







# COMPREHENSIVE CARE CLINICS FOR TRANSGENDER & NON-BINARY YOUTH:

CONSIDERATIONS AND BEST PRACTICES



# **Comprehensive Care Clinics for Transgender** and Non-Binary Youth: Considerations and Best Practices

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# **FOREWORD**

Dear colleagues,

To provide the best care for all young people, we need to understand the needs of all of our patients and their families – and find innovative ways to respond to those needs. This guide provides advice and best practices for clinics and hospital systems to promote the health and well-being of transgender and non-binary youth.

This guide has important insights from many nationally recognized experts, including my colleagues at Children's Hospital of Philadelphia. Our Gender and Sexuality Development Clinic has cared for hundreds of patients from all over the world and our clinicians and administrators have collaborated with many other hospitals that are developing their own youth gender clinics. This work is a testament to the importance of sharing ideas and solutions to create the best experience for young people and their families.

We know that all patients have better outcomes when they receive personalized, culturally competent care. We also know that we have much to learn from each other. Whether you want to create a new clinic for transgender and non-binary youth or expand an existing one, this guide has the advice and resources you need from colleagues who share your goal of providing the very best care for all young people.

Madeline Bell President and CEO Children's Hospital of Philadelphia

# **EDITOR'S PREFACE**

Like the many advisors to this guide, I too was drawn to the care of transgender and non-binary youth. Caring for these youth in many ways is no different than caring for youth in general – they all thrive on being treated with respect, love, and most importantly, unconditional acceptance for who they are. But learning the nuances of the clinical, social and ethical concerns related to gender care was not something that I encountered in my training. Fortunately for me and other providers, there are an ever-growing number of professional and educational opportunities available today to expand our knowledge and expertise to better serve the needs of transgender and non-binary youth. What has been missing, however, is an operational guide or blueprint showing how to take an idea, like creating a youth gender clinic, and bring it to fruition.

That is why this guide was created.

The guide's advisors and contributors come from a variety of backgrounds, training and institutional structures. Many are health professionals who have had success in their communities improving the health and access to health services for transgender and non-binary youth. In sharing their stories and experiences, the authors demonstrate that there is no "one-size-fits-all" approach to creating a youth gender clinic. Instead, they share a common narrative of listening and responding to their communities, utilizing available resources, garnering institutional buy-in and support, and ultimately developing new programs.

As you read this guide, bear in mind some general principles which will be helpful in your overall planning:

- This guide is meant to be scalable and customizable to local community needs.
- General principles of diversity and inclusion apply in creating health services, including:
  - O Hiring diverse staff including sexual and gender minority people.
  - O Assessing the needs of the local gender diverse community, with a particular focus on transgender and non-binary youth culture and services.
  - O Developing opportunities for transgender and non-binary youth and their families to contribute to the health service in an advisory role.
  - O Being sensitive to the intersectionality of gender identity, sexual orientation, race, ethnicity, age and privilege when discussing and planning services and programs for transgender and non-binary youth of color.
  - O Adopting policies and practices espoused in the **Healthcare Equality Index**.

I hope you will find this guide a useful tool to care for transgender and non-binary youth in your community. Together, we can better care for all our young people.

Henry Ng, M.D., M.P.H.

### INTRODUCTION

ver the past few years, more of us have heard, read stories about, or know transgender and non-binary\* youth.\*\* Similarly, healthcare providers across various specialties have seen an increase in young people recognizing that their sex assigned at birth does not match the gender



they know themselves to be. Acknowledging this increasing awareness, clinicians are recognizing the medical and psychological needs of transgender and non-binary youth and are seeking ways to care for them and their families.

Youth gender clinics that offer transgender and non-binary young people access to comprehensive, multidisciplinary clinical care have begun to emerge over the past decade. The first clinic of this kind in the United States was started at Boston Children's Hospital in 2007 by Dr. Norman Spack. Youth gender clinics typically combine providers from different specialties to meet the varied physical and mental health needs of transgender and non-binary youth and offer or connect them to an array of other services, such as support groups, playgroups and legal services.

In early 2015, the HRC Foundation created an online map of youth gender clinics as part of a collection of resources for transgender and non-binary youth and their families. The original map featured 32 clinics in the United States. This number has grown significantly over the past four



years as the increasing demand led more and more specialized clinics to open. The map now includes over 50 clinics and there are many more not on the map or that are in development. Demand for this resource was high. Hundreds of young people, parents and healthcare providers accessed it each month, hoping to learn of a clinic near them. In late 2015, the HRC Foundation conducted a survey of youth gender clinics and found that half of the programs dedicated to transgender and non-binary youth had opened within the past three years.

While the term "transgender" is inclusive of non-binary people, this publication intentionally uses "transgender and non-binary" to ensure non-binary people are acknowledged and considered.

In this publication, the term youth is used to refer to people who have not reached adulthood, including children and adolescents.

Since 2015, the HRC Foundation has worked closely with advisors from these clinics to develop more resources for transgender and non-binary youth and the adults in their lives. The HRC Foundation's publication Supporting and Caring for Transgender Children — co-released with the American Academy of Pediatrics and the American College of Osteopathic Pediatricians — provides helpful background on transgender and non-binary youth, including information from medical and education experts, myths about gender transition in childhood and approaches to gender-affirming care. While this guide includes some overlapping information, it assumes the reader has a preliminary understanding of transgender and non-binary youth and should be used in conjunction with the earlier publication. Here, we focus instead on the institutions being built to care for transgender and non-binary youth — youth gender clinics — and cover some considerations for health-care providers and administrators setting up their own clinics.

#### **Evolution of a Youth Gender Clinic**

In February 2012, Dr. Ximena Lopez, a pediatric endocrinologist in Dallas, received a referral for a 9-year-old child who had been assigned female at birth but identified as a boy. Dr. Lopez had no experience treating transgender patients, but she had been exposed to the pioneering work of Dr. Norman Spack while doing her pediatric endocrinology fellowship in Boston. She accepted the referral and saw the patient and his family.

During the first visit, Dr. Lopez was incredibly moved by the desperation of the parents. For many years, they denied their son's gender identity and attempted to help him "fit in his own body," but he struggled with depression and enrolled in psychotherapy. When he was 7, they finally accepted him

"If [health providers] care for [transgender] patients, they'll earn the best, most compliant patients. Because they'll never miss an appointment, they'll take their meds... **They're the most grateful patients** and families. So as a physician, that fulfills your mission. That fulfills why you started this profession."

**Dr. Ximena Lopez** 

as a boy, allowed him to socially transition and renamed him Evan.

