finally medical professionals and social workers supporting a young person through partially reversible or irreversible gender affirming medical care such as hormonal treatment or gender-affirming surgery (Human Rights Campaign 2016, WPATH 2011). Gender affirmative care is ultimately a collaborative process between a child, their family, and health providers, with the child's self-described best interests always at the forefront. Both guides also suggest that families and care providers become advocates for gender affirmative care for all queer, gender-nonconforming, and transgender young people (Human Rights Campaign 2016, WPATH 2011).

This project will add to these standards of care and provide a nuanced and personal perspective due to the researcher, myself, being a queer young person. This research specifically asks queer and trans young people (aged 14-26 years old) their suggestions for doctors in order to create a guide that outlines the role of "healthcare provider" in LGBTQ affirmative care, honoring them as the best knowledge keepers of the kinds of care that's best for them. It also seeks to update the W-PATH Standards of Care, the latest version being 2011, to match the current state of queer and trans youth healthcare and the role of care providers in gender and sexual affirmative healthcare. Instances of discrimination and not only reflect the current state of healthcare for queer and trans young people, but also the current state of healthcare for children and healthcare for people in marginalized communities. People of color, people under the age of 18, non-Western people, people with low-incomes, and many other lay peoples often experience questioning and gatekeeping from providers who do not believe their patients are the penultimate experts on their own bodies (Farmer 2006; Kleinman 1978; Hunter 1993; Gill-Peterson 2018; Crossley & Davies 2015). The experiences of gatekeeping and scrutinizing questioning is not specific to queer and trans young people, and the levels of intensity and number of times that scrutiny may occur seems to depend on their various other identities and income options. Thus, while this understanding of persistence of non-affirmative care is based in the lives of queer and trans young people, these findings will hopefully shed a light on the current state of healthcare for any patient, particularly children, seeking medical care based on their bodily expertise. It also will provide a framework for doing research with young people and how youth voices can be highlighted and advocated for through research. This research provides a framework for care providers who are curious as to how to support queer and trans young people as well as an in-depth understanding of the care that queer and trans young people are currently receiving and the kinds of care they envision for the future.

#### 2.0 Literature Review

The recent movement in the medical field toward affirmative care for queer and trans youth has led to American society to fear that this healthcare may be too affirmative, as referenced in a 2018 Atlantic article, "When Children Say They're Trans" by Jesse Singal. In this piece, Singal attempts to shine a light on what he believes is a contemporary era of "gender identity awareness", where parents, educators, and medical providers are supporting young people experiencing gender dysphoria and aiding them through social and medical gender transitions at very young ages (Singal 2018). Singal, among many others, treat the prevalence of trans and gender nonconforming children as a new phenomenon and cultural moment in American history. Singal's article presents the common transphobic narrative that there are "no easy answers" when it comes to children who express interest in transitioning to another gender because young people may decide to de-transition later in life (Singal 2018). To further his point, Singal decides to primarily feature children who decide to transition back to their gender assigned at birth after transitioning at a young age. However, Singal's research represents the culmination of decades of work by media and medicine to de-center representative populations of trans youth in commentary directly about their identities and experiences. It also reveals a new version of a neo-eugenic, heterosexualcentered societal fear: that gender and sexual affirmative healthcare can go "too far". This fear is connected to 19th and 20th century eugenics, a set of beliefs and pseudoscientific pursuits to promote population control through enhancing the reproduction of "normative" (i.e. heterosexual and cisgender) white bodies and culture and diminishing the reproduction of non-normative, nonwhite bodies. Singal's worry of gender and sexual affirmative healthcare going too far and his unconditional acceptance of gender and sexual norms reveal this neo-eugenic fear by suggesting

that these young people, who in Singal's piece are predominantly white, do not have the skills to truly understand the significance of becoming non-normative through gender affirmative transition. Working on these fears by primarily focusing on children who de-transition in their adulthood is a neo-eugenic tactic to keep privileged white children as "normal" as possible to create a normative adult population to be perpetuated forever.

Prominent gender and childhood sociologist Tey Meadow, in a response to Singal's piece, names the largest problem with Singal's focus on children who decide to re-transition to their gender assigned at birth:

While it is true that there are 'no easy answers' to the questions raised by significantly gender-nonconforming kids ... it isn't up to [their] parents, or Jesse Singal, or the general public to determine where [they] will end up in time. That is a question for [them] to answer [themselves], ideally with the love and support of parents and professionals who can be fully present and supportive, no matter how circuitous [their journeys] may be (2018).

Secondly, Meadow notes, that by focusing so much on children who de-transition, Singal actively plays into a narrative that pathologizes transness as a disorder. Singal claims the children assert they are transgender because of an emotional disturbance, and thus they need to be doubted and thoroughly tested for gender dysphoria in order to make sure they don't become "victims of abuse" or "false consciousness" (Meadow 2018). In actuality, even the most conservative clinicians who speak with Meadow express that "they rarely, if ever, see someone make a full social and medical transition and then experience serious regret" (Meadow 2018). Despite Singal's perception of the prevalence of trans children being a new cultural moment in which parents and children do not understand the seriousness of gender transition, Meadow's research and many

others' point to the opposite: the biggest issue facing the queer, trans, and gender non-conforming youth community seeking medical care is "how to access clinically competent, trans-affirming care for children who desperately needed it, even in the largest American cities" (Meadow 2018, Durso and Gates 2018, Katz-Wise et al. 2017, Ginsburg et al. 2002, Hoffman et al. 2009, Knight et al. 2018). Singal's piece specifically misrepresents and thus actively discounts the reality of access to affirmative gender health care, in which almost no children actually have the access to the type of care he is questioning, undermining his claim that gender affirmative healthcare is pervasive in present society.

The pervasive false narrative of a surplus of affirmative care for gender non-conforming, queer, and trans children is a tactic by adults to take away the bodily autonomy of children and young people. This is occurring in the same period of the anti-vaxxer movement, where parents can decide whether or not to vaccinate their children, leading us to wonder about the implications of children not being able to decide what happens to their own bodies. It also comes during the 2010's bathroom debate about what bathrooms transgender individuals should be legally allowed to use, which started in school districts about transgender children. Adults are the people with access to state, media, and medical authority over children, and often use these powers to push narratives of protectionism onto children, ultimately taking away their bodily autonomy. Parents are the ultimate gatekeepers of medical and legal affirmative care which ends up being a way for the state and medicine to further hinder children's decisions over their own bodies.

Medical research as well as clinical health practice regarding queer and trans young people have historically been reparative and anti-affirmative, functioning as one of the largest gate keeper of what normative sex and gender look like in America. Reparative or conversion therapy is the use of hormones and other forms of physical and therapeutic healthcare to attack and attempt to eliminate queer and trans identities and to create a sexual binary through unconsensual surgeries on intersex children. Providers often enacted reparative therapies during someone's childhood, in the idea that if you "catch it early," the child will grow up to be a "normal" adult. This history, as well as work from anthropology, social work, sociology, psychology, childhood studies, and gender & sexuality studies, is vital in understanding why queer and trans young people are still struggling to find clinics and providers who offer sexual and gender affirming healthcare in the United States despite their seemingly higher visibility in the present social and political climate. It also helps us to understand the individual interactions between healthcare providers and their queer and trans youth patients, in which this long history is enacted in the biases, assumptions, and stereotypes created by 20th century scientists on this population.

#### 2.1 The History of Queer and Trans Youth and the Healthcare System

Health professionals and researchers denying young people their bodily autonomy through invasive procedures and therapeutic practices reflects the long history of medicine for queer and trans young people in America. Doctors historically prevented queer and trans young people from accessing procedures that could confirm their gender identities (Gill-Peterson 2018). Providers often pushed queer and trans young people toward psychiatric and psychotherapeutic treatments, which enforced 'non-normative' gender and sexual identities (i.e. what we now understand as nonheterosexual and non-cisgender) as pathological disorders (Roberts 2011, McGann 2011, Gill-Peterson 2018). The present-day climate of queer and trans youth healthcare still reflects this history because of the biases and assumptions that clinicians still act on in their interactions with LGBTQ young people. The ways that medical researchers and providers have worked on queer, gender nonconforming, and trans children since the 19th century are often tragic and painful. During the mid-19th through 20th centuries, medical researchers and providers pathologized gender and sexually deviant bodies, either forcing people (often children) into 'corrective' surgeries for perceived sex abnormalities or into 'corrective' psychiatric treatment (Gill-Peterson 2018, Kessler 1990). Almost all of these procedures were to optimize binary gender norms based on the decision of the providers instead of the patients (McGann 2011, Roberts 2011). These medical practices reflected the biases of people in power and also actively produced new biases by creating a pathologized perception of gender and sexually non-normative people. These biases often came from religious trends toward heterosexual, monogamous reproduction, but also came out of Western binary-based thought in categorizing humans (Roberts 2011).

Medicine since the mid-18<sup>th</sup> century replaced religion as the central source of knowledge about sex (Foucault 1979, Roberts 2011). While religion certainly continues to have an effect on how individuals view race, queerness, and gender roles, 18th century medicine became a highly popular method of understanding non-normativity. Medical researchers in the mid-18<sup>th</sup> through early 19<sup>th</sup> century began studying sex as a subject of this purportedly objective science, creating the field of sexology. This "objective" science, infused with biases and assumptions from the scientists conducting the research, created biological models for heterosexuality and gender roles that come with heterosexual reproduction (Foucault 1979). These models turned into guides and parameters for what sexualities and gender expression needed to be treated and what did not (Gill-Peterson 2018). Sexologists, pioneered the pathologization of people based on their sexual acts, using the categorical framework of scientific racism to categorize groups of individuals and applying them to gender and sexual differences (Foucault 1979, Somerville 1994).

During this period of scientific racism and sexology, the child saver's movement began. This movement encompassed a largely white women base who advocated for the public health, education, and labor rights of children during the mid-19<sup>th</sup> century through the mid-20<sup>th</sup> century. A key aspect of recent childhood studies scholars is realizing the staunch gap between the lived experiences of being a child and the popular perception of childhood and how the cultural construction of childhood affects children's lived experiences (Sanchez-Zeppler 2011). Childhood as a concept is a societal invention, possibly only beginning in the 17<sup>th</sup> and 18<sup>th</sup> centuries, and definitions of what childhood means has differed across cultures and across time. In this particular era of the mid-18<sup>th</sup> century, media and child rights activists sentimentalized (white) childhood, in which childhood represented a time of protection, nurturing, and moral growth. Many children, predominantly children of color, were excluded from this narrative and even from legislation protecting children from labor and other welfare rights violations (Hogan & Siu 1988). Children became things to be protected from harm, leading to their voices often being silenced due to protection being based in adults knowing what is best for them. Secondly, the policies and practices surrounding the protection of children often were in a paradox where protection sometimes meant using children for opposing needs from adult institutions, such as orphanages taking child workers from the streets to work for the orphanages directly instead (Sanchez-Zeppler 2005). Through the child savers' movement and the rise of protectionism by well-meaning adults, children became a vessel for the future hopes of the current generation (Lovett 2007). Thus, many sexologists, racists pseudoscientists, and progressivists focused their attention onto the lives of children through extensive public health, education, and labor reforms (Lovett 2007).

It is important to note that not only did sexologists reinforce their preconceived biases into their scientific studies, they specifically used the framework of racist pseudoscience to fundamentally alter how society understands sexuality and gender (Somerville 1994). Scientists in the early 20th century created the field of eugenics to further white populations by supporting reproduction amongst white people and hindering reproduction amongst non-white people (Ordover 2003, Foucault 1979, Somerville 1994). Eugenicists significantly changed Western thought by applying binary-language to race, gender, and sexual acts and through these binaries defined normative and non-normative populations (white vs. Black, heterosexual vs. homosexual, etc.). The connection between race-based and sex-based eugenic practices cannot be separated, for the definition of "the homosexual", born in the labs of sexologists, encompassed all sexual or gendered behaviors that did not fit into white-centered heterosexual marital reproduction (Foucault 1979, Somerville 1994). Race-based eugenicists and sexologists both used comparative anatomy and psychological pathologization of groups of people who deviate from the white heterosexual 'norm' into categories that define their inferiority and difference (Somerville 1994). Both used therapeutic and surgical medical practices to force bodies and minds to fit into already-existing power relations of white heterosexual dominance and ideologies already firmly in place (Somerville 1994, Ordover 2003). Thus, sexologists perpetuated and actively added to the Western eugenic project to enforce white-centered heterosexual reproduction and the eradication of nonwhite people by categorizing, defining, and "treating" people with sexualities and genders that challenged the white eugenic future.

Recognizing the relationship between eugenics and gender allows us to understand why the medical field primarily treated children in their attempts to control gender and sexual preferences: treating children meant control of immediate future generations (Gill-Peterson 2018). By treating non-normative genders and sexualities as disorders or illnesses, medicine can treat people without consent from the patients or pathologize patient narratives to diminish their bodily autonomy (Roberts 2011, McGann 2011). Since the future of white society depended upon the reproduction of white heterosexual children and instilling in them principles of reproducing more white heterosexual children, white queer and trans children *must* be changed to fit the cis heterosexual standards (Gill-Peterson 2018). Secondly, because of the whiteness of these children, medical bias based in believing in the plasticity and mutability of whiteness and children entails that white children can be altered through medical therapeutic treatment (Gill-Peterson 2018). This, in turn, meant that queer and trans children of color are considered disposable to a heightened degree and are only worth the knowledge their bodies bring to the field of medical research, and thus do not get access to any of therapetutic care (Gill-Peterson 2018).

Queer and trans youth medicine cannot be separated from its origins in medical therapeutic practices forcing sexual (re)assignment surgeries on 'intersexed' children. Medical researchers and providers, after learning about the possibilities of "sexual reassignments", used these techniques on children who did not fit into heterosexual reproductive-based sex categories (Gill-Peterson 2018). All of these treatments of children who did not fit into the sex binary (that medical scientists created based on presumptions of what genitals should look like rather than on actual function), preceded the gender affirmative procedures and therapeutic practices that are now performed in the context of affirmative trans medicine (Gill-Peterson 2018). In fact, trans people during the 1930's-1960's began seeking medical gender affirming care due to the popularity of intersex surgeries (Gill-Peterson 2018). In order to get the care that affirmed their preferred gender, gender non-conforming and transgender patients used intersex-based medical language such as complaining of hormonal imbalances (perceived ones or ones actively induced by medications such as birth control) or of possible internal reproductive organs that aligned with their preferred sex (Gill-Peterson 2018). However, if researchers found no 'abnormality' that fit into their

biological model of treatment for 'intersexed' patients, then they forced these queer and trans patients into a pathological model of treatment for the psychiatric disorder of homosexuality (Gill-Peterson 2018).

As transgender adults who surgically transitioned such as Christine Jorgensen became more visible to the public eye, more gender non-conforming and transgender youth began seeking treatment out of their own volition (Bryant 2006, Gill-Peterson 2018). In turn, researchers such as John Money, Richard Green, and Harry Benjamin – who initially studied and practiced on intersex children - began to study those children. This research culminated throughout the 1960's and 1980's, in which sexologists and researchers of gender variance created new concepts to explain gender diverse children, eventually leading to a disorder in the DSM III called "Gender Identity Disorder of Childhood (GIDC)" (American Psychological Association 1980, Bryant 2006). Researchers at this time, for the most part, did not affirm these children's preferred gender identities, instead they attempted to "potentially solve the problem of adult transsexuality through preventing its development in the first place" (Bryant 2006, 26). In the 1950's and early 1960's, researchers focused on young gender variant and effeminate boys in this research on gender variance, forcing them into a medicalized system of upholding cis-heteronormativity through procedures that attempted to masculinize them (Bryant 2006). The late 1960's and 1970's genderbased medical practices led to medical treatments for these gender variant boys, attempting to intervene on almost all aspects of their personal and social lives in order to change their effeminate behaviors (Bryant 2006). Thus, GIDC directly came out of research which attempted to reverse effeminate and behavior and did not fit into the heterosexual-based gender binary (Bryant 2006). Slowly, critiques of this practice began to pour in with the addition of the GIDC into the DSM-III, especially since it was this year that the DSM finally removed homosexuality from its list of psychiatric disorders; the new addition of GIDC in DSM-III perhaps was another way of pathologizing homosexuality as well as specifically pathologizing childhood gender variance (Bryant 2006). Whatever the case, the inclusion of the GIDC in the DSM-III is a recognition of the history of researchers attempting to deny transgender child patients the right to affirm their gender identity in the ways they see fit and the societal fear of homosexuality and medical attempts to eradicate queerness.

During the 80's and 90's, medical practices with neo-eugenical implications became incredibly popular in the field of gender-based medical practices regarding queer children, in which scientists claimed to be able to find biological indicators of homosexuality and transexuality (Ordover 2003). Homophobic lawmakers, media journalists, and medical practitioners immediately jumped on this claim, tying it to the history of eugenic sciences who claimed social identities were biological and thus able to be fixed with medical practices (Ordover 2003). However, many LGBTQ activists also hopped on the biological gay indicator because of the belief that biological explanations for non-normative genders and sexualities could solidify their claims to rights and equal treatment from society (Ordover 2003). However, biological explanations for queer identities requires "no change in the status quo and [offers] up the promise of eradication not of marginalization, but of the marginalized" (Ordover 2003, 67). A 1992 Newsweek article also reveals the ways in which parents of queer and trans young people have stakes in the discovery of a biological basis for LGBTQ identities because "it could lift the burden of self-blame from parents... for parents, a child's 'coming out' can lead to painful soul-searching" (Ordover 2003, 67). These attempts to find biological indicators of queerness significantly affect children because of scientific attempts to absolve the adults in their life from responsibility for their identities and

the likelihood (due to the long history of doing so) of medical-therapeutic practices aiming at children to try to reverse the effects of whatever biological indicator they find.

In the 21st century, medical researchers continue to reflect this severely harmful history of queer and trans youth medicine by consistently denying the autonomy of children who do not fit into the white heterosexual model of sex and gender. This history reveals how medical practitioners optimized heterosexual cis-ness through nonconsensual sexual (re)assignment and pathologization of queer and trans people. Thus, gender confirmation surgeries based on the patient's self-described gender confirmation needs were not available for 40 years after sexual (re)assignment procedures was medically viable. Even after affirmative healthcare came into the medical field, where doctors actually used medical procedures to affirm self-described gender identities, this history is still reflected in care providers' implicit biases in their interactions with queer and trans youth. Clinicians are still optimizing heterosexual cisness as well as whiteness through gatekeeping gender or sexual affirmative care from these young people and choosing to ignore the self-described needs of these patients. These practices directly impact the health utilization and health practices of all queer and trans young people, but especially queer and trans young people of color, who learn through their interactions with providers that their self-described needs and experiences are often ignored or are decided against by providers who continue to enact the history of scientific racism and queerphobia onto their young bodies.

#### 2.2 Present Day: The Persistence of Non-Affirmative and Reparative Healthcare

Reparative and non-affirmative sexual and gender healthcare still characterizes the majority of care today and the effects of health providers' ignorance of LGBTQ youth health issues

are still severe. Many studies based on qualitative and quantitative research with LGBTQ people reveal the serious effects of queerphobic comments, non-affirmative healthcare, and the complete erasure of patient wants and needs.

There are various ways that doctors perpetuate the queerphobic history of medicinal practice. This ranges from: revealing complete lack of knowledge of queer and trans people and the healthcare they need (Bauer et al. 2009, Corliss et al. 2007, Israel et al. 2008, Kattari et al. 2015, Knight et al. 2018, Vance, Halpern-Felsher and Rosenthal 2015); questioning patients' self-described identities (i.e. "how do you know?", "how can you identify as gay if you're trans?", etc.) (Bauer et al. 2009, Corliss et al. 2007, Katz-Wise et al. 2017); continuously misgendering and dead-naming patients (Bauer et al. 2009, Grant et al. 2011)<sup>1</sup>; referring to parents and other medical providers as the primary experts of their children's bodies over the young people themselves (Corliss et al. 2007, Katz-Wise et al. 2017); and actively withholding sexual or gender-affirmative healthcare from patients who are asserting their need for it (Corliss et al. 2007, Bauer et al. 2009, Grant et al. 2017, Knight et al. 2007, Bauer et al. 2009, Grant et al. 2017, Knight et al. 2007, Bauer et al. 2009, Grant et al. 2017, Knight et al. 2007, Bauer et al. 2009, Grant et al. 2017, Knight et al. 2007, Bauer et al. 2009, Grant et al. 2017, Knight et al. 2007, Bauer et al. 2009, Grant et al. 2017, Knight et al. 2018).

Even the current Standards of Care from the World Professional Association for Transgender Health (WPATH) perpetuate frameworks from reparative healthcare such as the intense scrutiny of patients who seek gender affirming healthcare. This is not necessarily a surprise however due to this organization's own history of being founded by Harry Benjamin, a leader in transgender medicine who despite being one of the first renowned doctors to support gender affirmative care, often based his gender affirmative practices in optimizing heteronormativity

<sup>&</sup>lt;sup>1</sup> Misgendering is when someone does not use someone's correct pronouns and deadnaming is when someone uses the name someone was given at birth instead of their preferred name. Both of these can be avoided by simply asking people their preferred pronouns and names.

(Ekins 2005). Benjamin based his work in placing his patients into various categories through intense scrutiny of his patients to decide who would be pathologized by psychiatrists who believed transsexuality a mental disorder and who would receive his renowned sexual reassignment surgeries (Ekins 2005). He also towards the end of his life based much of his practice on aiming to optimize heteronormativity, wherein "true" transsexuals were usually patients who expressed desire to take part in heterosexual nuclear families after their transition (Ekins 2005). The original WPATH Standards of Care is based on Benjamin's The Transsexual Phenomenon which categorized patients into these various categories and taught providers who to practice intense scrutiny when patients came to them for gender affirmative care. Despite being updated seven times over, the current Standards of Care still reveal these biases of scrutiny, categorization, and pathologization, especially in their section on transgender and gender non-conforming children which emphasizes mental health counseling and social transition over any other form of medical care (WPATH 2011). There is still an incredible amount of hoops trans and gender diverse people have to jump through such as "well-documented gender dysphoria" by a mental health or primary care physician, preferably over multiple years, referral letters, at least 12 months of documented living in their preferred gender, and hormone treatment before gender confirmation surgery (WPATH 2011, STP 2012). For children, there is even more scrutiny involved, in which parents must notice their child having a preference for "clothes, toys and games that are commonly associated with the other" (WPATH 2011, 12). This not only emphasizes the role of parents in understanding a young person's identity but also reinforces a binary notion of sex and gender. Thus, despite proporting gender affirmative healthcare as the best form of healthcare for transgender and gender-nonconforming people seeking medical gender affirmative care, the WPATH's version of gender affirmative healthcare still features an incredible amount of nonaffirmative and reparative healthcare practice models.

These experiences often lead to extreme stress and distrust of all providers in trans and queer patients, and thus an under-utilization of health services which could lead to negative health and overall well-being (Grant et al. 2011, Latham 2017, Bauer et al. 2009, Corliss et al. 2007). These experiences also perpetuate the fears of emotional and physical harm that queer and trans young people and their families have because of queerphobic and transphobic experiences (Katz-Wise et al. 2017, Corliss et al. 2007). In Pennsylvania specifically, LGB young people aged 14-18 (this study does not ask about gender identity unfortunately) are more likely to have sex before the age of 13, experience sexual violence from an intimate partner, drink alcohol, smoke cigarettes, and plan or attempt suicide than their heterosexual counterparts (YRBB Youth Survey 2017). By practicing non-affirmative and reparative healthcare or ignore the specific needs for LGBTQ young people, either due to lack of knowledge or to deep-seated bias against LGBTQ identities, doctors and care providers are actively harming these patients. Given the persistence of these institutionalized dynamics, how can we transform a system built to regulate non-normative bodies to create a healthcare system that truly affirms all aspects of the identities of queer and trans young people? Secondly, how can we transform medicine from understanding gender, sexuality, sex, and race as being immutable and definable concepts in order to include identities and bodies that constantly will challenge simplistic medical categories?

#### 2.2.1 Non-Affirming Guides About LGBTQ Health

We need to provide platforms for the field of medical research that actively centers narratives and opinions of LGBTQ people who are on the receiving end of healthcare, instead of creating more research that does not center the agency of LGBTQ communities. Many research and health guides written by care providers or parents are not yet centered on the lived experiences and opinions of queer and trans (QT) youth regarding their healthcare (Alegria 2011, Hendricks and Testa 2012, Kreiss and Patterson 1997), and thus continue to perpetuate reparative healthcare. Even more thoughtful guides still often miss nuances that come from the knowledge of patientcentered healthcare, which can provide specific details of how to make their care better.

Unfortunately, this study's scope does not include surveying physician perceptions of their relationships with queer and trans youth patients. However, the research that highlights the physician-perceived barriers to their interactions with these patients, although often not centering queer and trans youth narratives, helps us to understand the negative interactions between doctors and their QT young patients. Studies have found that an incredible number of clinicians provide services to LGBTQ youth without proper cultural competency or norms and values that can support LGBTQ youth populations (Knight et al. 2018, Hendricks and Testa 2012, Snelgrove et al. 2012). By researching providers, these studies reveal how to best implement cultural competency trainings and education and how to address the institutional barriers that are affecting both patients and doctors (Snelgrove et al. 2012, Stoddard et al., Knight et al. 2018). If I continue this research in the future, my goal is to also incorporate analysis of provider perceptions of their relationships to queer and trans youth with the population's lived experiences and narratives to see where some goals and knowledge align and where they do not.

In theory, with more visibility comes more activism and public support for affirming practices of LGBTQ youth; however this visibility is useless if the people who are given platforms to speak on affirmative healthcare are not the queer and trans youth on the receiving end of this care. More doctors, parents, and community activists are pushing medical systems (hospitals, insurance, individual doctors) to learn and allow treatment for LGBTQ youth because of the effects mentioned in the previous section, but their activism must shift to center young people in the push toward affirmative care. Queer and trans young activists have historically led the charge to get us to this point of visibility, envisioning a future where they can access care that affirms their sexualand gender-based needs in collaboration with parents, providers, and community activists.

## 2.3 LGBTQ People Subverting Medicinal Control

Queer and trans patients and young people are the key change agents in pushing for affirmative healthcare for the LGBTQ community. Whether it was creating clinics for their own community members or advocating for their own or their peers' rights in healthcare settings or creating culture of do-it-yourself outside of clinical medical perceptions of gender identity formation, queer and trans young people and LGBTQ adult activists are the center of the affirmative healthcare movement (Gill-Peterson 2018). Many people in the LGBTQ community are incredibly resilient and replete with tactics to find and create spaces of support and knowledge to navigate the healthcare systems. Trans and queer people have been at the vanguard to gain the medical care they need for themselves (Cobos and Jones , Dewey 2008, Gill-Peterson 2018, Stockton 2009, Singh 2013, (Califia 1997).

As early as sex assignment surgery began with intersex patients, trans and gender nonconforming patients came to clinicians at places like John Hopkins claiming hormonal imbalance or other medical terms that indicate physical sexual 'abnormalities' in order to gain access to surgery that would align with their sex and gender identities (Gill-Peterson 2018). As queer and trans activists began to push institutions to recognize their rights, such as through the Compton Cafeteria and Stonewall protests, advocates began to push medicine to respect the bodily autonomy of LGBTQ people seeking affirmative care (Gill-Peterson 2018). Trans 'DIY' culture subverted medical care by creating information and support networks to gain access to hormones and affirmative medical care without the transphobic process of pathologizing and testing one's queer-or trans-ness (Califia 1997, Gill-Peterson 2018).

Queer and trans young people have always been at the center of this advocacy. The leaders of the Compton Cafeteria and Stonewall protests were largely queer and trans youth, and thus this translated to advocacy surrounding their healthcare as well, albeit these protests were often more under the public eye's radar<sup>2</sup>. From escaping psychiatric hospitals treating them for their queerness to writing letters to "experts" in the field of trans medicine, queer and trans youth worked tirelessly to create a medical future that includes them in decisions surrounding their own bodies (Gill-Peterson 2018). Young patients as early as the 1970's began asking clinicians for help in receiving gender affirmative care and sometimes asking to clinicians to recognize their own bodily autonomy and override the standard of parental consent in receiving hormonal treatments (Gill-Peterson 2018).

Today, aspects of these underground networks and advocates pushing for LGBTQ affirmative healthcare still prevail, and young people through middle school, high school, and college are creating their own peer networks as LGBTQ young people become more and more visible in the media and social justice advocacy. Tey Meadow's *Trans Kids: Being Gendered in the Twenty-First Century* (2018) and Ann Travers' *The Trans Generation: How Trans Kids (and* 

<sup>&</sup>lt;sup>2</sup> Compton Cafeteria riots began with the actions of the Vanguard organization of queer youth: <u>http://www.vanguard1965.com/</u> and Stonewall began with the actions of Marsha P. Johnson (age 24) and Silvia Rivera (age 18): <u>https://sites.psu.edu/womeninhistory/2016/10/23/the-unsung-heroines-of-stonewall-marsha-p-johnson-and-sylvia-rivera/</u>

*Their Parents)* Are Creating a Gender Revolution (2018) are both powerful ethnographies on this present day activism and networks of support that queer and trans youth are creating and maintaining by and for themselves. Thus, the problem is not that queer and trans young people are silent about their experiences in medical systems; rather, queer and trans youth have been exercising their voices for change throughout history and it is the people in the field of medicine who have actively chosen to ignore them.

The context of queer and trans young people in healthcare is within a system of medicine that is constantly seeking institutional power of "lay" people and clinicians often enact these power dynamics in their individual interactions with patients. Thus, many medical clinicians enact this system of power by ignoring patients' advocating for themselves by communicating their perceived bodily needs, which may lead in turn for lay patients to question their own knowledge and sense of self. However, the idea that queer and trans kids, and almost anyone with marginalized social identities, have no expertise about their own bodies and their needs from the medical field is incredibly untrue and they have known about these needs ever since sexual and gender affirming procedures became viable.

## 2.3.1 Healthcare Guides that Center Queer & Trans People as Change Agents

While medical researchers, providers, and institutions historically marginalized LGBTQ youth, and continue to do so, there are now networks of supporting and affirming healthcare providers and researchers working to create an affirmative healthcare system for LGBTQ youth. There are numerous providers, researchers, and clinicians who listen to these young people and work to help them navigate parental biases, insurance barriers, and general life situations that could prevent them from getting the care they need. Getting doctors on board with affirmative healthcare

and guiding them toward roles that empower queer and trans young people is key to getting LGBTQ young people the care they deserve. One of the best ways to collect all of the nuances of experience and positive healthcare is through centering the LGBTQ youth narratives, thoughts, and opinions on their own healthcare in these guides.

Affirming clinical practice marks positive perceptions from LGBTQ youth toward providers and their overall health and well-being (Coleman et al. 2012, Israel et al. 2008, St. Pierre 2012, Hoffman et al. 2009). To create truly affirmative research and medical practice, guides and research meant to empower queer and trans healthcare must center the experiences of queer and trans youth patients who receive this care. LGBTQ youth are and will likely always be the primary "change agents" of their medical care by constantly challenging medical knowledge that assumes legitimacy in clinician and parental perception of queer and trans child bodies (Cobos and Jones, Dewey 2008, Meadow 2018, Travers 2018). This challenging comes from breaking the assumptions adult make of children's own knowledge about themselves and the world around them as well as the constantly changing their expressions of gender, sexuality, and sex. Secondly, queer and trans young people wanting affirmative practice where they get to decide what medical care is best for them completely challenges the institution of medicine itself. As we can tell from the specific history of gender and sexual healthcare for children throughout time, adult, non-queer medical practitioners have constantly tried to define the identities of queer and trans youth, and yet constantly fail. However, truly affirmative healthcare not only has better results, but actually reflects activism to change the medical system that queer and trans young people have worked hard at over the past 60+ years (Gill-Peterson 2018, Travers 2018, Meadow 2018, Dewey 2008, Hendricks and Testa 2012).

#### 3.0 Methods

## **3.1 Primary Questions**

1. What is the current state of queer and trans youth healthcare based on the narratives of this population's experiences with healthcare?

2. What are the specific thoughts, opinions, and suggestions that queer and trans young people have for healthcare providers to make their healthcare experiences better?

3. How do different social identity markers such as race, age, and gender identity affect LGBTQ youth's healthcare experiences?

#### 3.2 Study Design

My research uses qualitative data and participatory research utilized by applied social sciences, medical anthropology and social work research, as well as theory and studies from childhood studies, history, gender and sexuality studies, and sociology, to create a framework for understanding young patient experiences in healthcare. Each step specifically challenges medical models of research and understandings of lay people by de-centering clinician and parental perspectives and centering voices of young queer and trans people. I did my literature review with the help of queer and trans young people, asking them during my interviews of medical sources that spoke to them and sources that did not. I compensated my participants for sharing their knowledge with me, acknowledging that they were acting almost as consultants to the medical

clinicians and administrators I hoped to share my research with later on. I spoke to my participants about what brought me to this project before we even began collecting data, such as how my own experiences as a queer non-binary young person leading me to ask these questions about LGBTQ youth healthcare as well as my privilege of being a white cis-passing student at a very well-funded university to be funded in this research and to have a support system throughout my time as a researcher. With my participants of color, I spoke about how I appreciated them being comfortable with speaking to me about their racialized experiences in healthcare and that I want to collaborate with them on how they want to be represented in my project. I worked with community organizations such as Garden of Peace, Project Silk, and PFlag to recruit and to gain feedback on this research from folks who already have done incredible work in uplifting the voices of queer and trans youth in the Pittsburgh area. I created a community event with a panel of queer and trans young people (primarily Q/T people of color) answering questions about their experiences with the healthcare system and their suggestions on how to make this system better. Finally, I filmed this event and will be sending out this video to as many hospitals around the country as possible so these voices can be heard firsthand from curious providers and administrators who want to make the healthcare experiences of queer and trans young people better.<sup>3</sup> Each of these steps resists the power structures of medical institutions, as well as research-based institutions such as the University of Pittsburgh, because of the collaboration between myself as a queer non-binary researcher, queer and trans young people from around the city of Pittsburgh, and Pittsburgh LGBTQ organizations as equally important to the structure of medical research and practice.