Evan began feeling better living as a boy, but at age 9 started developing breasts that he said he wanted to cut off. He also said he was thinking about dying. His

mother searched for an answer for her son and learned about medication that could delay puberty. She called at least 100 endocrinologists and asked them to treat her son. They all turned her away – until Dr. Lopez. Dr. Lopez initially offered to refer the family to Dr. Spack in Boston since she had not previously treated a transgender child, but traveling back and forth to Boston was not financially viable for the family. Evan's mother told Dr. Lopez, "I will do anything for the mental health of my child and I don't mind if this is the first patient that you treat."

Dr. Lopez began searching for a mental health provider who would collaborate with her. She was surprised to find that there were no local psychologists or psychiatrists with experience seeing transgender youth, so she was forced to send Evan to a psychiatrist four hours away.

Evan's parents referred other families to Dr. Lopez, and the number of transgender children she treated began to grow. It didn't take long for Dr. Lopez to see that there was a tremendous need for



both medical and mental health care as well as social support for these patients and their families. She began to consider building a multidisciplinary program where Evan and other patients like him could access all the care they needed under one roof – and where doctors from many different disciplines could easily interact and consult with one another for the better care of their patients.

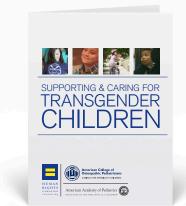
Dr. Lopez's manager and the hospital administration at Children's Medical Center Dallas (now Children's Health) supported the idea and she found passionate staff who wanted to join the program. A group of providers travelled to Boston to receive direct training from Dr. Spack's team. In fall 2013, they started seeing patients and officially opened a youth gender clinic the next year. The GENder Education and Care Interdisciplinary Support program, known as GENECIS, brings together endocrinologists, adolescent medicine specialists, psychologists, psychiatrists and social workers to provide access to gender-affirming medical care and to meet the psychological health and emotional needs of the youth they serve. The clinic that Evan inspired now serves more than 400 patients and is the only youth gender clinic in the Southwest.

#### **Purpose of this Guide**

Many youth gender clinics share an origin story similar to GENECIS: a provider or small group of providers start to see the need as one patient turns into many. The need for multidisciplinary care leads to the development of a program – often referred to as a youth gender clinic – to support these patients.

This guide is meant to provide a helpful starting place for providers and organizations interested in creating youth gender clinics for transgender and non-binary young people. It includes information on how youth gender clinics support the management of social, medical and surgical affirmation, as well as how to help families navigate their children's journey. The resources and information included will also be helpful to healthcare providers who are not gender specialists but seek to create a more gender-affirming practice.

Information was gathered from a HRC Foundation survey of existing programs and from interviews with clinic leaders and caregivers, current literature, established protocols and standards of care. Together, these resources provide readers with a sense of how clinics are operating today.



This guide should be used in conjunction with the HRC Foundation's resource "Supporting & Caring for Transgender Children" that includes medical and education expert opinion on why gender-affirming care is the right and necessary approach.

Available at: hrc.im/supportingtranschildren

#### **BACKGROUND**

#### **Gender-Affirming Care for Transgender and Non-Binary Youth**

While scientists and doctors aren't yet sure of the exact reasons some youth are transgender or non-binary and others are not, the vast majority of experts – including the American Academy of Pediatrics – believes that gender-affirming care is the right approach for these young people.<sup>1</sup>

What this care looks like can differ significantly from patient to patient, but one thing is common: gender-affirming care follows the young person's lead and does not restrict them from expressing their gender. Instead, mental health providers and medical professionals work with the young person to affirm their identities. This care ranges from a therapist working with a gender-expansive young person on how to deal with bullying, to a medical provider working with a transgender teen on how to administer hormones. While not all transgender and non-binary youth transition – socially, medically and/or legally – all will experience social barriers and challenges. Comprehensive, affirming care provided by a multidisciplinary team can be a potentially life-saving approach regardless of the patient's path.

In fact, the American Psychological Association has issued guidelines encouraging psychologists to work with other healthcare providers to coordinate the care of transgender and non-binary young people. Ultimately, clinics that bring in a range of providers who can coordinate care for these young people are simply following best practices in pediatric and psychological care.

#### **Barriers to Health Care for Transgender and Non-Binary Youth**

Transgender and non-binary youth are underserved in the medical and mental health community and face numerous health disparities as well as discrimination.<sup>2</sup> The lack of knowledge, awareness and skills in providing transgender and non-binary care among providers can create barriers to

"Transgender youth and transgender people—they're everywhere. We see our patients come from all walks of life: from urban areas, from suburban areas, from rural areas—all over."

**Dr. Henry Ng, M.D., M.P.H.**, Internist-Pediatrician, Ohio

health care within the medical community at large.³ A 2015 study of transgender adults found that 24 percent of the 27,715 respondents had to teach their medical provider about transgender care.⁴ While this was a survey of adults, families of transgender and non-binary youth similarly report having to educate their children's providers about appropriate care.

These barriers continue to exist even though evidence suggests that gender-affirming treatment is safe, effective and can improve the overall health and well-being of patients. Youth who do not receive affirming medical and mental health care are at higher risk for substance abuse, depression, homelessness, HIV and suicide. A 2016 study revealed that as many as 30 percent of transgender youth attempt suicide at least once in their lifetime and 42 percent report self-harm. Unfortunately, many youth are not seeking the care that they need; one study found that only 9 percent of gender-expansive youth had come out about their gender identity to their doctors or other healthcare providers.

Families in rural and/or ethnic minority communities have even more limited access to care and acceptance from providers. Primary care physicians are often the only providers available to treat transgender and non-binary youth in these communities and they may not have the specialized knowledge, systems in place, or resources to provide necessary psychological and medical care. For providers in rural settings with limited access to training opportunities, technologies such as video/webinars can be used to supplement their knowledge base. 10

#### **Evolving Policies and Stances on Gender Affirmation**

In the last 10 years, many medical and mental health organizations have established position statements and guidelines that address the need for competent and comprehensive care for transgender and non-binary youth. As noted earlier, the American Academy of Pediatrics endorses gender-affirming care<sup>11</sup> and the American Psychological Association issued guidelines calling for coordinated care among providers. Healthcare providers should be aware of the social, psychological, medical and legal needs of the transgender and gender-nonconforming population.<sup>12</sup> To address the many aspects of transgender and non-binary care, multiple disciplines and outside resources will be required to provide comprehensive services. When possible, bringing these disciplines together under one roof in a coordinated effort will provide the best quality of care for young people and their families.

Another area where health professional societies and state legislatures have taken a strong stance is the topic of conversion therapy. Some youth and families may be vulnerable to claims that specific therapies can change one's sexual orientation or gender identity. These treatments, known as conversion therapy, are ineffective, cause psychological harm and have been <u>denounced by multiple national health professional societies</u>. In addition,19 states and the District of Columbia have passed legislation protecting youth under age 18 from receiving conversion therapy. Clinicians should be sensitive that patients and families may have considered or experienced conversion therapy and should be prepared to address their resultant psychosocial needs.

#### **GENDER CLINIC MODELS AND SERVICES**

In fall 2015, the HRC Foundation conducted a survey of youth gender clinics to learn more about their growth and practices. Invitations to participate in the survey were sent to 41 youth gender clinics operating in the United States. Twenty-six clinics – or 63 percent – responded to the survey. In the section that follows, we draw upon these results as well as further interviews with

"At our new duty station in Maryland, our local military hospital provides AMAZING comprehensive transgender-related healthcare. It has made all the difference in our lives, to see Blue finally be able to just be a kid and not worry about access to healthcare."

Jessica G.,

mother of a transgender daughter

providers to provide a sense of how youth gender clinics are typically structured and staffed.

# Hospitals, Clinics and Private Practices

While many youth gender clinics are housed in a hospital or an affiliated clinic, these programs exist in a range of different environments, including community health centers, and group and private practices.

#### **Clinic and Staffing Structures**

The treatment of transgender and non-binary young people is not limited to one specific specialty. Multidisciplinary teams of pediatricians, adolescent medicine, Med/Peds physicians, family practitioners, pediatric endocrinologists, pediatric gynecologists, nurse practitioners and social workers provide invaluable care for these patients.

#### THE GENDER WELLNESS CENTER, ONEONTA, NY

Some gender clinics are planned and some happen by accident. In 2007, a transgender man called Dr. Carolyn Wolf-Gould's family practice in Oneonta, New York, asking if she could see him for primary care and to refill his testosterone prescription. She told the man she could not help him as she did not have any training in the field, but he persisted and asked if she'd be willing to learn. She agreed and visited the website he recommended: The World Professional Association for Transgender Health. There, she found clinical information and other professionals who were willing to mentor her. Over the next few years, more transgender adults sought care in Dr. Wolf-Gould's office and she developed the necessary skills to provide trans affirming care as part of her primary care practice.

In 2012, she met Arlene Lev, LCSW-R, CASAC, a therapist working an hour away who had over 20 years of experience working with transgender clients. Arlene invited her to participate in her office's clinical supervision sessions, where Dr. Wolf-Gould learned cultural competency skills and how to provide collaborative care alongside mental health providers. Arlene's office cared for gender-expansive youth but lacked a medical provider for services. They asked Dr. Wolf-Gould to acquire the skills for care of gender expansive children and adolescents and began referring their patients to Oneonta.

Dr. Wolf-Gould's practice was based in a rural, community hospital in a small town and lacked the resources of large academic centers. However, because of the scarcity of transgender resources in upstate New York, the number of patients seeking care grew quickly and many traveled hours to see her. To accommodate the increasing demand for services, Dr. Wolf-Gould reached out to local mental health providers, other medical partners and surgeons who all pursued specialized training and began to offer additional services.

By 2016, Dr. Wolf-Gould had served over 350 transgender patients and recognized the need to develop a plan to meet the exponential growth in demand for services. She renamed her practice The Gender Wellness Center at Susquehanna Family Practice and received a Robert Wood Johnson Foundation grant to create a rural-based center of excellence in transgender health. At this time, she and her team are exploring how to create a sustainable, rural-based program for the provision of excellence in medical care, surgical care, mental health care, advocacy, education and research for transgender people in their region.

A third of the patients at the Gender Wellness Center are age 21 or younger and the team of multidisciplinary providers has advanced training in the provision of care for transgender youth. Family practice offers a unique model, as providers offer routine pediatric care, as well as gender-specific care, and can follow patients into adulthood.

Without that first patient asking for help, there wouldn't be a gender center in Oneonta, New York. Dr. Wolf-Gould tells her patients not to underestimate the effect their lives and stories will have on their providers. Her clinic grew in response to the needs of the patients who called, and demonstrates how rural primary care offices can develop the resources to provide quality, multi-disciplinary care for transgender people who might not otherwise have access to services.

According to the HRC Foundation survey, youth gender clinics had a mean of approximately three physicians (including psychiatrists), one psychologist or counselor, and one full-time social worker with another half-time social worker. Nurse practitioners and physician assistants averaged fewer than one per clinic. About 60 percent of clinics included adolescent medicine and endocrinology specialists, while 40 percent reported providers trained in general pediatrics, psychiatry and family medicine. Gynecology expertise was more common than urology. Beyond these healthcare providers, nurses (LPN, RN or APRN) were the most common type of staff mentioned, followed by clinical support professionals such as medical assistants. Five clinics reported having a program coordinator.

"The first 'gender clinic' we went to was strictly for psychiatric evaluation and follow-up. This left us feeling as if our child had a mental illness. They did not have programs in place for the medically necessary interventions our child needed. We have now found a comprehensive clinic which takes care of all of our family's needs."

Sarah W.,

mother of a non-binary child

Not surprisingly, as patient volume grows, staffing at clinics often grows as well. The role that each type of provider plays in the care of transgender and non-binary youth is outlined below. As noted above, some of these providers are key members of the clinical care team, while others may be adjunct members or available upon referral.

Not all health professionals who care for transgender and non-binary youth

are able to work in the same physical space. Health professionals working in rural areas, for example, may be hours away from medical specialists and behavioral health providers. Some providers in a youth gender clinic may find themselves leading a "virtual team" with selected partners in care at various institutions and practices across the community. In these decentralized clinics, maintaining clear and frequent communication among the various care members is critical to staying aligned with a young person's evolving needs.

#### **Major Health Professional Roles**

Whether health providers are co-located or used on a referral basis, youth gender clinics consistently rely on a range of mental and physical health providers.

#### Pediatric Endocrinologist

The role of a pediatric endocrinologist within the youth gender clinic team is critical, and for transgender or non-binary youth entering puberty, urgent; gender dysphoria symptoms can become significantly worse when a child begins to develop secondary sex characteristics typically associated with their sex assigned at birth. Some existing clinics direct transgender and non-binary youth to endocrinologists to learn about possible options for affirming care even before they recommend the involvement of a mental health professional. However, optimally, youth are connected with a professional who is able to take a more holistic approach, addressing the physical and emotional aspects of transition.

For youth who are medically transitioning, hormonal puberty suppression and — depending on the age — hormones are the most common types of medical treatment initiated at the beginning of the process. Because hormonal puberty suppression (also known as GnRH agonists, or "puberty

blockers") is quite safe and its effects completely reversible, pediatric endocrinologists can provide this crucial service while patients and families continue to consider other paths around social and medical transition. Youth who begin their medical journey with support from pediatric endocrinologists can transition smoothly and comfortably into gender-affirming hormone replacement therapy (HRT) if they so choose when they enter puberty. Working collaboratively with a mental health professional who is also responsible for the patient's care, a pediatric endocrinologist can prescribe an HRT regimen of testosterone or estrogen with an anti-androgen medication once the patient consents. It is critical that a pediatric endocrinologist be prepared to talk patients through the risks, benefits and unexpected results that may come from any kind of HRT regimen.