<sup>&</sup>lt;sup>3</sup> To watch this video, you can click this link: https://pitt.hosted.panopto.com/Panopto/Pages/Viewer.aspx?id=1d1c6214-50ca-46ca-94fc-aa1f0126cf57

I chose to do qualitative data collection through semi-structured interviews and focus groups in order to understand the specific thoughts, experiences, and narratives of queer and trans regarding their views of the healthcare system. This could not have been accomplished through surveys or questionnaires due to the specificities and nuances that occur in face-to-face interviews and focus groups. The semi-structured format of the interviews and focus groups also led to me being able to clarify and tailor questions to each interview and focus group to get to answers that I may not have accounted for at the start of this process. Thus, I was able to provide an emic perspective of my participants in which this research is based in figuring out the thoughts and perceptions of healthcare and care providers from queer and trans young people themselves. I believe I was able to gather this emic perspective in-depth due to my own experiences of being a queer young person myself because I could look at my own experiences and knowledge of the situated social identity of being a part of this group. I also specified my inclusion criteria for my focus groups to create two focus groups consisting of queer and trans young people of color aged 14-26 years old and one focus group of trans youth aged 14-18 years old. Coincidentally, the participants in my focus group of 14-18 year olds all identified as transgender or on the trans spectrum. Making my inclusion criteria smaller for my focus groups was to make sure I had enough of these two specific populations represented in this research to make sure I could understand the differences among age, gender identity, and race. Specificity of these two populations was also important due to my own identity as a white college-aged researcher; I had to work harder to gain trust from these two populations through more extensive discussions of the goals and questions of my research, likely due to a distrust of a person researching communities they are not fully a part of and the power dynamics between the University of Pittsburgh (Pitt) and the people of color (particularly Black residents) of Pittsburgh<sup>4</sup>.

I conducted a total of 9 individual interviews and 3 focus groups with 23 total participants. I applied for and received IRB approval under expedited review on August 16<sup>th</sup>, 2018. All 12 interviews and focus groups were conducted between September 9<sup>th</sup>, 2018 through November 4<sup>th</sup>, 2018 in the Pittsburgh Oakland area, Lawrenceville neighborhoods, and at the University of Pittsburgh. I gave my interview participants the option of coffee shops, a room on University of Pittsburgh's campus, or another suggestion of a relatively public area to conduct the interview. I conducted my focus groups in University of Pittsburgh conference rooms.

I used a semi-structured interview format to entice narratives, feelings, and thoughts from participants during interviews and focus groups. Interviews were conducted only by the primary researcher and recorded with Protect + recording encrypting software. Interviews lasted between 20 minutes to 80 minutes and focus groups lasted between 50 minutes to 100 minutes. My interview guide attempted to get specific narratives and stories from my participants (Appendix A), while my focus group guides had questions about general thoughts, suggestions, and opinions as well as questions pertaining to the specific identities of each group to try to start more conversations (Appendix B, Appendix C). All my participants received a copy of a resource guide for queer and trans young people (see Appendix D) and \$20 compensation through the WePay system.

<sup>&</sup>lt;sup>4</sup> These power dynamics include, but are not limited to: the recent murder of Antwon Rose II, a Black unarmed 17 year old boy, by an ex-University of Pittsburgh police officer (<u>Hassan 2019</u>); the founding of the Pitt School of Public Health by Thomas Parran, the notorious overseer of the Tuskegee Syphillis experiment and imprisonment of Black women rumored to have STI's (<u>Stern 2018</u>); and the closing down of University of Pittsburgh Medical Centers in predominantly Black neighborhoods (<u>Farine 2014</u>). Each of these instances my Black and other non-white participants brought up during focus groups or interviews.

## **3.3 Inclusion Criteria**

Participants must identify as queer and/or trans and be between 14-26 years old to participate in the interviews.

The age limitations are based in the clinical age range for adolescents and young adults. The reason I follow this clinical age range is because it is more likely for adolescents and young adults to utilize gender- or sexuality-based healthcare on their own rather than younger ages (Coleman et al. 2012, Hoffman et al. 2009), often because they have access to certain healthcare without parental knowledge. Specifically looking at adolescence and young adulthood also can reveal medicine does reproduce popular conceptions of categories and how these biases are reproduced onto the bodies of this specific population (Gill-Peterson 2018). Focusing on this population shapes this study because of the specific situatedness of adolescence and young adulthood in present society, in which these young people are getting closer to becoming autonomous adults, and have incredible access via technology and internet spaces to envision that future for themselves, but still are constrained by their economic and physical mobility.

The reason for using the terms "queer and/or trans" instead of LGBTQ+ is deliberate. Julian Gill-Peterson's work on transgender childhood and Kathryn Bond Stockton's work on queer childhood reveal the importance of honoring the blurred lines of young people's performance and understanding of their own gender and sexuality. Many adults in young people's lives, ranging from family members to clinicians to teachers, may attempt to push young people to decide on a singular identity so their personhood and performance of gender and sexuality can be better understood by the outside world. Thus, I specifically de-center those specific labels that those adults created in order to contextualize experiences they did not understand and to leave room for those young people to also acknowledge that they may not completely understand either.

My focus groups have more specific statutes of participation due to the lack of historical representation of queer and trans people still in high school/middle school and queer and trans people of color (Gill-Peterson 2018). While I attempted to recruit people from these intersecting identities without explicitly limiting the statutes of participation- mostly by recruiting through non-profits that cater to specifically underage queer and trans young people and queer and trans people of color- the initial participants who expressed interest in joining the project were primarily white college students. Thus, the specified statutes of the three focus groups aim to fill this gap in my participant demographics to try to get a fuller picture of the current state of queer and trans youth relationships to healthcare and care providers.

#### **3.4 Recruitment**

I recruited participants namely through Facebook posts in Pittsburgh LGBTQ groups and organizational pages, presentations at meetings of non-profit organizations that specifically cater toward queer and trans youth and queer and trans people of color, and through flyers in the Oakland, Lawrenceville, and Shadyside neighborhoods of Pittsburgh (See Appendices E-G for flyers and social media recruitment materials). Each of these areas have LGBT-specific health centers and colleges and high schools with plenty of young people. I chose these areas because of their historic connections to LGBTQ residents and LGBTQ clinics. I did not recruit in any clinics specifically, only organizations that have connections to clinics, because I did not solely want participants to feel like they were coming to me to give reviews for the particular clinic(s) they use. Participants would email me with initial questions, and I would give send them an email back detailing more about the goals of my research and other information (Appendix H).

Table 1 Participant Demogra	aphics
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Name (changed to	Age (stage of life)	Gender Identity (self-	Sexual Identity	Race and	Pronouns	Focus Group or	
protect anonymity)		identified)	(self-identified)	Ethnicity		<b>Interview?</b>	
				(self-identified)			
Sebastian	High School	Trans Boy	Not available	Puerto Rican &	He/him/his Interview		
	Sophomore			Mexican Hispanic			
Jamie	High School Junior	Non-Binary/Queer/	Queer	White	They/them/theirs	14-18 yr old FG	
		Trans Spectrum					
David	High School Senior	Trans Boy	Not available	White	He/him/his	14-18 yr old FG	
Madison	High School Senior	Trans Girl	Pansexual	White, Latina &	She/her/hers	14-18 yr old FG	
				Jewish			
Charlotte	High School Senior	Not available	Lesbian	Multi-Racial	She/her/hers	POC FG	
				(Black-Indian-			
				White)			
Tim	College Freshman	Trans Man	Not available	White	He/him/his	14-18 yr old FG	
Maria	College freshman	Cis Woman	Lesbian	Latina She/her/hers		POC FG	
May	College Sophomore	Cis Woman	Lesbian	Asian, Filipino She/her/hers		Interview & POC FG	
Carmen	College Junior	Cis Woman	Bisexual	Latina, Cuban She/her/hers		Interview & POC FG	
Sarah	College Junior	Cis Woman	Lesbian	White She/her/hers		Interview	
Penelope	College Senior	Non-Binary/Queer	Queer	Chinese-	She/her/hers or	POC FG	
				Taiwanese	They/them/theirs		

Katie	College Senior	Cis Woman	Queer	Chinese American	She/her/hers	POC FG
Sara	College Senior	Cis Woman	Queer	Indian She/her/hers		POC FG
Viti	College Senior	Queer Woman	Queer	Indian She/her/hers or they/them/theirs		POC FG
Sage	College Senior	Trans & Non-Binary	Pansexual & Asexual	White	They/them/theirs	Interview
Henry	College Senior	Cis Man	Gay	White	He/him/his	Interview
Lester	Recent College Graduate	Non-Binary & Transmasculine	Queer & Pansexual	White	They/them/theirs or he/him/his	Interview
Carl	Graduate Student	Trans Man	Gay	White	He/him/his	Interview
Beth	Graduate Student	Trans Woman	Not available	White	She/her/hers	Interview
Avery	Working Adult	Queer Woman	Queer	Black	She/her/hers	POC FG
Valerie	Mother of Sebastian	Cis Woman	Not available	Hispanic	She/her/hers	Interviewed with Sebastian

#### **3.5 Analysis Methods**

I conducted a thematic analysis of transcripts of interviews and focus group through NVIVO. Initial themes I hypothesized would show up in my interviews were written down based on my literature review, then were clarified during the transcription process, and further clarified as coding ensued in NVivo. Initially from my literature review I postulated that there would be negative relationships with healthcare providers, such as providers forcing youth into psychiatry or refusing to treat a young person's gender or sexual affirmative needs. I also postulated that young people would trust doctors who were well-versed and/or trained in LGBTQ health. Them, throughout my transcripts, I started to notice nuances within those categories such as my participants focusing on secondhand stories to understand their fear of healthcare and my participants of color being concerned about family friend providers outing them to their family or community members. In putting everything I wrote down into my codebook, I began to notice the larger themes come up by noticing the actions and subjects of certain themes such as an instance of a provider enacting something that elicited a feeling, an instance of hitting an institutional barrier to healthcare, or an instance of a young person directly speaking to providers and hospital administrators on how their experiences could be better (see Table 1 for example of my NVivo Codebook). Thus, the final themes based off of three times of combing through the data are: Navigating the "Chess Game", Distrust in Doctors, Trust in Doctors, and Suggestions for Doctors. For each theme in my results section I have a table of the subthemes in each, with how many times

each subtheme was referenced in my entire set of interviews and focus groups, and how many sources (i.e. each focus group and interview) the specific subtheme came up in.

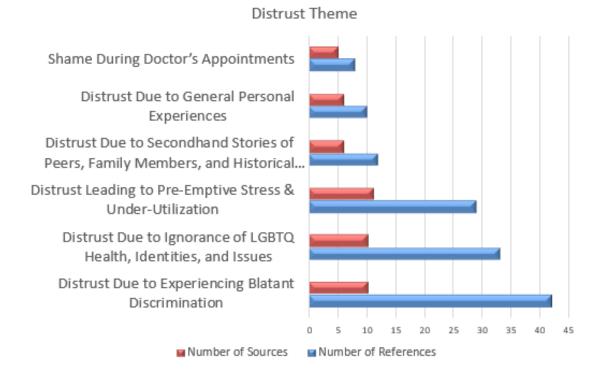
les		
Name	Sources	References V
) Chess Game	12	158
Subverting Control	11	52
Information Networks Outside Hea	9	22
Strategic invisibility	6	13
With parents	3	5
With providers	2	4
With mental prep or intuition	2	4
With community or peers	1	1
Strategic visibility	1	1
Lack of Bodily Autonomy	7	32
Induced by doctors	7	32
Gatekeeping Care	7	20
Forced Medicalization	4	9
Parental Complications	7	25
Pressure to Perform for Providers	8	22
Insurance Complications	8	11
Severe Stress	5	11

Figure 1: Example of NVivo Codebook

# 4.0 Results

Through thematic analysis, I found four central themes from the narratives of queer and trans young people regarding their relationships with care providers and the healthcare system: "Distrust in Doctors," "Trust in Doctors," "Suggestions for Providers," and "The Chess Game." For each of these themes I breakdown the subthemes into the number of sources (i.e. individual interviews of focus groups) this subtheme came up and the number of times participants said something that fit into that category.

## 4.1 "I just don't feel like I can trust them": Narratives of Distrust Toward Care Providers



**Figure 2: Distrust Theme Breakdown** 

The "Distrust in Doctors" theme encapsulates the actions care providers do to induce distrust, such as breaking or threatening to break confidentiality, revealing ignorance of LGBTQ and non-white (if applicable) people and culture, and making harmful comments and assumptions based on patients' identities. Participants revealed the severe stress induced by these experiences from doctors, leading to a pre-emptive lack of trust in the healthcare system as a whole and avoiding utilizing health services. These experiences listed above also did not only have to be experienced firsthand by the young people; my data reveals how stories from participant's families, peers, and community histories were key factors in this distrust in doctors and the healthcare system as a whole. Thus, these young people did not even have to experience a negative experience with a doctor to have feelings of distrust toward doctors and healthcare and to actively avoid utilizing healthcare. A final piece of the distrust of doctors theme is a pattern of doctors not seeming to trust queer and trans young people as agents of their own bodies and healthcare, leading to often tumultuous relationships between these youth and their health providers.

Distrust in doctors came up in all 12 sources and was referenced 136 times. Distrust came from a variety of places: familial or cultural beliefs, stories from peers, past personal experiences, or knowledge gained from the historical context of queer and trans health. Participants reported significant distress based on this distrust, often getting pre-emptively nervous before a doctor's visit but also feeling shame and fear during the doctor's visit itself. The most referenced sources of distrust came from experiences of queer- and trans-phobic discrimination and ignorance of LGBTQ issues, health, and identities from doctors such as: misgendering, harmful language, questioning their identities and sexual histories, and assumptions about them based on their identities (such as promiscuity, unsupportive parents, or mental health troubles)<sup>5</sup>. Even if one of these young people had not had a personal experience of discrimination, they still referenced distrust of doctors and health providers as a key part of their relationships with the healthcare system. These came from stories of the people around them or before them, the past and present connections to queer and trans people experiencing discrimination based on their bodies, presentation, and identities. This section will explore the mechanisms of how young people bring together the experiences of their family, friends/peers, and people from their community from the past and connect those to their present experiences with health providers and decisions on when and when to not utilize healthcare.

#### 4.1.1 Stories of Blatant Discrimination in Healthcare Settings

There is an assumption in today's popular society that there is a surplus of affirmation and acceptance from parents and health providers toward queer and trans youth; that we are entering a new age of gender identity awareness and affirmation regarding LGBTQ young people. However, this research and many others, have found that to be largely untrue. The stories that the participants told in my research are harrowing and indicative of how far medical practice and research still has to go in practicing consistent affirmative healthcare. The first theme of distrust is the references participants made to discrimination they have experienced from care providers and the effects of these experiences on their trust in those providers and future providers.

One of the most disturbing stories of my interviews was told by Carl, a graduate student who started his physical transition when he began his first year at graduate school. His story will

<sup>&</sup>lt;sup>5</sup> Misgendering is when someone does not use someone's correct pronouns.

also be told in the "Chess Game" theme due to his doctor's extreme gatekeeping techniques, but is also relevant to this theme due to those techniques resulting in extreme perceptions of discrimination and deep mistrust from Carl. He describes this doctor "completely ruining" his transition, something he had hoped to be a liberating experience. Her inexperience in trans medicine, despite being advertised as a doctor who works with trans patients and provides hormonal transition services, severely impacted his experience. She gave him no resources to other local Pittsburgh LGBTQ health clinics, and constantly berated him for wanting to be more in control of his healthcare. One quote of his reveals her manipulating Carl by suggesting that he did not have business in making decisions about his own physical transition process:

She was totally oblivious as to who she was working with, that was my reaction to her. She would tell me all the time about how I insisted too much on control, like when it got to a certain point where I said "okay, we are going to start now, I have everything set up for you, let's do start [testosterone injections]" as if [my wanting to start] was a bad thing... I felt so powerless.

Carl's doctor actively gaslit him here, where she would shame him for wanting to be actively involved in his own healthcare, instead of accepting him as someone wanting to receive medical care to affirm his gender identity. She also made many harmful comments based on his exploration of his sexuality, revealing to him how little she understood people who identify as LGBTQ, leading to severe distrust in her abilities to be in charge of his healthcare:

"So then the next appointment or whatever, I said something like 'I think I'm gay, not even bisexual, like those things that I thought before'... and she was like "you're not that" like, "I don't want you to be, so you're not that"... before, when I told her I was bisexual, she would tell me "you're trans, you can't be with a cis girl." And I said "that's not true." She said, "is she a cis female?" and I said "yes," and she said "well she's going to be attracted to a cis male then" and I said "you're not right." I was angry. And she said something like "oh, so that was a trigger point for you" or "so that was a soft spot" or something like that, and I said "that's just not true."