#### Primary Care Physician

# (Typically specializing in Adolescent Medicine, Med/Peds, Pediatrics, and/or Family Medicine)

It was previously thoughout that a pediatric endocrinologist or other specialist had to treat transgender or non-binary patients, but it is now recognized that a range of primary care providers (e.g., family medicine, adolescent medicine, general pediatrics) can play a pivotal role in their care. Many youth gender clinics include primary care physicians within their programs, as transgender

"When we look at Max today, as the thriving, articulate, courageous goofball of a boy that he is, we feel incredibly grateful. It is such a blessing to know that at his tender young age, he already has many of the resources he needs to thrive—loyal friends, a loving home, and properly trained professionals just outside our front door."

Amber and Adam B.,

parents of a transgender son

and non-binary youth need non-gender-identity-related care as well, while others coordinate care with primary care physicians outside the clinic. Primary care providers possess essential skills for working with transgender and non-binary young people, including their ability to address a young person's social context and to consider multiple dimensions of health at once.

Regardless of their formal connections, it's a good idea for youth gender clinics to build relationships with primary care physicians in the region. Primary care physicians are usually the first providers a family consults with when seeking for help for their transgender or non-binary young person.<sup>14</sup> It is critical that all primary care providers – including those not associated with a youth gender

clinic – have a basic understanding of psychological and medical approaches to providing gender-affirming care. Youth gender clinics can provide basic trainings to primary care providers so that they can recognize transgender and non-binary young people among their patients and offer referrals to local youth gender clinics as necessary for specialized care.

#### Mental Health Provider (LCSW, Pediatric Psychologist, and/or Pediatric Psychiatrist)

Mental health providers play a pivotal role in helping the patient and family understand a young person's gender identity and gender expression and can assist the family in setting treatment goals. These providers can be invaluable in helping youth and their families manage gender dysphoria and make decisions about social gender transition, including when and how to disclose information about the young person's gender to school communities and extended family, how to navigate binary social and educational spaces, and how to be resilient in the face of the societal challenges they may experience.

Mental health providers often also work with the medical team to guide the treatment plan. Ongoing therapy is a good idea for many transgender and non-binary youth, even those without significant mental health symptoms. A skilled therapist can help patients navigate family relationships,

"Research shows us that there are many, many children who identify as trans who experience very high levels of anxiety, depression, and ultimately, suicide, if they're not connected with affirming resources. When kids are affirmed, they learn better, they're able to have better relationships with their peers, they feel more support from their family system, and more connected with the people around them ... It's not uncommon for us to get calls from families across the country just seeking information or education about where they can go."

**Heather Newby**, LCSW

peer relationships, and typical adolescent concerns like dating and sexuality, to which being transgender or non-binary may add another layer of complexity. Although therapy is highly recommended in conjunction with medical care and as part of evaluating a young person's gender-related needs, clinics vary in how strongly they recommend or require ongoing therapy, particularly when cost or transportation make frequent therapy visits difficult. <sup>16</sup>

Mental health providers can also help determine when medical interventions such as hormone therapy or surgery may be appropriate.

# Obstetrics and Gynecology

Transgender and non-binary youth are generally followed by their primary care provider or managed by a specialty team, but obstetricians-gynecologists also play an important role in some clinics, both for routine care and anatomy-specific specialty care.

All young adults assigned female at birth require the same screening and preventive services as same-age female peers, including human papillomavirus (HPV) vaccination, Pap testing and breast cancer screening. (It's important to remember that transgender and non-binary youth can fall anywhere on the sexual orientation spectrum, and that Pap tests are recommended regardless of sexual partner gender starting at age 21.)

Additionally, transgender and non-binary youth should be offered referrals to fertility services prior to the initiation of hormonal therapy as this care may irreversibly impact the youth's fertility (see Reproductive Endocrinologist section). Fertility services are often housed within Departments of Obstetrics and Gynecology and those providers may not be very familiar with working with transgender and non-binary youth and their families.

Some youth may experience gynecologic problems such as bleeding, discharge or pelvic pain before, during and/or after starting testosterone treatment. Others may experience pregnancy or develop the symptoms of a sexually transmitted infection. Transgender and non-binary patients may engage with gynecologists for a diverse number of health concerns, but they often face barriers to accessing these services, including:

- Discomfort presenting for care in a "Women's Health" program or being observed in a "Women's Health" waiting area.
- Expectation that providers will misgender them (label them with a discordant name or gender) either during the visit or in a public setting like the waiting area.
- Discomfort with their physical anatomy that may be triggered by an exam.
- Higher rates of sexual trauma, including childhood sexual abuse and medical trauma, that may make physical examinations intolerable.

To avoid developing negative associations, it is important that transgender and non-binary young people's early experiences with gynecology be as affirming and comfortable as possible. Clinicians have identified promising practices that can reduce the stress and trauma associated with gynecology visits for this population. Working with an experienced, transgender-competent gynecologist (or another provider who can conduct routine gynecology screenings) allows clinicians to make these referrals with confidence. Alternately, gender specialists may work with interested gynecology providers to develop these skills.

#### Nurse Coordinator/Navigator

Although not always available, a nurse coordinator or navigator housed in a youth gender clinic can provide a tremendous amount of support to healthcare providers, patients and caregivers. They can help triage new families, provide information on outside resources, coordinate care when a patient is in crisis, and help navigate insurance authorizations and/or denials.

#### Reproductive Endocrinologist

Patients using puberty-delaying medication or gender-affirming hormone therapy should always be made aware of long-term reproductive consequences and may wish to discuss fertility and reproductive issues with a reproductive endocrinologist. This is a service that is typically offered on a referral basis rather than as a regular part of a youth gender clinic's services.

#### The Spectrum of Services Provided at Gender Clinics

Nearly all clinics in the HRC Foundation survey offered medical evaluation, puberty suppression with GnRh analogues and cross-sex hormone therapy. Sixty percent also offered primary care and more than 70 percent provided psychological evaluation, psychotherapy and social work services. While not all clinics offered ongoing psychological evaluation, nearly every program required a mental health assessment before medical treatment could begin. This aligns with the Endocrine Society's 2017 guidelines for the treatment of transgender adults and youth which calls for treatment to be managed by "an expert multidisciplinary team comprised of medical professionals and mental health professionals."

Every patient and every family brings a different experience, set of objectives and level of understanding to a youth gender clinic. Clinics can help manage the competing expectations among patients and families by outlining the services they provide. That said, in any youth gender clinic, it is essential to develop an individualized treatment plan that considers the specific goals the patient wishes to achieve. For some transgender and non-binary young people, transition does not involve medical intervention, and is instead purely social. For others, medical intervention is critical. Clinic staff should be prepared to work with young people to explore all options, understanding that

many do not choose a linear path. Gender-affirmative clinicians should also consider each young person and family individually and in terms of the patient's developmental stage, not their age.

Regardless of how a patient transitions, patients and their families will need support along their journeys – whether medical, emotional or psychological, legal or logistical. Common experiences such as joining sports teams and attending summer camps can be complex and even painful to navigate as a transgender or non-binary young person. Providers should be able to address these realities, or at least to direct patients and their families to sources of social support and community resources.

# **Acknowledging the Patient's and Family's Journey**

By the time a patient and their family present to your clinic, they may have encountered multiple barriers and challenges. The family has likely searched online for your clinic and services. They now are looking to find out if you accept the family's insurance, if you are a network provider or out-of-network provider, if they can they afford co-pay fees and how to plan for a potentially long trek to see you at your clinic.

Some patients required special referrals to see you. Others had to obtain permission to have your consultation as an out-of-network provider. Others may have been told that they needed a "letter of support" from their local mental health therapist to see you. Though the patient may be excited to finally be receiving treatment, the family may be frustrated by the challenges they have encountered along the way. It is important for the care team to be sensitive to these unspoken issues and experiences and to provide support whenever possible.

#### **Consent Models**

The approach to obtaining proper consent should be family based. Well before discussing and obtaining consent, providers must fully understand the relationships in a youth's life. Providers must also clearly establish and document who has legal authority over the young person. Failure to determine parental rights, custody or guardianship can delay treatment and put the practice at risk.

Before any medical intervention, informed consent should be obtained from the patient's parents or legal guardian, and assent should be obtained from patients under the age of 18. There should be a discussion of the benefits and risks of treatment, alternative treatments, and the reversibility or irreversibility of each intervention. A discussion about the implications on fertility preservation and reproduction is also necessary. The information must be written and explained using language that allows youth to fully understand the implications.<sup>17</sup> 18

Obtaining consent for minors poses problems when both parents are not in agreement about treatment, the patient is in the foster care system, or they are an emancipated minor. The medical and mental health team can help caregivers involved in medical decision-making to understand the risks and benefits of medical interventions. Legal assistance may be needed if the youth is in the custody of courts, in the child welfare system or experiencing homelessness.

#### **Treatment Protocols**

Many patients and families seeking care at a clinic may make unreasonable assumptions about what to expect on their first visit. It's important to outline your protocol for incoming patients so expectations can be managed from the outset.

The first step for many clinics is often a phone intake appointment – anywhere from 30 to 90 minutes long – by a social worker or nurse who assesses the patient's situation. The patient is usually then connected with a mental health provider. Clinics vary in their requirements for therapy, but mental health is a core component of patients' treatment plans.

For patients desiring hormone therapy, some clinics will ask for a detailed letter of support from a mental health provider before any treatment options are discussed. Others regularly schedule introductory meetings with pediatric endocrinologists so that patients and their families can understand their treatment options earlier. Remember that some patients may already be established with a mental health provider in their home community, but that provider may lack experience and knowledge working with transgender and non-binary youth. Whichever protocol your clinic chooses to follow, the crucial role of ensuring a patient's mental and physical health requires that all clinics work to coordinate care. Co-located behavioral health professionals in the clinic can supplement, and in some instances replace, the patient's local therapist. Having a mental health provider housed within the clinic can help significantly to prevent confusion or delays in accessing gender-affirming care.

Given the growth of youth gender clinics over the last several years, many providers are developing their own specific protocols based on established guidelines and protocols they've seen used by other clinics. For example, in 2017 the Endocrine Society released guidelines outlining, among other recommendations, that every patient should "receive information and counsel on options for fertility preservation prior to initiating puberty suppression in adolescents and prior to treating with hormonal therapy in both adolescents and adults." Seeking out conferences where providers present on their clinic's practices – for example Gender Spectrum's Professionals' Symposium – can also provide a wealth of information as you consider which protocol might work best in your clinic.

#### **Coordinating Care**

According to results from the HRC Foundation survey, only five of the 26 youth gender clinics surveyed had coordinators on staff. That doesn't mean care wasn't being coordinated, but rather that it was being coordinated by other staff members, often social workers. To ease the coordination of care, it's essential to not only develop and communicate a clear and established protocol, but to also establish a strong network of care providers who will work with your youth gender clinic. For those clinics that do not have a mental health provider on staff, working with a set of providers who understand your clinic's protocols can ensure patients and your practice do not experience unnecessary complications. For clinics that have many different providers on staff, some will set aside weekly or monthly check-ins between mental health and medical providers to track patients' progress and troubleshoot any challenges. Establishing a formal process for how you intend to coordinate care – beyond notes in a patient's file – can be extremely helpful for both your clinic and your patients.

#### **Supportive and Auxiliary Services**

In addition to medical and mental health care, many youth gender clinics offer other supportive services such as support or playgroups, legal services and school advocacy. In general, clinics should be able to offer referrals to other organizations in the community for the services they do not provide in-house.

#### **Support Groups**

Many families benefit from peer support groups as they explore their young person's gender expression and the different stages of transition. Having support from relatives, friends and community members (e.g., school, church, etc.) can greatly benefit the entire family. Supportive families can directly increase the well-being of their young person and reduce the risk of low self-esteem, depression, suicide ideation and risky behavior. Face-to-face interactions with other families are invaluable in the transition process. Many established youth gender clinics help facilitate support groups for parents, caregivers, youth and their peers.

In addition to support groups offered by the program, there are local and national email listservs, blogs, chat rooms and private Facebook groups available for parents, youth and teens. This is an easy way for families to connect, get support and access information. Clinics may want to offer families guidance on accessing these other types of support venues.

#### **Playgroups**

Many transgender and non-binary children benefit from being in a playgroup with other kids who are experiencing similar life experiences. Playgroups also give parents a non-structured type of support in which friendships can be created. Some youth gender clinics offer playgroups or help parents find playgroups through local PFLAG chapters and other local resources.

#### Legal Services

Transgender and non-binary young people often take the steps to change their birth name and gender recorded on identity documents, such as school records, birth certificate, driver's license, social security card and passport. These document changes, or gender marker changes, can take place at any stage of the transition process, but federal and state regulations vary and some require evidence of medical treatment. In most cases, a letter from the treatment provider is sufficient. Under U. S. federal law and in many states, gender-affirming surgery is no longer required to obtain a gender marker change. However, in many cases, healthcare providers must provide documentation that their patient has met the necessary medical and/or psychological treatment for transition. Some clinics have legal services on site that can provide these services while others partner with local legal organizations.