Carl attributed this experience as one of the most severe in his realization that this doctor did not have the ability to actually care for a trans young person in the way she initially promised. By implying that Carl knows less about his own sexuality and who will be attracted to him than she does, Carl's doctor perpetuated the history of providers assuming they know about their patient's identities than their patients do. This can lead to patients questioning themselves even more and also deciding to keep these parts of them a secret from care providers in the future. The combination of withholding his hormone treatments (which will be discussed further in the "Chess Game" theme) and her queerphobic comments led Carl to profoundly distrust her and to seek healthcare elsewhere.

Another story reveals how a provider's severe transphobia and disrespect led to a distrust in providers. Madison, a high school senior who participated in the focus group with 14-18 year olds, began coming out as a trans girl while in therapy, and her therapist was one of the first people she came out to. Despite Madison asking her therapist to use pronouns that were not he/him to help her not feel dysphoric in her therapy sessions, her therapist refused:

"When I first came out, basically to myself, I asked my therapist to use they/them or at least anything but he/him for me. And she just didn't at all really. And then it wasn't until a couple sessions after that I just said 'she/her please and not my birth name either.' That wasn't really a thing that she respected either. She tried to get to the root of it but was very adamant of like 'oh, maybe this is a religious thing.' It was weird. I did ask her politely if I could see a different therapist and I was able to do that luckily."

Madison's story, similar to Carl's, reveals how much a provider misgendering and blatantly disrespecting a patient's gender and sexual identities can lead to queer and trans youth deciding to leave their care. Both Carl and Madison, and many other queer and trans young people I spoke to, attributed these discriminatory experiences as to why they hold a deep distrust of any doctor they come into contact with. Thus, providers who are not held accountable to their discriminatory actions through the institution that employs them or through the justice system end up harming the trust that queer and trans young people have in the healthcare system as a whole. Each interaction between a queer and/or trans young person and a care provider is tinged with that individual's past experiences of discrimination as well as the stories of past discrimination they hear from their family, friends, and community members. Providers may think that these interactions are harmless or not as severe, but to these individuals who have likely already experienced discrimination or have heard many stories of discrimination from people around them, these interactions are key in deciding what to disclose to doctors and when to avoid healthcare altogether.

What also struck me is that in these stories and in multiple others, how many other care providers knew of the discrimination that their co-workers were inflicting upon this population, making me think of the systematic upholding of discrimination against queer and trans young people. These young people would move between care providers within the same clinics and practices, often telling their new providers exactly what happened to make them switch from their previous providers. Why were these discriminatory providers able to inflict even more pain, as proven by the same names coming up multiple times in my interviews? These stories of discrimination spread around to health practitioners and other queer and trans young people alike. The stories also severely affect the queer and trans young people who don't experience them firsthand, but use them to contextualize their distrust of doctors while not even having experiences of firsthand discrimination.

### 4.1.2 Incorporating Secondhand Stories into Perceptions of Healthcare

A very consistent subtheme when participants would speak about their distrust of healthcare providers was how much secondhand stories of discrimination affected queer and trans young people's perception of the healthcare system. I noticed this theme almost immediately, with my first participant noting how she noticed that her anxiety levels about going to the doctors seemed to spike the more she learned about negative experiences her friends and peers have had. Another interviewee named Lester, a recent college graduate working in the Pittsburgh area, explained this phenomenon perfectly:

It [hearing other people's negative experiences] makes going to the doctor an anxiety-inducing experience despite the good experiences I've had. It's still ingrained: "this is going to be a negative experience." Hearing those kinds of bad things or things that people have said, it's like "what am I going to have to deal with today?" Like, what am I going to have to deal with regarding how I dress, how I look, or how I identify, today?"

Lester describes one of the most central aspects of my interviews: the constant vigilance that queer and trans young people feel they need to have in doctor's offices, whether or not they have experienced something negative firsthand by a medical provider. Many of my participants felt comfort with having as much knowledge as possible from their peers' and families' experiences with various healthcare providers, even though this knowledge often made them extremely stressed before going to any doctor's appointment, especially with a provider they have never seen before. However, negative stories about a particular doctor did not always sway participants from going to those providers: another participant Sage, when asked to clarify how they feel about their peers' negative experiences with their current psychiatrist, noted that this knowledge is "helpful for me, because I can be watching what she's doing and know that she's done these things in the past, but for now... it's okay." While they know that this psychiatrist does not have the best track record with their queer and trans friends, they are not immediately leaving because they have not had a firsthand negative experience with her. Thus, these secondhand stories do not always completely dictate healthcare decisions, but are helpful tools in remaining diligent with providers in order to notice possible discrimination.

Knowledge of the history of queer and trans medicine also significantly affected the distrust that participants had toward their care providers. One of my participants who is a graduate student, Beth, discussed how knowing the history of trans medicine and stories from her queer and trans peers led to extreme anxiety regarding her transition:

"There is my reading and understanding of historical aspects of [trans healthcare], then there's my experience with other people. The first one has been helpful contextually, in the sense that... shit's a lot better than it was at one point. But, I can't help but still see all the arcs of that history... I think part of the reason why I was extremely distraught when I had to wait a month and then another month in terms of getting my hormones was because I was familiar with these narratives and familiar with the gatekeeping and thought it was going to result in my not getting care or them [the care providers at the clinic she went to] finding a reason to not give me healthcare."

Almost every person I spoke to used their knowledge of history regarding queer and trans people to contextualize their current experiences and thoughts about their healthcare, especially the people who identify as trans. Pointing out the history of medicine was also prevalent in the focus groups with queer and trans young people of color (POC), who also seemed to report the most avoidance of utilizing Western healthcare. In one of those focus groups with queer and trans POC, a conversation between Maria and Avery explains how history and secondhand stories lead to them avoid Western healthcare:

Maria: If you hear shitty stories, why would you put yourself through that too? Especially if it's multiple accounts of people telling you that something happened to them.

Avery: It's also just a fear factor of it, it's a fear thing. You don't want those same things to happen to you or worse things to happen to you. I'm a history nut so I be looking into shit and it's like dude I already know, so no! I also think it's really hard to find doctors who are trustworthy because a lot of doctors here are white. Even in trying to get therapy, like if you're trying to find someone of color, or even specifically trying to find a Black woman doctor in my case, is so fucking difficult. Secondhand stories and the history of medicine's injustices toward LGBTQ people and people of color significantly affects queer and trans young people's distrust toward care providers. We are in an era of having access to incredible amounts of knowledge, and my participants seemed to utilize this access in ways of understanding their individual interactions with providers as well as their experiences with the healthcare system as a whole, which led to a constant state of vigilance, fear, and severe stress when interacting with these people and systems. This knowledge of the magnitude of negative experiences that people in these communities have with providers also seems to magnify the negative experiences that queer and trans young people experience firsthand, leading to what may seem to providers as "innocent ignorance" having much more weight on the psyches of queer and trans young people than they might expect. This is why providers need to learn about the ways that institutional practices reflect histories of discrimination and oppression toward LGBTQ youth in order to remedy how these practices may affect providers' interactions with people from this community.

# 4.1.3 Experiencing Assumptions, Othering, and Questioning from Care Providers

Participants often experienced ignorance from providers based on LGBTQ identities, ranging from denying them healthcare options to assuming things about them based on their gender or sexual identities. This section discusses the comments, questions, and assumptions that providers make when caring for these queer and trans young people and their understanding of these situations in regards to the healthcare system as a whole.

Penelope, who participated in the first focus group of queer and trans young people of color, spoke a lot about assumptions they have experienced from care providers and doctors based

on their various identities. One instance reveals the assumption one doctor made to Penelope regarding their experience as an Asian queer people and how that affected their trust with that doctor:

I had a doctor who was a woman of color, she was southeast Asian, but one thing that upset me was when she asked my mom to leave the room, she made a lot of assumptions about my mom being a 'tiger mom' and things like that. And she was Asian so she gets it obviously, but it was one of those things where... being LGBTQ and being a person of color, those things interact in a lot of ways. Like there's some things I can't tell my mom, but I definitely am very protective over the connection that we have, so I'm very defensive when people make judgments about my relationship to my family.

While Penelope's doctor may have been trying to relate to Penelope based on her and Penelope's shared experience of growing up in an Asian family, this provider's assumption of familial dynamics severely deterred that relationship because of Penelope's situated experience of being a young queer person of color. Penelope's experience reflects many of the struggles that young queer and trans people of color face while trying to find a doctor that will accept all of their identities, specifically their familial/cultural context and their gender and/or sexual identities. In my section on the Chess Game, I go into this more, noting how this is actually a barrier to that young QTPOC people face when trying to utilize healthcare, in which white doctors will often not understand how their cultural/familial experiences affect their health and well-being and doctors from their own cultural background might ignore their LGBTQ-specific health needs.

During the focus group of 14-18 year old queer and trans young people, we talked a lot about the assumptions that providers make and the questions that ensue when they encounter this particularly young group. One enlightening discussion revealed the affects of doctors trying to place a young person into categories so they can understand their situation in contexts they can understand better:

Madison: Every time I've gone to the doctor and I've had to tell them that I was trans, the immediate following question is "Okay, so who do you fuck?" Not phrased like that specifically, but said in a way that might as well have been!

*Tim: I feel like when they ask that question, it's kind of like, "oh, you're a part of that community, are you even more a part of it?"* 

David: "How many boxes can we check off?"

*Tim: It's like "oh, you kind of stick out in that way; where's the rest of you?", just so they can try to place you, and it's like "okay, but that's not what we're talking about here."* 

Madison: "What's in your pants?" "I have a cold!"

This conversation reveals that queer and trans young people severely notice and can understand when doctors do not understand the dynamics and differences between sexual and gender identities. It also reveals how their understanding of historical discrimination can lead them to feel even more offense in an interaction with a provider than they may have without this knowledge. The history of medical categorization of sexual and gender identities comes into play in these appointments, such as the conflation of sexual desire and gender expression/identity, leading to deep discomfort. Later in this conversation participants brought up how they view the phenomenon of doctors sexualizing them when they come out as trans or non-binary to the historical disorder of "autogynephilia." "Autogynephilia" is a concept created by sexologist Ray Branchard in 1989 and connects Male-to-Female transgenderism to a sexual desire to be in a woman's body. The young people of this focus group had almost all heard of this and found it on online and noted how they connected this popular concept in medical sexologist research to doctors asking them about their sexual orientation when they come out as trans. This relates to how young people are able to connect historical context to their present experiences, leading to connections to queer and trans young people of the past and adding this to their information networks regarding navigating healthcare. It also relates to the still-pervasive phenomenon of care providers confusing gender identity with sexuality and the ways in which gender non-conforming and trans youth are assumed to be hyper-sexual and sexually active at younger ages. This focus group of teenagers, who all identified as on the trans spectrum, revealed how much they were aware of these dynamics through their own experiences and knowledge of the history behind the medicalization of queer identities and how that affects when they decide to visible and open about their identities in doctor's visits or when attempt to hide them to avoid harm.

## 4.1.4 Under-Utilization of Care Based on Past Discriminatory Experiences

Many young people reported that they actively avoid healthcare as much as possible because of past discriminatory experiences. This theme seemed to be particularly relevant in interviews and focus groups with people of color, who often reported avoiding healthcare altogether because of past discrimination that they experienced firsthand or that friends and family experienced. Maria, a Latina college freshman who identifies as a lesbian, spoke in the focus group consisting of queer and trans people of color about how one experience of assumptions severely impacted her utilization of healthcare services in the future: I feel like the doctors there are already expecting a certain type of demographic that they have an automatic attitude about whatever you're coming to them with versus if I was just to go to my regular doctor. I go and I say, "I need an STD panel," and then right off the bat they were already assuming things about me. I feel like that's one of the main reasons that I don't like doctors or whatever because of that bad experience that I had and just how uncomfortable I felt the entire time and how disrespected I felt the entire time.

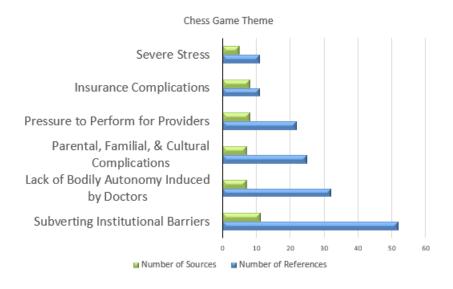
Many of the other people in the room agreed with her, that they had experienced things or heard of experiences that led them to avoid healthcare. This group also spoke extensively about their families pushing them to avoid Western medicine practice, often also based on discriminatory experiences as well. Charlotte in the group shared a particular story as to why she is uncomfortable going to the doctor without another person in the room:

My mom at one point, when she was 19 right after she gave birth to me, got cervical cancer from HPV. Her doctor actually sexually assaulted her while she was getting treatment for it, and I think since then it's always been a sore spot with doctors and my family being overprotective in the doctor's office. Since then even just for getting vaccines they have to be in the room. In general, there's a lot of distrust especially with my family with doctors because you just get ignored and talked over all the time.

Charlotte's family has incorporated her mom's experience of sexual assault into how they navigate the healthcare system, even telling her to actively avoid going to the doctor's by using

homeopathy or other at-home fixes for illnesses. Many people in this focus group concurred with this influence from their parents to avoid healthcare and noted that their queerness also resulted in this fear of care providers.

# 4.2 "How do I play this very massive chess game that has three players in it?": Queer and Trans Youth on Playing the Game of Accessing Adequate & Affirmative



#### Healthcare

Figure 3: "Chess Game" Theme Breakdown

The name for the "Chess Game" theme comes from a participant's description of the different performances and "acts" he feels he must put on for his parents and doctors in order to get the healthcare he needs. The "Chess Game" theme thus encompasses the times where patients referenced the various barriers and borders to care that affected their relationships with healthcare providers and their comfort with the healthcare system. Parents, doctors, and insurance providers all participate in blocking queer and trans youth's access to sexual and gender affirming healthcare.

The "Chess Game" also includes the ways in which queer and trans youth subvert and get around these barriers and borders such as utilizing online queer and trans youth information networks and strategizing when to keep their identities visible or invisible. While the biggest references subtheme is "Subverting Institutional Barriers", I analyze this subtheme at the end of this section because I want to paint the picture of all the barriers that these young people learn to navigate through before I discuss their tactics to do so. The largest referenced barrier to care is a lack of bodily autonomy by doctors, which includes both gatekeeping care (such as refusing hormone treatment even after extensive review of a patient's "case", withholding pertinent information on a patient's diagnosis or care treatment, or rejecting a patient's request for hormonal birth control based on their sexual orientation) and forced medicalization (namely imposing psychiatric treatment upon someone's admission of their sexual or gender identity). Another common experience for queer and trans young people was the pressure to perform for doctors, ranging from performing as part of a sexual or gender binary, agreeing with homophobia and transphobia in order to get care, pretending to happier or more settled in their identities than they feel they actually are, and not admitting suicidal ideation for fear of losing gender or sexual affirming healthcare. These themes are to understand the barriers that doctors actively perpetuate, the barriers that providers can help queer and trans navigate, and the ways in which queer and trans young people learn to pilot through a system that often fails them in providing adequate healthcare.

# 4.2.1 Lack of Bodily Autonomy Induced by Doctors

The most referenced theme of a barrier itself (outside of subverting institutional barriers, which will be analyzed at the end of this section so we can get a picture of all the barriers first) was the pattern of doctors diminishing queer and trans young people's bodily autonomy. This

included both forced medicalization, such as forcing queer & trans patients into psychiatric care when they seek medical treatment, and gatekeeping of healthcare, such as denying birth control methods based on patient's perceived sexual risks or withholding hormonal treatment even after the standards of care & diagnosis of gender dysphoria have already been met by the patient. The stories of care providers diminishing patient bodily autonomy with this population are harrowing and are a significant part of the severe discrimination in the healthcare system that many of them face. This theme is where a lot of the history of queer and trans medicine reveals itself in the present day, in which the current standards of affirmative healthcare are not being met by providers, who in turn do not seem to be held accountable by the clinics and institutions they work for.

Forced medicalization by doctors usually occurred in cases of trans patients, in which coming out as transgender led to care providers pushing or forcing them into psychiatric or mental health care. This medicalization is only considered forced when patients did not express wanting these services or actively requested to not be involved with mental health care; it also is only used in cases where patients are over the age of 18, in which they legally have more ability to decide on the gender affirming care that is best for them, instead of needing a diagnosis of gender dysphoria from therapists and/or psychiatrists. One participant I interviewed, the graduate student named Beth, expressed her concern with doctors requesting transgender patients go into therapy:

This is another interesting thing that I kind of get, but is also kind of weird, where [my new doctor] encourages every trans or potential trans patient to go to counseling. And I get that, because it's a super stressful anxiety-ridden complex thing that you could use help with. But also, there is the association of... DSM'ing a little bit, DSM'ing transness.<sup>6</sup> And, you know how there's a limit on the number of counseling sessions you can have [at the student health center]? There's the exception: you don't have a cap if you are a victim of assault or a survivor of trauma, which obviously makes sense, or **trans**."

While the resource was appreciated by Beth, she was 26 at the time of this appointment and had already been on hormones for many years. Why did she need to go into counseling now, despite telling her doctor that counseling was not something she was interested in pursuing? Providers must walk this fine line between support for the mental health of trans patients and pathologization of transness though psychiatric care, both physical and mental health providers alike. While it may make sense based on age-range and patient history of mental illness, instilling psychiatric-based counseling as the most important way to alleviate stress in trans patients, instead of physical transitions to alleviate dysphoria, may lead to severe distrust in doctors and enact a severe barrier to adequate care for queer and trans young people. Patients who reported being forced into counseling consistently attributed their severe distrust of the healthcare system due to that experience. They felt that system was actively trying to stop them from getting the support they wanted by forcing them into psychiatric care before any other kind of treatment to affirm their gender.

It was through this psychiatric-based care that participants experienced some of the most gatekeeping practices. Tim, a college freshman who participated in the focus group with 14-18 year old queer and trans young people, spoke a lot about his experience at the Johns Hopkins

<sup>&</sup>lt;sup>6</sup> "DSM'ing transness" here means the pathologization of trans identities as psychiatric disorders, which was perpetuated by the DSM-III's inclusion of transexuality as a disorder needing to be treated (American Psychological Association 1980).

gender clinic, the birthplace of American trans medicine. He knew about its history with trans medicine, both the good and the bad (he mentioned the presence of a doctor who shut down the trans health clinic in 2014), and was both nervous and excited to seek gender care with his parents at the famous institution. However, his experience was a bit less professional than he expected. He was immediately brought to psychiatry and forced to go through hours of questioning about his gender identity formation:

At the psychiatrist appointment I went to, they sat me down and grilled me for like two hours trying to... I knew what they were doing, they were trying to see if I fit the criteria for gender dysphoria. But they had the old questions on it, where they would said "did you play with dolls or trucks when you were a kid?" I didn't have trucks when I was kid, and I'm just like "we both know that this is dumb" and the person who was grilling me acknowledged that fact that it was dumb but just said it was the list of questions for the thing, and I'm just like... I think she was specifically a student there not a 'full-fledged with the tail coats doctor', so I guess she had to follow the instructions, but we both know that this is outdated, so why are we doing this?

This is just a snippet of the intense process that queer and trans young people go through to gain gender affirming care. Almost every single one of my trans participants who sought out gender affirming healthcare had to go through intense interviewing processes, in which they had to answer very specific and personal questions in order for care providers to gage the legitimacy of their trans identities. Carl, the graduate student who told me a distressing story about his experience in trying to physically transition through a Pittsburgh health center, experienced some of the most severe gatekeeping methods I came across in these interviews. Carl's doctor identified as being "new to trans care" and revealed just how new she was through her actions of gatekeeping hormones from patients who came to her seeking gender affirmative treatment. Her patients were like Carl: in college and often seeking out gender affirmative care for the first time, college being the first time they were over 18 and able to seek care without the presence of their parents. She forced Carl through an incredible number of preliminary interviews, questioning him about his childhood, how he dresses day-to-day, his sexual preferences, and much more. He had three months of preliminary interviews, far more time than is the standard or deemed legally necessary:

It was interview after interview after her emphasizing that because "I'm working with people who are in their early 20's or 19, I want to make sure they're not making a mistake," and I didn't know better.

After finally putting him on hormones after many months, Carl almost immediately started to feel uncomfortable. After a month or so of trying to wait it out, he finally "caves" and sends her a message about how he feels that this dosage might be wrong (he told me that he later found out that she had prescribed him a dosage that was unusually high for people of his 5'0" stature). He was afraid to tell her about the struggles he was having on hormones because of her attitude toward hormonal treatments for her patients:

Her whole philosophy was "I don't want my patients going on and off testosterone. You're on it for life, or you're not." She had very plainly said that. I think her only caveat was "if you get to 50 or something and you are satisfied with all the changes and whatnot, I think that's acceptable, but other than that you're on it or you're not." She wouldn't treat you if you were unsure. This philosophy is not part of the standards of care that WPATH enacted in 2011, which Carl unfortunately only discovered later due to his connection to other trans folks his age also going through gender affirming hormone therapy. After Carl expressed his concern about his hormone dosage, his doctor had him stop them immediately, as he predicted. She then continued to put him through counseling (from herself, not even a licensed mental health care provider) for months on end, forcing him to get written notes from his therapist and an in-person visit from his mother, before she would write another prescription for hormones. Carl then decided to seek other clinicians to support him with getting adequate gender affirming care when his doctor still refused to prescribe him hormones even after forcing his mother to join them in a doctor's appointment (in which she not only broke confidentiality, but also gave Carl's mother incorrect information on various LGBTQ identities). He was able to find a clinic that gave him hormones the day he came in to express his need for hormones and his history with this provider.

This particular barrier, directly enacted by providers, reveals the unnecessary stress that providers can put on their queer and trans youth patients by denying them of their own agency regarding their healthcare. Most of the barriers in this section I regard as secondhand barriers, in which providers may not be the ones at the forefront of enacting them, but absolutely can perpetuate them by standing to the side and not supporting the patients trying to navigate a system that is often rigged against them.

## 4.2.2 Parental Barriers to Care

Due to the age of participants as being 14-26 years old, parental control often came up in narratives surrounding their experiences with the healthcare system. This ranged from a fear of

lack of confidentiality due to being minors, to needing financial support from their parents to gain gender or sexual supportive healthcare, to doctors needing permission and input from parents before deciding to give these young people affirmative healthcare. This varied based on age, wherein the young people still in high school or dependent on their parents' funds for college felt significantly more pressure from their parents than my other participants. In fact, the title of this theme the "Chess Game" came from Tim, a college freshman who participated in the 14-18 year old focus group, discussing his struggle with performing for both his parents and his health providers. He struggled a lot with gaining gender affirmative healthcare, especially since the program he used was very family-oriented. Here is a quote from him discussing his experience in trying to get his doctor to acknowledge his diagnosis of gender dysphoria in group therapy with his doctor, parents, and a social worker on staff:

I was like "so you said that I qualified for the gender dysphoria diagnosis," but he kept shying away from that and trying to talk to my parents. And I get that, I know that you don't want the parents to go "I don't like this doctor" and leave, right? That doesn't help the problem. But it also kind of felt like he wasn't picking sides, he wasn't fighting for anything. To quote Hamilton, "what are you gonna fall for?"

Doctors attempting to cater to unaccepting parents happened many times throughout these narratives, especially in the focus group of 14-18 year olds. Most of the participants in this group had negative experiences with these attempts by doctors because often they said something at the expense of the young patients in order to try to maintain trust with their parents. These seemed to be the times where these young people constituted their experiences and awareness of them being "youth," in which their parents had an incredible amount of control over their bodily autonomy.

Strained parental experiences about their genders and sexualities led to an incredible amount og tension and acknowledgment of the hardship in being at the mercy of their parents' opinions. Many doctors new this and attempted to repair some aspects of strained parent-child relationships, often at the expense of the queer and trans young person:

The doctor came back [after talking to my mom individually] and gave me this whole speech about how "I know your mom is weird about this, but you know she does really care about you and she cried about this"... like not guilting me for being angry at my mom, but very actively like "yeah, your mom doesn't support you being trans, but you should love her anyway because she's still a good parent." The thing that really bothered me was that she said, "you know no one else will ever love you as much as that woman right there." And I was like "I really hope that's not true... because if that's the person who is going to love me the most then I'm fucked."

By focusing on the sanctity of the parent-child relationship, this doctor harmed her relationship with David by not only trying to absolve his mother of any wrongdoings for him, but also ignoring the possibilities of the sanctity of other familial or intimate relationships. This doctor's perception of David's relationship with his mother also does not take into account the severe barrier that his mother is putting up between him and his healthcare needs by, in this case, refusing to fund any gender affirmative healthcare despite his 3-4 years of asserting his gender identity to her. This withholding of funds by parents and families was also a constant barrier to healthcare and is very connected to the insurance-based barriers many young people felt. Often the withholding of funds was one of the main reasons that queer and trans young people couldn't access the healthcare they needed, as stated by high school senior David:

"I am super petrified that my parents will switch my insurance when I turn 18, because you can stay on your parents' insurance until you're 25 which had always been the plan for me, but now that I am trans they're like 'we got to stop you, no health insurance.'"

By prioritizing the parent-child relationship as sacred and an automatic relationship full of love and support is very damaging to queer and trans young people because of the struggles so many go through in gaining healthcare that aligns with their gender and sexuality due to not having access to familial funds for it. It also does not reference different cultural or familial values, in which money does not go toward healthcare but toward education, or many other variations. The next section will talk specifically about cultural and familial barriers to accessing gender and sexuality affirming healthcare, as a separate but similar barrier to parental complications to access.

### 4.2.3 Cultural and Familial Contexts Affecting Healthcare Utilization and Barriers to Care

My interviews and focus groups with people of color, particularly people whose parents are immigrants or who grew up in communities comprised of people predominantly from their ethnic background, revealed how much their cultural and familial contexts affect how they approach healthcare. Many participants noted how hard it was finding a provider, especially a mental health provider, who would affirm both their cultural and familial backgrounds and their gender and sexual identities. For example, May, who participated both in an interview and focus group, told a story as to why she finds it hard to find mental healthcare that speaks to all of her identities:

Around middle school I definitely started hating my parents, because every time I talked to someone, not necessarily a professional but even just a friend, they would just be like "your parents shouldn't act like that, no parents in the US should act like that." Now there's a lot of hatred that I had for my parents, but I also didn't take into perspective being an immigrant and being from the Philippines. Their parenting is set to a different cultural standard than the parenting in the US and just comparing those two wasn't equivalent. My guidance counselor in high school was a professional therapist and I always had to explain, she would validate me and stuff but she would validate me in a way that was like "yeah your parents are so bad" and I would have to be like "they're really not bad people they are just doing what they've known their whole life, they're just not communicating it properly or doing it in the best way that they can." I felt like I had to make her step back and realize that.

Many participants talked about mental health professionals as well as other healthcare providers expressing a level of Western-based individuality that did not take into account their deep connections to their families. This was often connected to their queerness, where Western and/or white professionals would assume that individuals needed to become more separated from their families and cultures in order to truly come to terms and except their gender and sexuality. Another story from one of the focus groups of queer and trans people of color between Viti and Charlotte reveals more struggles with white therapists who ignore the importance of cultural and familial ties: Viti: I feel like my cultural identity shapes how I do queerness in such a specific way that the one time I did go to a white therapist, it felt like most of the time I was just explaining Indian culture to her. And then I'm halfway defending the culture but also problematizing it because it's affecting me in X, Y, and Z ways, but it's not a bad thing, it's just how it is and it was a really weird balance of me explaining things to her and I just wasn't really getting anything from it. It feels like it might have been easier to go to an Indian person or a person of color who would have understood the familiar things that happened because of my coming out or all these things, but who might not have the right things to say about the queer stuff, it's a weird balance or play-off type thing.

Charlotte: I've kind of had to do the same thing with the therapist that I've had. Part of why I'm messed up now is because of this sort of experience with my culture and me being gay, but then also defending the people that have hurt me by saying "that's just the culture from the Caribbean, they're so old," but then still having to be like "yeah but they still have kind of traumatized me."

Providers not accounting for cultural and/or familial ties often lead to participants not being able to receive relevant healthcare that speaks all of their identities and experiences, leading them to give up on trying to utilize healthcare unless absolutely necessary. Many had tried to find doctors from their cultural and racial backgrounds to avoid culturally insensitive situations from doctors such as noted above, but when they finally managed to do so, complications arose there as well. Viti, a college senior who participated in a focus group with queer and trans people of color, explains this paradox perfectly: It is hard to find someone from within the community who is queer-friendly. I just feel like it's a trade-off, where you could go to a queer-friendly person but it's not going to be a person of color for the most part. Do I go to someone who understands my community a little bit more, but isn't well-versed in queer issues, or do I go to someone who is more well-versed in queer stuff but isn't a part of the community?

The connection between having family friend providers or providers of their same culture or ethnicity often came up in these interviews with queer and trans youth people of color. Most often it was due to the knowledge of anti-queerness in their cultures as May was worried about above, but also there was a fear of this provider being so closely connected to their parents to break confidentiality and tell them about the patient's sexual or gender identity. Viti, a college senior who participated in the focus group with QTPOC, discussed this dynamic of family-friend providers here:

There are the people that my mom goes to, but that's an Indian doctor who's a family friend, and they know all the things and that's not where I want to go. My mom's like "oh, it's easy because we all go there" and all our family friends go there and it's super like everyone knows everyone else's business and that's not what I want from my doctor. I'm also not comfortable saying things to that doctor because then we also have dinner parties and they're there too... and we do know a lot of people who are doctors, it's very word of mouth, where she'll call a friend and get an opinion. But they're not seeing me, they're not my doctor, it's like a family friend said this one thing and so that might be what's wrong with me. And it's because she trusts them and they

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know us, but it's all so weird because obviously I'm not going to tell my mom the whole story about certain things in terms of my queerness and everything like that.

Viti's story mirrors many other stories from queer and trans young people of color, who grew up with family friends who acted as their main source of healthcare, but as they grew up realized that they don't feel comfortable telling aspects of the gender or sexual identities to people so close to their family. For queer and trans young people of color, cultural and familial ties are intimately connected to their perceived ability to be out to providers or health professionals, significantly more than the white queer and trans young people I interviewed. Often these participants felt they had to choose between a queer-friendly provider or a provider that was from their own cultural or racial background; while this choice varied from person to person, it seemed that participants often chose to have a doctor from their own cultural or racial background rather than a white queer-friendly provider.

#### 4.2.4 Pressure to Perform for Providers to Receive Care

One of the biggest themes in my focus group with 14-18 year old queer and trans people was the pressure to perform various ways for providers and their parents in order to get the care they want. Tim from this focus group discussed this dynamic a lot, revealing how stressful this dynamic can be:

I feel like a lot of the time you have to be more sure of yourself than you actually are. You walk in and you kind of get scared and you fall back on ideas that may not be true. And you just kind of have to fake it til you make it, even if you don't agree with it. You kind of have to belly up and face all of the ideas that they think trans people are and be like "yes, I am what you think, please give me what I want" instead of say "yeah, I also have insecurities and fears about my future but I can't tell you any of them because then you'll say no."

Tim's perception of how to get what you want out of a doctor's visit is to actively play into stereotypes that providers may have about you to get the care you are asking for. Many people reflected this sentiment, largely trans-identifying folks who had to go through the intense process of questioning by providers in order to be able to start gender affirming treatment. Beth, the graduate student studying trans healthcare standards of care throughout time, also had this feeling of needing to perform for providers. Her description of how she felt when she first started to seek gender affirming care reveals the severe distress that came along with not knowing if she "passed the test" to receive hormone treatment:

I was terrified at every question... I'm like, okay, if I say that I've only known known recently, is it that going to be like "well, you should have known for at least two years, blah blah blah". If I indicate that I don't know if I want to get surgery, is that going to be a problem? Like, if I tell them that I'm not out to people, will they not give me hormones? And that was, the first time was extremely fucking nerve-wracking, and I left that appointment deeply concerned and upset because a) I had to wait a month to get a follow-up and b) I didn't know that they were going to do it. And that was horrifying. Also, that is probably like, not to speak for everyone, but from my perspective that is one of the most vulnerable positions you can ever be in. Especially as someone who had been engaged with it [being trans] relatively recently, and had

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struggled with it and struggled with it, and then thinking "I know I want to do this," but then go into a situation where you are put into so much doubt is one of the shittiest fucking things.

Tim and Beth's stories of their experiences in trying to gender affirming care expose the barriers that providers can perpetuate by basing their practice on stereotypes and assumptions. These stories also reveal the institutionally-based tactics to pressure trans individuals to fit into extremely small boxes based on their perceived ideals of who a queer and trans individual looks and acts like. These interactions and tactics of questioning individuals about their identities teach queer and trans young people how they should act and who they should be in order to be considered queer or trans *enough* to get care to support their well-being. This is also where the W-PATH Standards of Care, despite it being a large step toward affirmative healthcare for trans people, still fails specifically queer and trans young people; it still creates lists and categories of who is considered trans and what care is best for them, not emphasizing the necessity of the young people leading the collaborative process between their parents, clinicians, and supporting care providers. While the system of healthcare does put doctors as the main gatekeepers of healthcare, it is important for doctors to understand the incredible amounts of barriers that queer and trans young people face in gaining healthcare in order to appreciate that should not be the foremost barrier for queer and trans young people getting the care they want. In fact, doctors have an incredible power to help queer and trans young people through this system of borders and barriers, actively supporting them in these journeys. However, many doctors do not see this as a role of theirs; thus, queer and trans young people have come up with various techniques such as information networks, non-Western healthcare strategies, and strategic levels of visibility in order to subvert medical control over choices they make over their own bodies.