#### **Transitioning Services to Adult Care Providers**

Youth who have been receiving gender care from health professionals and youth gender clinics will eventually "age out" of those services. Transferring care to knowledgeable, clinically and culturally competent providers of transgender and non-binary health care is paramount to promoting these young people's health as they continue to mature. Some practices and providers have the capacity to follow patients as they age, especially those clinics staffed by family doctors and Med/Peds physicians. For those patients who are unable to be seen in the pediatric-centered gender clinics that

they had used in the past, they will need to transition their care to adult- and/or family-focused providers. Though not exhaustive, the <u>GLMA Provider Directory</u> and <u>WPATH</u> maintain lists of providers who are knowledgeable and skilled in caring for transgender and non-binary patients. These resources can be a good start in finding a new clinician. Additionally, pediatric-focused gender clinics may be able to make referrals through their relationships with area providers and clinics.

# **KEY CONSIDERATIONS AND PRACTICAL TIPS**

While there are many variations from clinic to clinic, there are certain best practices exemplified by all successful youth gender clinics. This section contains key considerations and practical tips as you consider starting your own.

# **Creating an Inclusive and Welcoming Environment**

A welcoming office environment can set a positive tone for patients and their families and will most likely lead to increased satisfaction. Patients and families who feel comfortable and confident with their providers will most likely return for follow-up care.

This isn't only an area of concern for the healthcare providers. Front office staff members are often the first point of contact for patients and their families and set the tone for the office visit. It is very important that all staff members are welcoming and familiar with the unique needs of transgender and non-binary youth. Consider that the names that transgender and non-binary people use in many instances do not match the names on their health insurance and medical records. Because of this, mistakes can easily be made when talking to patients and when submitting claims to insurance. Systems should be put in place to ensure that even as insurance companies are billed using the names on the insurance policies, every patient is called by the name they use in their everyday lives. Clinics can create systems to easily track and record chosen name, pronoun and gender for all patients. Some clinics develop simple protocols to remind staff when patients' names or pronouns may not match their record or appearance, even as simple as placing sticky notes on patient records.

Below are a range of practical tips that can help ensure a patient's experience is as respectful as possible.

#### FOR MEDICAL RECORD & FORMS

- Add gender identity options to forms and/or electronic medical records.
- Add an option on forms for chosen name and pronouns.
- Forms should include gender-neutral language and should allow patients to have options for them to express their self-identification.

#### FOR WAITING ROOMS & EXAM ROOMS

- Post nondiscrimination policies stating that all patients will be treated with dignity and respect.
- Have multilingual pamphlets and brochures in the waiting room related to the LGBTQ community.
- Hang posters/pictures of racially and ethnically diverse people.
- Display LGBTQ-affirming symbols such as the rainbow flag or transgender symbols.

- Ensure that single-use restrooms are not unnecessarily labeled with gender-specific signs.
   When possible, identify clinic space where single-use, all-gender restrooms are available or can be created.
- Brochures and other materials should include topics relevant to transgender and nonbinary youth.
- Provide a list of community-based resources, such as LGBTQ meetings, events, support groups or clubs.
- Include language in the Patient Bill of Rights that guarantees health care and prohibits
  discrimination based on gender identity or gender expression. If the facility has policies
  protecting transgender and non-binary patients from discrimination, post them in the waiting area and/or include them on patient forms.

#### **FOR MEDICAL & OFFICE STAFF**

- Wear pins showing support of the LGBTQ community.
- Ask patients what name and pronouns they prefer and address them accordingly.
- Train staff to not make assumptions about gender expression or identity. Coach them to use gender-neutral language.
- Ensure confidentiality in the office and when making referrals. This will pave the way to patients being more open about their gender expression.

#### **Staff Training**

One of the most critical steps toward creating a welcoming environment is providing training to all medical and office personnel to ensure that everyone involved in the patient's care is culturally competent. Such training will prepare staff to be sensitive to and respectful of patients and their families and will ultimately improve the quality of care provided.

Initial training upon hire, as well as annual in-services, should be offered to all employees in the organization. Such training could include:

- Role-playing exercises for staff on how to engage in respectful, open-ended questioning using culturally relevant terminology regarding gender identity, sexual history and risk factors.
- Lessons for offices to build an organizational culture that promotes respectful, supportive and caring treatment of all patients.
- Invitations to parent and caregiver advocates to speak to staff at staff meetings.
- Invitations to LGBTQ community members or representatives from LGBTQ organizations to speak to staff about health risks.
- Lessons for staff on how to use gender-neutral language.
- Exercises for obtaining medical histories when dealing with sensitive topics such as genital anatomy – without alarming patients.
- Lessons for performing physical exams with extreme sensitivity.
- Ideation for making the extended healthcare facility, outside the youth gender clinic, inclusive and welcoming.

#### **FIRST ASK YOURSELF:**

Before you ask patients personal questions, ask yourself these questions: Is my question necessary for the patient's care or am I asking for my own curiosity? What do I know? What do I need to know? How can I ask for the information I need in a sensitive way? Am I relaxed, making eye contact and being friendly?

#### **Billing Considerations**

In 2013, The Diagnostic and Statistical Manual of Mental Disorders-5 (DSM-5) was revised and an older psychiatric diagnosis for transgender and non-binary youth, gender identity disorder (GID), was replaced with the current diagnosis of gender dysphoria. This was an important change because cross-gender identity is no longer considered pathological.<sup>20</sup> Gender dysphoria was the diagnosis code used by more than half of the youth gender clinics surveyed by the HRC Foundation, while more than 40 percent used the medical diagnosis of "endocrine disorder, unspecified." Some programs continued to use GID or "hormone disorder." Insurance acceptance of these codes varies by state and carrier. If a GID code is used, the provider should explain to the patient and family that the term "disorder" is outdated and inappropriate but must be used for the claim to get paid. Explaining this upfront will alleviate any distress or discomfort and provide reassurance that the provider does not believe that being transgender or non-binary is a disorder.

Medical services may be required that do not correspond with the patient's gender marker registered with their insurance plan, such as a routine Pap smear for a transgender male. This discrepancy can cause claims to be inappropriately denied. Billing specialists should refer to state requirements when submitting insurance claims with a gender specific code. A "code 45" modifier can be used in cases when a patient's gender marker does not match required testing or screening.<sup>21</sup> This claim-level condition code identifies these unique claims and allows the sex-related edits to be bypassed.