#### 4.2.5 Subverting Institutional Control

Almost every participant during their interview or focus group discussed their techniques to getting healthcare that works for them, either through finding clinicians known for affirmative care or utilizing different techniques of visibility during interactions with less knowledgeable or non-affirmative clinicians. Information networks of other queer and trans young people were vital in achieving nuanced understandings of where to look for healthcare and how to navigate sexual or gender-based healthcare. These information networks came through people at school, programs or groups started by non-profit organizations or LGBT health clinics, and, of course, the internet. Talking to each other was an enormous part of my focus group with 14-18 year olds, which was unsurprising given all of them signed up for this group through a presentation I did to recruit for this project at a potluck with a group of trans young people and their families hosted by a local LGBTQ non-profit. I remember walking in and immediately becoming emotional at how relaxed all of the kids seemed to be, who were in their own room separate from their families so they could talk amongst themselves. It feels like trans young people rarely have time or space to converse with one another in a setting sans the adult gaze. In our brief conversation there, young people talked to me about how much this group had changed their lives, both due to gaining connections of fellow queer and trans young people but also the connections their parents were able to make with each other. At my focus group with 14-18 year olds, a few of the participants made comments about their connections to each other that still makes me laugh:

David: We'll talk to each other and be like "this place is pretty good" or "I had a terrible experience at this place."

Jamie: We are a strong community. I love it.

#### Madison: The one stereotype that's true is that we do all know each other!

Another one of my participants, Sebastian, who was also still in high school, talked about how his gender transition process was so incredible due to his peers and older LGBTQ people he didn't even know would "throw resources at" him. He takes these resources in and then gives them to other people, creating a "big spiderweb" of knowledge. It was in his interview that his mom Valerie was present, a factor that he preferred because "she knows more about the insurance aspect of everything," despite me emphasizing the non-necessity of his knowledge of insurance. This led to a fascinating glimpse at the side of parents throughout this process and how parents can help their child through the barriers of the healthcare system to get the best care possible. I asked her about her process in supporting Sebastian through his transition, and she referenced a parental support group she joined as a primary reason for her getting resources for Sebastian and resources to support her emotional processing through his transition. One of the most interesting pieces of my interview with Sebastian and Valerie was their experience with the clinic they were at actively helping them with the insurance process ("we didn't even have to do anything, they took care of everything") and giving them resources outside of the clinic itself. The parent group was one of the most significant resources, helping both Sebastian and Valerie:

Sebastian: When we went to the clinic for the first time, they immediately gave us resources to all these places... They are good at getting parents in contact with other parents. Because if you're a parent alone, you don't have anyone to talk to about this individual experience, so them being able to have parents come together and talk about their individual experiences to ease their own nerves a little bit. Valerie: Yeah, it makes you feel less alone going through it, because it's an emotional ride for everybody I think. Then you get an idea of what to expect with your kids and recommendations if we ever needed anything. I definitely love meeting other parents because I know I'm not alone. I know that it's tough on the kids, but it's tough on the parents too.

Sebastian also noted how this support group helped him by being a source of education on trans kids that he did not have to teach his mother himself. Sebastian's doctor also told him how to get the testosterone he needed in the correct dosages if insurance decided not to cover it, as well as other alternative methods. It is incredibly important to note that Sebastian and Valerie found these amazing resources through information networks of queer and trans youth, their parents, and local LGBTQ-supportive providers. Their story is an amazing example of how providers can specifically support queer and trans youth navigating the medical system, specifically by providing resources, connections, and support as a part of their health visits.

When Western medicine fails people, many of my participants turned to "alternative" or homeopathic methods in attempts to clear their bodies of illness or to support their overall well-being. My two focus groups with queer and trans young people of color revealed how central homeopathic methods are based on their various cultural backgrounds. The homeopathic methods described in these focus groups came from information networks of family and friends who share the cultural backgrounds of each participant, namely their immediate parents. The homeopathic discussion in one group came up when almost everyone in the room exclaimed that they avoid healthcare as much as possible due to the discrimination they have faced or expect to face in healthcare settings based their various identities. Many of these young people, such as college senior Viti, made fun of their use of homeopathy, acknowledging that some of the suggestions from their parents on how to cure an illness or mysterious malady were a tad ridiculous:

We have a whole stash of plants in our basement and my mom just asks what the illness is and then goes down and gets a leaf! Like, I was home yesterday and my parents are out of town, but I was facetiming my mom and telling her what was going on with my body, and she goes: "go downstairs to the plant on the left." And I was like "okay," and I ate the leaf. Nothing's changed, but I ate the leaf! Obviously, I'm cured.

This use of parental homeopathy connects back to the theme of the significance of cultural ties that queer and trans young people of color have to their families and how they can incorporate those ties into their maturing identities.

The final primary way that queer and trans young people subverted medicinal control was strategic levels of visibility within healthcare settings themselves. Many decided for themselves when they would or would not be out, often choosing to not tell their provider about their identities whenever they felt the care did not pertain to their gender or sexual identities. Madison, from the focus group of 14-18 year olds, talked about her strategies when confronted with questions that might lead to dysphoria or unnecessary prying of her gender identity:

If whatever I'm seeing a doctor for doesn't have anything to do with me being trans, then it doesn't matter. I should be able to go to the doctor for being sick without having to tell them that I'm trans. I have my excuses that don't out me but also aren't lies, for example if they ask if I might be pregnant, then I just say that I don't have a uterus, which isn't wrong [laughs]. To be fair, I don't and I'm not saying the whole story because the whole story isn't important.

Choosing to hide their identities whenever possible was often based in wanting to avoid possibly discriminatory experiences whenever possible, however it is possible that this could be a dangerous practice in situations where doctors need to know hormonal medications these young people may be on. It is an avoidance strategy used when they decide to finally utilize healthcare due to an illness they cannot handle on their own. Queer and trans young people have, over many years of being barred from healthcare access and discriminated against by providers, have come up with incredible ways to gain medicine and healthcare that they need to support their health and well-being. Understanding them is incredible important so that providers and allies can work with those strategies and not against them, thus hopefully supporting the agency of these individuals and honoring the incredible work this community does to support themselves and those around them.

## 4.3 "He just talked to me as if I was a real person": Gaining Trust from Queer and Trans



### Young People in Healthcare Settings

**Figure 4: Trust Theme Breakdown** 

Participants reported trust in their experiences with healthcare providers in 9 sources and 51 times, the least coverage of any of the themes, despite me asking every participant to speak on their positive experiences with doctors alongside the negative. However, many participants did describe extremely positive relationships with providers and the ways these providers significantly improved their health and well-being through various trust-building techniques. Providers who had significant knowledge of LGBTQ culture and health and who normalized LGBTQ identities were some of the most significant reasons for patients feeling comfortable and able to trust their providers. Providers who participants deemed knowledgeable did things such as asking patients about their latest drag shows, knowing the dynamics of queer sex and intimate relationships, or discussing their long history of working with queer and trans young people. Normalizing identities entailed similar dynamics, but did not necessitate a deep knowledge of LGBTQ identities, instead was when providers would ask questions only relevant to the current care and not reacting to patients admitting to non-heterosexual sexual activities or non-cisgender gender identities. An

important discovery in this section is the non-necessity of doctors knowing a ton about LGBTQ issues and identities in order to be trusted by their queer and trans youth patients. In fact, the most referenced reason for trust in care providers was due active and supportive listening, in which providers asked questions and listened without judgment to patients expressing their concerns and health needs. Participants also expressed relief when providers connected them to resources such as community organizations, affirmative research, or providers more experienced in LGBTQ youth health. Thus, providers do not need to be perfectly versed in LGBTQ issues and culture in order to gain trust from their patients, although gaining at least a baseline knowledge of LGBTQ issues and identities is a significant way to create positive relationships as well. In order to gain trust from and create positive relationships with queer and trans youth, providers need to learn enough about LGBTQ identities, culture, and health issues in order to normalize patient identities as well as listen, support, and collaborate with queer and trans youth who come to them seeking healthcare.

## 4.3.1 The Effects of Active Listening & Collaboration from Care Providers

The highest levels of trust in care providers that queer and trans youth reported throughout my interviews and focus groups were when care providers would utilize active and supportive listening during their doctor's appointments. Many providers believe that due to their overwhelming work and personal pressures, they simply cannot spend the time to learn about certain specifics of LGBTQ identities and experiences. This aspect of the trust in doctors theme is so novel because it turns out that being trained in LGBTQ youth specifically may not be a complete necessity in gaining the trust of queer and trans young people. However, knowledge of LGBTQ identities and experiences is almost just as high of a theme, as I will discuss in the next section of this theme. I also discuss the subtheme of collaboration in this section due to its significance toward trust in providers despite its non-specificity to LGBTQ issues.

One of the most profound stories of trust in providers during my interviews was the story of Sebastian, a high school sophomore who I interviewed alongside his mom. Sebastian, with help of his mom Valerie, had a remarkably smooth path to medical transition, due to information networks of queer and trans young people and their parents, but also due to a psychiatrist that Sebastian initially went to for anxiety and depression. Throughout their time together, Sebastian's gender identity and gender dysphoria became a key part of their sessions. Sebastian described his gender dysphoria as a key reason for his mental health struggles, and his psychiatrist was able to help him through those things through supportive listening and connecting him to other services:

She's tried to get to know more since they [his depression, anxiety, and gender dysphoria] are all kind of connected, and she would say "obviously I'm not a professional at this," but she would listen and then she would talk to me about it and all that other stuff. Then she recommended me to Adolescent Medicine, and she was like "I would rather you have a psychiatrist who was really, really in the know about these topics rather than just me who knows a little bit about it," but I'm still seeing her so it doesn't matter [laughs].

Despite his psychiatrists' claims to not being a professional in working with LGBTQ young people, Sebastian decided to stick with her because of her capacity to listen and guide him in his various journeys regarding his gender, mental health, and beyond. Many other participants also stuck with providers for this very reason, often discussing the ways in which providers used listening, questions, and personal stories to relate and affirm to their experiences and point of view. Providers did not need to immediately launch into a perfect understanding of every aspect of what it may be like to be a queer young person, but needed to simply show interest and support in the well-being of each of the lives of these individuals. To be clear: this non-judgmental listening and support likely does not come naturally for these providers interacting with queer and trans youth; that is clear from the many stories of discrimination and disrespect from providers throughout these interviews. The providers who did reveal respect for their queer and trans young patients likely had to work through their own biases through workshops and training in working with young people and/or LGBTQ people and beyond. Queer and trans young people have experienced a lot of disrespect from doctors due to bias, and so trust in doctors came from simply feeling respected, such as in college senior Henry's story of a doctor he went to at his local LGBTQ health clinic:

He just talked to me as if I was a real person. I didn't feel like I was being talked to as a patient so much, it felt almost like a therapy thing, where I'm talking to this person, but he's also taking my blood. It felt very calm, chill, relaxed, and he was willing to answer a lot of personal questions that weren't directly health related. He was great!

Very personable conversation was incredibly important, and made queer and trans young people feel like their care providers were actively involved with their well-being. It also revealed to them that this provider understood how their experiences affected their health and well-being. These conversations also led to a feeling of providers respecting queer and trans young people through active collaboration with them regarding their healthcare, as described by recent college graduate Lester about his primary care provider:

She just asks the questions necessary to know from a medical perspective. And it's not a condescending thing, like "well you should be doing this," it's very much like "well this is all your decisions, I just care about you and your wellbeing and that's essentially what I'm here for, so let me navigate this space with you."

Trust in doctors seemed very largely dictated by care providers who show their respect for queer and trans youth through listening, personable conversation, and collaboration in their medical choices. The ability to do so likely comes from a respect for queer and trans young people's agency in their own health choices and decisions and understanding the role as care provider being one of guidance and support. Providers who receive the most trust from queer and trans young people view their experiences and thoughts as key signifiers of what care is right for them.

### **4.3.2** The Importance of LGBTQ Youth Health Literacy for All Care Providers

Half of the subthemes of what made queer and trans youth trust their care providers had to do with LGBTQ health literacy, ranging from clear advocacy for LGBTQ youth outside of provider's professional lives, to significant knowledge of LGBTQ youth experiences and health needs, and to the normalizing of LGBTQ youth identities in healthcare settings. I see these as three levels of involvement for providers, normalization being the simplest and least time consuming to train yourself and your clinic to do, to advocacy and seeking knowledge about LGBTQ youth outside of the necessities for your work being the most involved. This section also includes the importance of providers having a list of resources for LGBTQ youth and their families on hand, no matter if they usually work with this population. Each and every aspect of these themes are incredibly important in gaining the trust of queer and trans youth patients, which is a necessary step in getting them the best care as possible. This section lists out the specific ways care providers elicit trust from their queer and trans youth patients through advocacy, knowledge, and normalization of LGBTQ identities and health needs of young people.

The most referenced theme of these three subthemes was trusting doctors who knew a lot about LGBTQ youth health and culture, largely based in conversations that young people would have with their doctors during appointments. For example, the primary care physician of the college senior Sage, always asks them about their drag performances at every appointment. This not only made their relationship more personable, it also indicated to Sage the "open and accepting" nature of their provider. Another conversation between a seemingly queer doctor and college senior Henry reveals how the specific knowledge of LGBTQ providers can lead to positive trust levels from patients:

He was great, he actually talked to me about the personal stuff of sexual health, and not just like "here's what you need to do to not get an STD", like here's the realistic situations of what people do. Like, nobody's going to wear a condom during oral sex because it's weird [laughs].

Queer- and trans-health trained physicians were particularly helpful due to their abilities to affirm experiences of queer and trans young people, such as navigating their sex lives in a country that did not necessarily prepare them in sex education classes. These physicians also provided a sense of relief for queer and trans youth, who felt more relaxed in LGBTQ-specific clinics due to the knowledge of LGBTQ identities in those spaces. In their interview, Lester describes the relief he feels going to LGBTQ clinics: They are very nice, like you can kind of go into a healthcare setting and not have to think about the really invasive questions that can come with just seeing a doctor who is not necessarily well-versed in the "language."

While it was clearly important that doctors know the language of LGBTQ identities, many participants felt that it was just as important to simply normalize LGBTQ identities by not acting like treating a queer or trans young person was a huge deal. For example, when asked about sexual partners, participants appreciated their care providers who did not react in any specific way when their partners were of the same sex or transgender or if the patient explained that they did not plan to have sexual partners in their lifetime. When care is not necessarily LGBTQ-specific, queer and trans young people reported feeling more comfortable with doctors who just try to treat them as they would anyone else.

This normalization did not stop at equality of treatment, but a group of participants talked about their experiences with their doctor attempting to make LGBTQ normalization an institutional part of the clinic or health center where they practiced. One of Lester's therapists did this quite well in his appointment, not only normalizing their identity and preferences, but also attempting to spread this practice around her entire clinic:

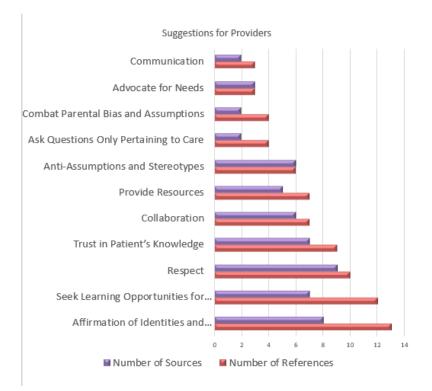
She immediately asked for pronouns, asked what you prefer to be called or be referred to as, and was upset that they didn't ask us both pronouns at the front desk! That was a really positive interaction and that was cool. My current therapist is very queer friendly and super awesome, she's a really big ally to the queer community.

In this case, normalizing also constituted simply asking all of your patients pronouns and their preferred names, a practice that led many participants to feel incredibly comfortable in a healthcare setting. Asking these questions does not require an incredible amount of knowledge of LGBTQ identities, they signify a baseline level of respect for those identities without the requirement of knowing every little nuance about them.

#### 4.3.3 Reflection

It is very important to note that this theme is the least referenced in my interviews and focus groups despite asking specifically for positive experiences with healthcare providers. Secondly, this theme came up only one time in all of my interviews and focus groups with queer and trans young people of color. This reveals the need for a radical change by individual health providers as well as health clinics to instill practices that lead queer and trans young people, especially queer and trans young people with intersecting marginalized identities such as not being white, to feel safe and secure in doctor's visits. My discussion and theme on the suggestions for providers that queer and trans young people have will address more specific changes for providers and health clinics to create a future in which queer and trans young people report overwhelming more positive than negative experiences with their health care providers.

# 4.4 "Respect is a Baseline": Queer and Trans Young People Suggest Guidelines for Their



## **Care Providers**

Figure 5: Suggestions Theme Breakdown

At the end of every interview and focus group, I asked participants directly what their suggestions for healthcare providers are. Eleven different categories came up, leading us to answer the question: what is the role of providers in queer and trans youth affirmative healthcare? Participants answered this question by stating that doctors need to affirm the identities and experiences of LGBTQ young people, respect them, and collaborate with them in healthcare settings. Providers can also be the ones to provide resources to queer and trans youth and their parents instead of forcing them into seeking these resources online or other non-medical spaces. Providers need to trust patient's knowledge about their own bodies and health needs and advocate for them across the many barriers they face in receiving healthcare. Queer and trans young people

not only have the knowledge of their own bodies, but at this age have incredible knowledge of how they can be supported in their own health by the adults who have the ability to withhold services that can support their transition into adulthood, making these suggestions even more powerful.