While more and more insurance carriers are covering treatment for transgender and non-binary youth, it is not uncommon for claims to be denied. Obtaining prior authorization is very common and a process should be put into place to have approvals completed well in advance of treatment. Also, having a system in place to appeal denials will help streamline the process. If appeal letters are not successful, the healthcare provider can request a phone call with the insurance carrier's medical director. This peer-to-peer process can be very beneficial and may be an opportunity to educate the insurer's representative.

Most youth gender clinics surveyed by the HRC Foundation had success in getting transgender and non-binary patients' primary care, medical evaluation and psychotherapy covered by private insurance and Medicaid. Coverage for hormone therapy and puberty-blocking treatment was highly variable with both Medicaid and private plans. Over 60 percent of programs were consistently reimbursed for psychological evaluation and psychotherapy.

#### **Electronic Health Records**

Transgender and non-binary youth often use a name that is not consistent with the name on their government-issued identification or on their health insurance policies. Failure to use the patient's chosen name and/or pronouns (e.g., he, she or they) can be distressing for the patient and may compromise patient satisfaction and quality of care. The majority of health records (e.g., intake forms, electronic health records, billing and coding, laboratory, radiology and pharmacy systems) use a binary approach to collect a patient's gender and do not provide an opportunity for the patient to indicate which pronouns should be used. This binary approach does not accurately represent the preferred gender of a transgender or non-binary patient, and it may not accurately represent the anatomy a patient might have at any given point during their transition. It is important for healthcare providers and institutions to identify how gender identity data are collected,

stored, accessed and displayed in electronic health records and to work with vendors to modify gender identity fields. <sup>22</sup> <sup>23</sup>

The Center of Excellence for Transgender Health at the University of California San Francisco and a Working Group of clinicians and medical information technology experts formed by WPATH recommend a two-step question technique to better collect and document gender identity information. This method collects the patient's current gender identity as well as their sex assigned at birth. <sup>24</sup> <sup>25</sup>

Additionally, including an anatomic inventory in EHRs, covering organs present at birth and those which have been surgically created or surgically removed, is part of best practices for medical documentation.<sup>26</sup>

#### Creating a Business Plan

Business planning is useful for describing what you want to do, understanding who your competitors are, and providing a roadmap for implementation of a new program. A youth gender clinic business plan should outline the need for the program and how the program will not only provide necessary treatment but also help the institution's bottom line. In some organizations, delivering a compelling business plan to the leaders could be one of your most powerful tools for obtaining institutional approval and support for a new clinic.

#### Components of a Business Plan

- Identify stakeholders
- Provide background on transgender and non-binary young people and barriers to healthcare
- Outline the internal and external environment
- Growth and sustainability projections
- Financial projections
- Proposal/Recommendation, to include:
  - Services to be provided
  - O Location(s) where services will be provided
  - Staff and professional development training
  - O Creating a welcoming environment
  - Referral sources
  - Partnering with the community
  - Research opportunities

Prior to 2014, The Children's Hospital of Philadelphia had several mental health and medical care providers who were supporting transgender children and youth in various ways throughout the network. While historically these providers could connect to each other and collaborate with the few patients they were seeing, the increasing awareness and general support for transgender and gender-expansive children started to create a demand that needed to be addressed more strategically and efficiently.

The goal was to bring the professionals from throughout the hospital system together into one clinic space so that families could have a 'one-stop shop' to receive support for their transgender child. Families only needed to remember one parking lot, one building and one floor where they could come consistently to meet with compassionate and competent care providers.

While it was easy for all the providers to see the need – and the benefit they'd also receive from being so closely connected to other care providers – it wasn't as easy for other stakeholders to understand why such a service was essential or would be more efficient. It was also important, from the outset, to develop a clear sense of what kinds of services the clinic would offer, projections for short- and long-term costs, and staffing requirements. A business plan helped serve both needs.

Today, the multidisciplinary team at the Gender & Sexuality Development Clinic at The Children's Hospital of Philadelphia includes specialists in gender, development, mental health, social work, endocrinology, adolescent medicine, psychiatry, fertility, education and law. In addition to clinic appointments throughout the week, the clinic offers support groups for parents, teens, children and siblings one Saturday a month. Countless patients and their parents have thanked the hospital for offering such a crucial service for their families.

#### **Prepare to Address Resistance**

It is not uncommon for individual providers and youth gender clinics to come under attack and face resistance from some community members, local entities, or national organizations that are opposed to gender transition and the provision of gender-affirming care to youth. These attacks have increased recently as the organizations behind them are emboldened by the Trump-Pence administration's attack on transgender and non-binary people and their rights.

Types of attacks experienced by gender-affirming providers:

- Letters, emails, social media or online comments (typically anonymous) that are threatening and harassing often received at places of work and on occasion at private residences
- Filing of complaints with State Medical Boards claiming unethical treatment
- Unauthorized filming or recording of providers speaking at conferences or in other venues
- Taking information or resources from provider websites and using them out of context
- Filing claims, petitioning or lobbying to try to remove access to funding sources such as grants or Medicaid

A common practice of these attacks is to use junk science and/or to make false and outrageous claims about the treatment that is being provided.

The goal of all of these attacks is to stop providers and clinics from providing gender-affirming care, either through intimidation or removal of resources. In the face of these attacks, it is more important than ever that providers stand up for the young people in their care. By taking some precautions to prevent or address potential attacks, providers and clinics can stand firm and continue the lifesaving services they provide.

# Steps to Take to Prevent or Address Attacks

- Know the real science behind gender-affirming care. Include information about the
  recommendations for gender-affirming care from the American Academy of Pediatrics,
  American Psychological Association and others on your website and other materials.
- Develop spokespersons. We know that personal stories change hearts and minds. Identify families and/or former patients (now adults) who are willing to share their stories. These speakers can be one of your most valuable assets, but make sure they are protected as well. Share with them the resource Going Public: Is Public Advocacy Right for You and Your Family?: A Guide for Parents of Transgender and Gender-Expansive Youth.

- Find your allies in the community. Work proactively with community organizations, including advocacy, legal, and social justice organizations; law enforcement agencies; affirming religious congregations; and other providers or academics in the community that can act as external validators of your work.
- Be thoughtful about the public information related to your services. It is important to maintain a balance between making potential patients and their families aware of your services through websites, brochures and fact sheets, and putting out information that may be taken out of context and used against you.
- Consider the personal safety of providers and the availability of online information. Some clinics do not list their providers on the clinic website. Many providers are careful about what personal information can be found online and some do not use their real names in social media.
- Consider the physical safety of the clinic staff and patients. Some clinics have adopted a lower visibility profile, installed extra security measures (e.g., panic buttons) and limited access to certain areas.
- Consider the emotional safety of the staff, providers and patients. Threats and harassment can take an emotional toll. Make sure your team has access to affirming, supportive counseling services.
- Make sure all providers and staff are aware of the safety and security protocols in case
  of a threat. A clinic may want to develop written security protocols and make sure that
  staff is trained on what to do in case of an incident.