#### 4.4.1 Learning and Affirming the Identities and Experiences of LGBTQ Young People

Some of the most discussed suggestions for providers are ways in which they can learn about LGBTQ youth identities and experiences in order to affirm and support queer and trans youth who may come into their office. What this learning may constitute is varied per suggestion, ranging from attending official trainings on LGBTQ youth health to volunteering or interacting with queer and trans young people in a non-clinical setting to doing research on one's own time of studies on LGBTQ youth experiences. This learning also had to happen specifically before or at least not when a queer and trans young person comes out to a doctor in a clinical setting; being in the position of having to teach your doctor about the ins and outs of your identity and how it relates to your specific health needs was considered highly uncomfortable for a patient. The next step that participants suggested providers do after learning about LGBTQ youth identities, experiences, and health needs is to affirm the identities of LGBTQ youth by being inclusive of pronouns, preferred names, and all possible sexual partners. The two biggest suggestions for doctors reflect the severe lack of training for care providers in LGBTQ youth populations and the immense effects that this training can have on the health and well-being of queer and trans young people.

Asking queer and trans young people about what they meant when their suggestions primarily centered around doctors learning about LGBTQ identities and the health needs of queer and trans young people was an extremely eye-opening experience. Many disparaged against what many described as "basic PowerPoints on diversity and inclusion," providing other examples they felt were better for care providers or really anyone to empathize with and learn to care for queer and trans young people. Penelope, a college senior from my focus group with queer and trans people of color, had experiences with trainings they felt worked better than standard diversity and inclusion workshops and felt those could significantly improve providers' abilities to empathize with queer and trans young people or anyone with marginalized identities:

I work with kids, and before that we're always trained about being traumainformed and not reacting viscerally to some statements that they might say that shock us or surprise us. To some extent, while I don't think it's all "big T Trauma," there is a lot of trauma ingrained in the experience of being a woman of color or a queer person. Oftentimes these trainings aren't always helpful as on the ground experience and just messing up, but learning from that and being critically thinking about that. Honestly, I also wonder if healthcare professionals going to more panels or taking part in focus groups or listening to people sharing their experiences about things I think is something that is might be more helpful than the run-of-the-mill PowerPoint diversity trainings.

Penelope's thoughts mirrored many others throughout the interviews and focus groups I collected, in which queer and trans young people did not necessarily see the need for specific trainings entirely on LGBTQ youth. Many also saw the need for more personal ways to learn about queer and trans young people such as going to panels or listening to young people sharing their experiences in healthcare instead of simply attending a diversity PowerPoint presentation without specificity or emotions attached to the training. They also emphasized the difference between learning about queer and trans young people and actually implementing this knowledge by asking

pronouns, preferred names and genders, and sexual partners was seen as a highly important skill to know how to do in a clinical setting, as described by college junior Carmen:

And not just knowing about it, but knowing how to go about it and knowing how to approach individuals without being disrespectful. It's one thing to know what pronouns are and another to know how to use them. And some people aren't educated enough or are just ignorant, and not necessarily because they want to be, they just haven't been educated on the matter, so I think it's really important to make that available to them.

While some doctors may be trained in diversity and/or LGBTQ inclusion, there is a difference between having the knowledge and actual implementation. Many young people described specifically what this implementation would actually look like for them and how much a difference that implementation would make on their healthcare experiences. Being affirmed in their identities meant providers and staff asking pronouns, using non-gendered terms when discussing anatomy, asking for the sex of sexual partners without assuming solely heterosexual encounters, and asking for patient's preferred names for every appointment. Lack of training and subsequent lack of empathy was attributed a lot as to why queer and trans young people felt uncomfortable in many interactions with doctors. Sara, a college senior in one of the queer and trans people of color focus groups, ascribed her knowledge of this lack of training in medical school to why she does not trust care providers whenever she enters a clinical space:

I know a lot of people who are going to med school or want to go to med school, because a lot of people who are in my ethnic group go to med school, and even they don't have a lot of cultural competency before they get into med school. And then med schools don't often talk about cultural competency or things like that, or even talk about ways that doctors can be more inclusive when talking about anatomy, and that always really bothered me a lot. I think that disconnect from the fundamental education of becoming a doctor is so flawed that no wonder they are they freaking worst! You know? Because there's not good training! I think now med school curriculums are adding more but they're "more" is still not enough because I think they have cultural competency training only once a year for three. I don't know if it's actually just three hours, but it just feels like in comparison it's just this much time to really understanding actual things that would make patients more comfortable.

Simply knowing how to respectfully speak to people different from you is something that many of these young people found important for doctors to know and implement. Doctors should be able to not only respect and talk to people who are different, but also should use inclusionary language no matter if someone seems queer and/or trans or not was incredibly important for the queer and trans young people I spoke to. Gaining knowledge about present day LGBTQ youth health issues and experiences related to health and well-being should be a constant throughout every single provider's careers as well as the ability to implement this knowledge into their clinical practices.

Lastly, one of the biggest ways to implement knowledge of LGBTQ youth is giving resources to young people who come out to their doctors as a gender or sexual minority. This was incredibly pertinent to doctors who may not be specifically trained in LGBTQ health, where they did not have to be professionals in order to significantly help queer and trans young people. For example, when high school sophomore Sebastian initially came out as gender variant to his primary care physician, he noted how much better his experience could have been with even just a set of succinct resources around Pittsburgh:

I had tried to talk to my doctor about it, and I think he was kind of confused. I know that he definitely had heard about [gender variance], but he wasn't informed enough to be like "here's an outlet" or "here's this resource," he was like "no, here's a psychiatrist, and maybe she'll help you!" I think just having the doctors have the information about certain resources to give to their patients would be very helpful instead of giving them someone who does have the resources, because it could skip you a whole step that you might not even need to do.

Providing resources was a very significant suggestion because it does not require a doctor to be an expert in LGBTQ youth; simply providing resources to this population such as lists of doctors and clinics who work with queer and trans youth (note that in the story above, the psychiatrist that Sebastian's doctor sent him too was not an LGBTQ-trained provider), community organizations, and resources specifically for parents of LGBTQ children (see Appendix D for the list of resources I gave out to my participants). Sage, a college senior I interviewed, also noted the necessity of giving resources to young people who come out as LGBTQ to a health provider:

If somebody does share their identity with a healthcare provider, it would be a good idea for them to have a moment of being caring and empathetic and being like "okay, thanks for sharing, we have resources here if you feel like you need them" because sometimes people can be okay for a while, but when someone is LGBT and something happens to them, like they might be in crisis and don't have time to get into the doctor, and so they need access to these resources ASAP.

These suggestions all reveal the immense significance of providers working hard to teach themselves about LGBTQ youth health and identity formation and implementing that knowledge in clinical settings.

## 4.4.2 Respect and Combatting Biases, Assumptions, and Stereotypes

These suggestions differed from simple knowledge of LGBTQ health to asking providers to actively take time to work through their biases in order to have respect for queer and trans young people in clinical interactions. Young people also specifically asked for clinics to keep providers accountable through post-appointment surveys and taking complaints of trans- and queer-phobia very seriously. Many participants wanted providers to "simply" treat queer and trans young people with a baseline of respect and as if they were any other patient. Lester, the recent college graduate I interviewed, expressed his frustration a lot at providers with negative biases toward queer and trans people with all of the resources and guides that LGBTQ people have been creating throughout history:

Just treat us like human beings, like normal human beings, like anybody else! It's the medical field, so in my head there should not be a level of bias that I'm being spoken to with, and it's finding a way to eliminate that. Respect is a baseline... We [LGBTQ people] have to hold the responsibility to share our information and then the people who receive that information have the responsibility to utilize it and to educate other people once they've been given that education.

While it is definitely the responsibility and necessity of LGBTQ people spreading knowledge about their identities and experiences, this has been happening for 100's of years, as discussed in my literature review. It is the responsibility of providers now to take that knowledge and unpack their biases as people of American society and products of the American medical system. Participants often saw unpacking biases and assumptions as a necessity in being a health provider, as told by Avery, a working adult in my queer and trans young people of color focus group:

I feel like they have to make a personal commitment to unpacking their own shit so they can properly serve different people. Oddly enough, I've sat in for trainings for doctors a couple of times, and no matter how many slides you watch and notes you take down, that's not going to do the work for you. You have to understand "hey, this is what I'm currently thinking about sex and gender, maybe I should try to unpack that a little bit so I can serve the population that I need to serve."

This is another example of a young person disparaging against the dependence on trainings and workshops as proof of learning about LGBTQ youth. While workshops may be useful in some capacities, they don't necessarily un-do the intense biases and assumptions that providers may have due to their personal experiences or experiences in the medical field. Respect is not a simple step, rather it is gained through intense commitment to unpack societal and medical/scientific assumptions of queer and trans young people.

### 4.4.3 Trust in Patient's Knowledge, Emphasizing Collaboration, and Advocating for Needs

A very significant theme in queer and trans young people's suggestions for healthcare providers is the hope that providers will trust in their knowledge of their own bodies and their needs for sexual and gender affirmative care. This suggestion was especially prominent in my talks with young trans people who have sought gender affirmative care, especially people still in high school. In fact, the title of this these comes from a conversation between high schoolers Tim and Madison during my focus group with queer and trans people between 14-18 years old:

Tim: I think one thing is, especially for a lot of us who are going from late childhood to early adulthood who are expected to know what to do and don't actually know what to do, I think a really cool thing is treating us as adults but not expecting us to know everything. Like I know some people are going to know everything and be mad when you try to treat them as a kid, but being understanding that we are young adults but not all-knowing.

Madison: We don't totally know how the healthcare system works, but we know who we are.

This conversation is so incredibly important because it very succinctly defines the role of the care provider in gender affirmative care for young people. In this version, doctors are not the gatekeepers of healthcare, but are instead guides through the healthcare system leading their patients to places their patients want to go. Instead of forcing queer and trans young people to learn and play the chess game of the healthcare system without the help of care providers, imagine a world in which care providers act as teachers and help these patients through the complicated system of receiving gender affirmative healthcare. The graduate student I interviewed

named Beth also discussed the need for care providers to trust in their patients knowledge and strongly believes that doctors need to let go of the idea that trans patients don't truly understand the gravity of their requests for gender affirmative medical care:

Stop fucking making people go through questionnaires, just don't fucking do it. I don't know, just give people shit! No one... as far as I know, no one goes to get hormones on a fucking whim! And if they do, it's not your fucking job to tell them not to. That is the main, main thing. I think the thing that doctors need to do better is engaging patients on what they actually want help on, and finding ways to advocate for that. I've not had doctors ask me for much about what I actually want coverage and assistance with, which would be electrolysis and voice therapy. I don't know. Have a gum dispenser that just gives out hormones, that's my true suggestion. You should be able to just go up and not even have to put in a quarter, just get all the hormones you want. That is my actual solution.

The suggestions for providers from Beth, Tim, and Madison all actively counteract the idea that Jesse Singal states in his piece "When Children Say They're Trans;" while young trans patients need their doctors to help them affirm their gender, this does not mean that doctors should be thoroughly gatekeeping this care from them. Rather, doctors should be guides for queer and trans young people seeking gender affirmative care, and recognizing that the non-reversible procedures may not even be the central need for affirming a patient's gender.

Care providers can fully support the health and well-being of queer and trans youth by becoming co-conspirators and collaborators with this community. Beth wants the need for collaboration between trans patients and their doctor to be the biggest take away from her story:

I definitely think [my main suggestion is] emphasizing that it is collaborative. I think even if they don't mean to be... the context of gatekeeping is omnipresent. I think that is on them to actively dismiss those fears. Which like to me, means like, when you come in, not putting them through the ringer and asking them a shit ton of questions, just being like "okay, cool, here's the process, my goal is to help you get the healthcare you need, whether that's hormones, whether that's not hormones, and just getting the best basic healthcare period." Whatever people could need. Emphasize that, and if you have formalities you need to go through, present them as formalities and indicate the flaws. If someone doesn't know the issues that are systemic and they are just experiencing them, even if the doctor isn't putting that on them, they are going to feel it.

This collaboration also means advocating for queer and trans young people to get the healthcare they need; as a provider, you are not only a guide for the young people, but once you become knowledgeable and take on this role as "guide," then it is also your job to advocate for the health needs that these young people know they want. For example, another significant suggestion for providers that my participants had was for providers to help with navigating parents and insurance providers. College freshman Tim expressed this a lot during our focus group, in which providers avoided convincing parents without understanding how significant parental support is in trans youth getting quality affirmative healthcare:

One issue that I've had with doctors is that they're the ones with the degrees and years of training. This is what they do, but they don't seem to be, from my experience, good at convincing parents. They're just kind of like "okay, you don't get it, we'll cross that road when we get there," but it's like you're the only one here that can really convince them without me pulling out emotional guilt or whatever. Like, you're the only one with the logos here!<sup>7</sup> Like I can pull up papers and stuff, but there's only so much credibility that I have with that. Like if you could talk, it would be better, since you're the one with the academic background.

Care providers have incredible power to sway the gatekeeping efforts of parents and insurance companies in favor of queer and trans youth affirmative care needs, and my participants truly see this as a role that care providers need to take on or facilitate in their health care practices. These suggestions from queer and trans youth challenge the very framework of medical knowledge by claiming that the care provider actually may not know the best medical route for queer and trans young people. In fact, care providers have to actively collaborate and listen to LGBTQ youth in order to fully understand how to best affirm their gender and sexual medical needs. They need to be able to un-do their biases about being experts on bodies and learn to respect and listen to the knowledge that queer and trans young people already have through their own social and bodily experiences.

<sup>&</sup>lt;sup>7</sup> Earlier, Tim talked about how he only had the emotional "pathos" argument in trying to convince his parents and that doctors are the only people in the chess game equation who can convince parents with facts and reason aka a "logos" argument.

#### 5.0 Discussion

## **5.1 A New Role for Healthcare Providers**

This research reveals that the new role of healthcare providers envisioned by queer and trans youth is being a guide through the borders and barriers to sexual and gender affirmative healthcare. Instead of acting as another barrier due to gatekeeping healthcare, LGBTQ youth need their providers to help them through the various systems that work to block them from receiving care to affirm their identities. This role has been one that has been suggested by LGBTQ activists for many years, and the young people of today are still echoing their cries for support from years past. To create adequate healthcare for queer and trans youth, we can begin with creating relationships between this community and their healthcare providers that spawn collaboration, support, advocacy, and much more.

### 5.2 Healthcare as a Chess Game

A significant finding of this study is the framing of queer and trans youth understanding healthcare access as a chess game they must learn to play in order to get gender affirming medical care. Even at the age of 15, the youngest of my participants, every person I talked to told me about how they not only understood the perceptions their healthcare providers had of a queer or trans young person who deserves medical care, but also specifically how to act according to those assumptions in order to get that care. This game has been played throughout time, ever since medical care for sex, gender, and sexuality became possible. This finding reflects how little has changed from the start of queer and trans medicine as well as how much these young people understand about their situatedness in the healthcare system whether they knew the history or not. This finding also reflects how much this community still has to rely on networks outside of healthcare in order to get the care that reflects their gender and sexuality needs, which leads to distrust in healthcare and ultimately deciding not to try to access certain medical methods for affirming their identities.

### **5.3 Framing Queer and Trans Youth as Experts**

This study presumes that queer and trans young people are the penultimate experts on their own bodies, minds, and identities, and they know the best ways to meet their needs. The questions that many cisgender, heterosexual adults have been asking about the best tactics for affirmative healthcare are already in the minds of the young people who are at the receiving end. By accepting that LGBTQ youth are the ultimate experts of their own bodies and health needs, practitioners can significantly help this population. Situating marginalized populations as experts on their own lives and bodies is a framework for any research trying to understand how to provide better healthcare for that group. While this framework has been used by many qualitative social scientific work, this framework needs to be implemented more by medical research as well as journalistic writings on these topics in order to fully honor the agency of marginalized individuals. This framework also needs to be applied to work with children, a population whose parents are too often considered the experts on their children's experiences and needs.

#### **5.4 Limitations**

The limits of this study include the limitations of my recruitment abilities, my positionality as a researcher, and my need to record and take notes during my narrative collection. While I tried to recruit namely through community organizations that work with LGBTQ people of color due to my analysis of how race plays into experiences of queer and trans youth, due to still recruiting through my predominantly white college campus and surrounding areas many of my initial participants interested in interviews were white, college-aged individuals. It was not until I decided to specify my focus groups to be with queer and trans people of color and queer and trans youth between 14-18 years old that I was able to recruit people from those communities. I also was unable to do work with youth under 14 due to IRB limitations, which could have led to a different analysis of knowledge of the healthcare system and suggestions for providers. Recruiting for this project also only reached people who had access to community organizations or college campuses, which leaves out plenty of queer and trans individuals without parental or financial support. Secondly, my position as a researcher at a huge university, a white person, and as someone who is cisgender-passing could have led participants to tailor their answers toward my expectations as I learned this community so often feels like they have to do when speaking to people from dominant groups. My whiteness and position as a researcher of the University of Pittsburgh also likely hindered the comfort of people of color to join this research, which is likely why most of the people of color who did participate in this research had a general idea of who I was through other projects I had done or through friends of mine. Due to my positionality, many people felt they needed verification as to who I am in terms of my identities and allyship abilities and the exact reasons I wanted to do this project. Thus, if some people were not able to get this verification through other people who knew me, then many individuals may have decided not to participate in this project.

Finally, my need to record and transcribe all of my interviews could have dissuaded people from this research due to wanting their identities to remain invisible to the public or large institutions such as the University of Pittsburgh.

#### 5.5 Policy & Personal Suggestions

Based on this research and on the suggestions that my participants gave, my policy suggestions are based in how healthcare systems, such as hospitals and clinics, can make queer and trans young people feel more comfortable and agents of their own bodies in healthcare settings as well as the individual ways in which providers can help this population in receiving adequate and affirmative healthcare. The first institutional policy I suggest is that every single hospital, clinic, and care center who works with queer and trans young people need a funded consumer advisory board of queer and trans young people of different ages, races, and cultural backgrounds. My research reveals how much this population already knows about what they need from their healthcare providers and they should be listened to and compensated for relaying that information to various healthcare institutions. Hospitals and clinics should also have their own continuing education credits (outside of the continuing education credits required of most care providers) requiring doctors to go to community organizations and community events who aim to serve queer and trans young people, namely QT youth of color. Health clinics and hospitals should also be making official connections with these community organizations to sponsor or create information networks for parents of queer and trans youth, providers who work with queer and trans youth, and queer and trans young people themselves for each of these groups to get in contact with each other. By working with community partners who have been advocating for the health rights of this

population for years, hospital staff will both learn the nuances of QT youth healthcare and will be able to foster connections for the people they serve.

A key piece of this research is the diverse ways in which doctors approach working with queer and trans youth, often differing from the standards of care created by W-PATH and the Human Rights Coalition or standards created by lesser-known LGBTQ organizers. Because the W-PATH Standards of Care still perpetuates incredible amounts of non-affirmative healthcare such as the focus on mental healthcare before physical transition, emphasis on parental permission for childhood gender identity medical assistance, and continued scrutiny by health providers of a child's proclaimed gender identity - I suggest hospitals and clinics create their own standards of care with LGBTQ activists and young consumers until W-PATH can create standards that are actually affirmative of young people. I suggest that hospitals and clinics should have these standards of care on hand and have this readily available for patients. This will ensure that patients know the policies and standards for this clinic in working with this population, so the patients can understand where providers may be not giving them the best standards of care. These standards should require doctors to ask for pronouns and preferred names for all of their patients, and to use non-gendered anatomical terms and terms for sexual partners. They also should specify that doctors do not assume anything about a patient's relationship with their family or parents, instead asking questions about these relationships only when relevant or if there is a concern of parents controlling the patient's healthcare choices. If a providers strays from these standards in a significant way, such as making harmful comments or assuming harmful stereotypes about a patient, there needs to be an accountability system for patients to report these doctors, and clear steps that will be taken when a doctor is reported for differing from these standards of care. Each of these policies will hopefully make queer and trans youth feel more respected and comfortable

in healthcare settings and keep care providers more accountable and educated when working with this community.

It is on both providers and their institutions to make a safe space for queer and trans young people, and providers can create much better experiences for these young people even when these various institutions may fail. Thus, it is incredibly important that care providers learn the ways in which they can support these young people even when their institutions may not mandate this education, such as asking for pronouns and preferred names as well as the effects of hormones with various medications. It is also incredibly important for providers to advocate for LGBTQ-positive policies in every institution they work for in order to facilitate respect and inclusion from future providers and administrators regarding LGBTQ young people.

#### **5.6 Implications for Future Research**

This research only scratches the surface of the context of queer and trans youth healthcare today. Taking an historical approach to this work reveals how little we know about this specific population's history and the guides that do not center queer and trans young people continue to erase their voices from this history. Thus, so much more dynamic and community-based work with this population needs to be done adequately to fill those gaps. There are so many more questions that research can explore in the future, ones I personally also hope to continue in my researching future. Larger studies of QT young people should take place, getting even more nuances and findings due to a larger population. I also would hope more research looks at the populations with intersecting identities as I did in terms of their views of healthcare, such as only interviewing queer and trans youth of color or trans youth under the age of 18 years old. My focus groups with these

populations revealed how different their experiences are from the general population of queer and trans young people aged 14-26. For example, in my two focus groups with queer and trans young people of color, there seemed to be a higher amount of distrust and avoidance of all healthcare settings as much as possible as well as higher fears of a lack of familial and cultural support for their sexual and gender identities. My focus group with queer and trans young people aged 14-18 years old revealed that this population seems to feel much more constrained by their parents and perceptions from healthcare providers than their older counterparts. For this reason, I also would want to study even younger populations of queer and trans young people, who may not be in contact with the healthcare system yet regarding their identities, but may be thinking about those possibilities in the future.

This work likely would have been much different if I had only worked with people exclusively over or exclusively over 18 as well as if I had worked with children before they reached puberty. I would love to see more work who works with any or all of these populations exclusively (see the Gender Moxie Project by Dr. Sally Campbell Galman) because queer and trans populations under 18 do interact with the medical system and it would be incredibly interesting to see the experiences of young queer and trans children in medicine versus my population. Another aspect that was interesting in this age group is the generational differences between people still in high school or recently out of high school and my participants who had been in college or post-graduation for a few years. The generation gap is set right in the 1995-1997 birth year range, which marks a staunch line between my 14-20 year old participants and by 21-26 year old participants. Thus, more research could be done on the differences between these generations and their experiences with healthcare regarding their sexuality, gender, age, and race.

Future research should also study more about the accessibility of queer and trans youth healthcare, for even if the majority of healthcare for QT youth is affirmative, how can as many young people as possible access it? This research could study more about the ins and outs of how insurance providers cover this healthcare and the processes to get coverage if it is not initially available. Research could also look more at how to facilitate parental support in healthcare settings specifically by interviewing parents of queer and trans young people. I also would love to see research that attempts to understand the care provider side of the equation of QT youth healthcare, to understand what these providers feel they need to best serve this community.

Ultimately, this research found a rich source of knowledge in these groups of young people. Future researchers and healthcare providers need to seek out even more narratives and thoughts from queer and trans young people regarding the healthcare they envision for themselves and their community to create a brighter future for the medical field.

#### 6.0 Conclusion

My research with these queer and trans young people taught me how passionate this community is in protecting their peers and do so through education, emotional support, and connecting each other to resources, even when institutions leave them behind. I met an incredible amount of people already doing the work of trying to make healthcare institutions take care of some of their most vulnerable populations, such as Garden of Peace Project and the Trans Buddy Program at the Adolescent & Young Adult Health Division at the Children's Hospital of Pittsburgh. Namely, though, I met an incredible group of queer and trans young people passionate about getting their stories out into the world to create a better future for the generations after them. Although it was devastating to hear some of the stories from my participants, their stories, and the many others I hear through my own community information networks, motivate me to continue to push large institutions such as the healthcare system to do right by this community. I hope these stories and the ones you will hopefully continue to seek after reading this thesis will push you to do the same.

#### **Appendix A: Semi-Structured Interview Guide**

1. Do you have any stories that come to mind when you think about your relationships and experiences with doctors and health care providers regarding your sexual and/or gender identity?

a. How did you feel interacting with this person?

- 2. What is a time where you felt comfortable talking to a care provider?
  - a. What did the provider do to make you feel this way?
  - b. What are some similarities between experiences with providers that made you feel comfortable?
- 3. What is a time where you felt uncomfortable talking to a care provider?
  - a. What did the provider do to make you feel this way?
  - b. What are some similarities between experiences with providers that made you feel uncomfortable?
- 4. Tell me about a time where you have talked to a care provider about your identity.

a. *How did they react?* 

5. If you have never talked to a healthcare provider about your sexual or gender identity, tell me about a time when you talked to a mentor/non-family member/teacher/etc. about your identity.

a. How did that person make you feel safe to talk?

### Appendix B: Semi-Structured Focus Group with 14-18 Year Olds Guide

- 1. What are your immediate thoughts, feelings, or stories that come to mind when you reflect on your relationships with healthcare providers?
- 2. Do you feel that you are treated differently than non-queer or trans young people by care providers?
  - a. Why do you feel this way?
- 3. What are your concerns about the transition from child healthcare to adult healthcare? a. Are you going through it now?
  - b. What are your thoughts and reflections on this process?
- 4. How do you think your age has affected your ability to feel comfortable with providers?
- 5. Are you open about being queer and/or trans with providers? Why or why not?
- 6. In your opinions, what can healthcare providers and hospitals do to make your health visits better or more comfortable?

### Appendix C: Semi-Structured Focus Group with QTPOC Guide

- 1. What are your immediate thoughts, feelings, or stories that come to mind when you reflect on your relationships with healthcare providers?
- 2. Do you feel that you are treated differently than non-queer and trans young people by care providers?
  - a. What makes you feel this way?
- 3. Do you feel that you are treated differently than White queer and trans young people by healthcare providers?

a. What makes you feel this way?

4. Do you perceive your race or ethnicity making it harder for you to be "out" to providers?

a. Why or why not?

- 5. Are you open about being queer and/or trans with providers? Why or why not?
- 6. In your opinions, what can healthcare providers and hospitals do to make your health visits better or more comfortable?

## **Appendix D: Resource Guide for Queer and Trans Youth Participants**

# **Resources for Queer and Trans Youth Compiled by Kate Eldridge, Dreams of Hope, and Garden of Peace Project**

## Southwestern PA LGBTQA+ & Supportive Organizations

Pittsburgh Equality Center (formerly GLCC) www.pghequalitycenter.org/ 412-422-0114 Provides LCBT individuals, their families

Provides LGBT individuals, their families, and supporters with resources and opportunities to promote visibility, understanding, and equality within the LGBT communities and the community at large through education, social support, networking, and advocacy.

Dreams of hope www.dreamsofhope.org/ 412-361-2065

Through the power of the arts, Dreams of Hope provides the region's lesbian, gay, bisexual, transgender, queer, questioning, asexual, and allied (LGBTQA+) youth a welcoming environment to grow in confidence, express themselves, and develop as leaders. Their creative contributions educate audiences, build awareness, and increase acceptance.

PFLAG Pittsburgh www.pflagpgh.org/ 412-833-4556

Promotes the health and well-being of LGBT persons, their families, and friends through: support, to cope with an adverse society; education, to enlighten an ill-informed public; and advocacy, to end discrimination and to secure equal civil rights.

Garden of Peace Project www.gardenofpeaceproject.org/ https://www.gardenofpeaceproject.org/qtpoc-resource-guide 412-879-0477 Encourages community-building, community-restoration, outreach, spiritual growth, increased self-awareness, conscious mindfulness, social justice, and informed research.

Initiative for Transgender Youth http://transyouthleaders.blogspot.com/

Positively impacts community life through professional and leadership development of transgender youth.

Project Silk https://chscorp.org/project-silk 412.532.2123 810 Penn Avenue, 8th Floor A space for black and Latino LGBT community.

Allies for Health + Wellbeing (formerly PATF) https://alliespgh.org/ 888-204-8821 Supports and empowers individuals living with HIV/AIDS and prevents the spread of infection.

Metro Family Practice https://metrocommunityhealthcenter.org/ 412-247-2310 Serves the un-insured, under-insured, HIV positive, and the GLBT residents of the region. Offers health care to all people, at every stage of life, without regard to their ability to pay. Cares for the whole person in a safe and respectful setting

Adolescent Medicine Clinic

http://www.chp.edu/our-services/aya-medicine

http://www.chp.edu/our-services/aya-medicine/gender-development

## 412-692-5325

Improves the health and well being of youth through research to increase understanding of disparities in adolescent health, promote adolescent health equity, and improve adolescent health outcomes. Provides accessible health care services for adolescents in the context of their family, culture and community. Check out their gender development program, one of the only gender affirming programs for youth in the US.

Carnegie Library Teen GSA https://www.carnegielibrary.org/events/?event-series-id=311 412-622-3114 This bi-monthly group is for all LGBTQ and straight teenagers who want to support each other and make new friends!

Andy Warhol Museum https://www.warhol.org/teens/ 412-237-8356 Works with small groups of young people to foster leadership with creative skills and offers relevant programming to a teen audience including queer youth meetings, fashion shows, and zine making.

# National LGBTQ Organizations

National LGBTQ Task Force

http://www.thetaskforce.org/

Creates change by building LGBT political power from the ground up, bolstering the strength of local LGBT activism in rural enclaves, small towns, and cities nationwide.

ACLU-American Civil Liberties Union, LGBT and AIDS Projects

www.aclu.org/issues/lgbt-rights

Works for an America free of discrimination based on sexual orientation and gender identity, where LGBT people can live openly, where our identities, relationships and families are respected, and where there is fair treatment on the job, in schools, housing, public places, health care, and government programs.

Lambda Legal Defense and Education Fund

www.lambdalegal.org

Works to achieve full recognition of the civil rights of LGBT people and those with HIV through impact litigation, education, and public policy work.

National Center for Transgender Equality

https://transequality.org/

Dedicated to advancing the equality of transgender people through advocacy, collaboration, and empowerment.

Transgender Law Center https://transgenderlawcenter.org/ Works to change law, policy, and attitudes so that all people can live saf

Works to change law, policy, and attitudes so that all people can live safely, authentically, and free from discrimination regardless of their gender identity or expression.

ISNA–Intersex Society of North America www. http://isna.org/

Devoted to systemic change to end shame, secrecy, and unwanted genital surgeries for people born with an anatomy that someone decided is not standard for male or female.

GLAAD–Gay & Lesbian Alliance Against Defamation www.glaad.org/

Works directly with news media, entertainment media, cultural institutions, and social media to lead the conversation for LGBT equality and changing the culture.

PYTA–Pride Youth Theater Alliance

www.prideyouththeateralliance.org/

Connects and supports queer youth theater organizations, programs, and professionals committed to empowering lesbian, gay, bisexual, transgender, queer, intersex, and allied (LGBTQIA) youth in North America.

Trevor Project www.thetrevorproject.org/ Provides crisis intervention and suicide prevention services to LGBTQ young people ages 13-24.

**Appendix E: Flyer for Interview Recruitment** 



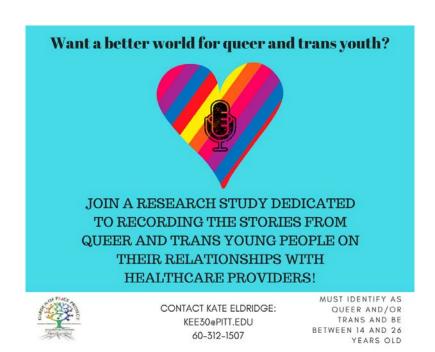
JOIN A RESEARCH STUDY DEDICATED TO RECORDING THE STORIES FROM QUEER AND TRANS YOUNG PEOPLE ON THEIR RELATIONSHIPS WITH HEALTHCARE PROVIDERS

			MUST IDENTIFY AS QUEER AND/OR TRANS AND BE BETWEEN 14 AND 26 YEARS OLD				
Kate Eldridge	Kate Eldridge	Kate Eldridge	Kate Eldridge	Kate Eldridge	Kate Eldridge	Kate Eldridge	Kate Eldridge
kee30@pitt.edu	kee30@pitt.edu	kee30@pitt.edu	kee30@pitt.edu	kee30@pitt.edu	kee30@pitt.edu	kee30@pitt.edu	kee30@pitt.edu
610-312-1507	610-312-1507	610-312-1507	610-312-1507	610-312-1507	610-312-1507	610-312-1507	610-312-1507

## **Appendix F: Focus Group Flyer**



# Appendix G: Social Media Recruitment Banner



### **Appendix H: Email to Interested Participants**

Hello! Thank you for your interest in my research project. My research is an IRB-approved interview- and focus group-based collection of stories and narratives from queer and trans youth about their experiences with healthcare providers. This research came out of an extensive literature review, in which I noticed a severe lack of research on this topic. I plan to use the data from these interviews to inform a presentation and final thesis to be presented to UPMC healthcare providers to try to facilitate positive relationships between queer and trans youth and their healthcare providers. I am asking people to participate who are identify as queer and/or trans and are in between the ages of 14 and 26 years old.

I would love to schedule an interview if this study interests you! The interview should take between one and three hours and will start and end on the day it is scheduled. It will take place wherever you feels comfortable. Suggested locations are the conference room in the UPMC Adolescent & Young Adult Health Clinic or in a University of Pittsburgh conference room. You will be compensated \$20 for your participation in this study.

I will be starting interviews on September 10th and will likely end around October 17th.

Do you have any more questions for me? Again, thank you so much for reaching out.

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