#### **WORKING WITH FAMILIES**

Families and caregivers play a key role in the health and well-being of their transgender and non-binary youth. Results from the HRC Foundation survey revealed significant variation in adult support for patients' gender transition and related care. While all clinics had seen patients with supportive relatives, foster parents, caseworkers and other professionals involved in their care, more than 70 percent had worked with a young person who had no adult support for their transition. Since no patient will have the same set of resources, support or treatment goals, providers must adjust to the needs of each patient and their home situation.

Transgender and non-binary youth whose families support them have better overall physical health, mental health and self-esteem. They are also less likely to be depressed, use drugs, abuse alcohol or have suicidal thoughts and/or suicidal attempts. Healthcare providers can play a crucial role in educating families on the best ways to support their loved one. <sup>27</sup>

Young people who experience rejection from their family are more likely to suffer depression, attempt suicide, engage in risky sexual behavior or use illegal drugs. Providers treating these patients have an important role in assessing and helping families along. It's imperative that they understand how rejecting behaviors can impact the youth's mental and physical health outcomes and put them at high risk for homelessness.<sup>28</sup> A 2018 study of transgender children who had socially transitioned demonstrated that youth supported in their gender identity have no greater levels of depression than other youth and only minimally elevated levels of anxiety.<sup>29</sup>

Specific challenges can arise when parents disagree on a youth's treatment plan. Some real-life examples to reflect upon include the following:

Example 1: A 16-year-old adolescent assigned male at birth comes to clinic with gender concerns, identifies as female, but has not begun social or medical transition yet. The youth's parents are separated, but not divorced. The mother is supportive of the youth's emerging gender identity, however, the father is not. The youth is on the father's health insurance policy. In the initial meeting with the parents, the father is verbally abusive toward the patient and forbade the treatment team from offering care, especially if his insurance was to be billed. The care team has been effectively prohibited from providing medical care until one or more events occur:

- 1. The father changes his mind, becomes affirming and allows the care team to proceed.
- 2. The mother divorces the father or otherwise obtains sole custody and decision-making authority, and the youth is no longer on the father's health insurance policy.

Example 2: A father who supports his son's name and pronoun change is challenged by a mother who refuses to even visit the youth's doctor. Initially, the youth and the father present to the clinic to discuss gender affirmation care. The youth has disclosed their gender identity to close friends and parents, but not anyone at school. During the visit, the father appears very supportive and refers to the patient using male pronouns and a gender-neutral name that the patient selected. As the visit concludes, you learn that the mother has been in the waiting room during this appointment, but she refuses to meet with you or any of the care team. As you try to engage her, she makes a belligerent outburst and loudly shouts crude remarks about the youth "being a freak" and that transgender people "are an abomination."

These types of conflicts can even result in custody challenges and other family crises. A therapeutic team should be put into place to help youth and their families come to a common understanding about treatment options, but the youth's journey should be based on what's in their best interest, not their family's. It is important to meet everyone involved where they are in the process, validate their concerns and provide all family members with information, understanding and compassion. The young person is the patient and ensuring medical decisions are made that reflect their needs is of utmost concern. In cases where consent cannot be obtained from both parents or the young person's legal guardian, a youth gender clinic may need to refer patients to outside legal counsel that can work with them.

#### **FAMILY ACCEPTANCE PROJECT**

The Family Acceptance Project (FAP) has developed a tool for healthcare providers to identify LGBTQ young people who might be experiencing harmful family rejection from parents, foster parents and caregivers and to guide practice and follow up care. Check it out to learn more.

Family Acceptance Project, San Francisco State University

Provider's Guide for Using the FAPrisk Screener for Family Rejection
and Related Health Risks in LGBT Youth

<a href="http://familyproject.sfsu.edu/assessment">http://familyproject.sfsu.edu/assessment</a>

# **RESOURCES**

#### FOR PROVIDERS

The following resources provide further information around best practices and legal requirements surrounding transgender and non-binary care. Some of these resources also offer conferences, trainings and webinars.

#### § Center of Excellence for Transgender Health

A program of University of California, San Francisco, offering an online learning center and information on providing routine care, HIV prevention, cultural competency, mental health, and policy for transgender individuals.

# § World Professional Association for Transgender Health (WPATH)

WPATH promotes transgender health through increasing education and research on a national level. WPATH emphasizes a need for a stronger international understanding of gender dysphoria and its treatment.

## § The National LGBT Health Education Center, A Project of the Fenway Institute

The National LGBT Health Education Center provides educational programs, resources, and consultation to healthcare organizations with the goal of optimizing quality, cost-effective health care for lesbian, gay, bisexual, and transgender people.

# § "Lesbian, Gay, Bisexual, and Transgender Healthcare: A Clinical Guide to Preventive, Primary, and Specialist Care"

Written by experienced clinicians and edited by Vanderbilt Program for LGBTI Health faculty, this book contains up-to-date expertise from physicians renowned for their work in LGBTQ health. This important text fills an informational void about the practical health needs of LGBTQ patients in both the primary care and specialty settings, and serves as a guide for LGBTQ preventive and specialty medicine that can be utilized within undergraduate medical education and residency training.

#### § TransLine: Transgender Medical Consultation Service

A free, online transgender medical consultation service, published by Lyon-Martin Health Services, offering answers to medical providers within two business days on questions related to gender-affirming surgery, hormone therapy, and improving services to transgender patients.

### § "Trans Bodies, Trans Selves"

A resource guide by and for trans, gender-expansive and non-binary communities. The first edition was published in 2014 and included hundreds of contributors. The book surveys a broad range of topics including health and wellness, relationships and families, and life stages.

# § "The Fenway Guide to Lesbian, Gay, Bisexual and Transgender Health, 2nd Edition"

A 2015 American College of Physicians textbook, edited by Harvey Makadon, M.D., Jennifer Potter, M.D., Kenneth Mayer, M.D., and Hilary Goldhammer, M.S., of the Fenway Institute. The textbook explores such topics as taking an LGBT-inclusive health history, behavioral health concerns, and development of gender identity in children and adolescents.

# § GLMA: Health Professionals Advancing LGBT Equality

GLMA works toward LGBTQ healthcare equality, both for patients and for those working in health-care who identify as LGBTQ. Members are professionals working toward improved policy and education through advocacy efforts.

# § "Voices of Transgender Adolescents in Healthcare"

This video, developed by the Adolescent Health Initiative (AHI) at the University of Michigan Health System (UMHS), offers perspectives from transgender and gender-nonconforming youth about their experiences and what they want from the healthcare system. AHI supports and trains healthcare professionals who work with teens to optimize their care, using a youth-friendly, adolescent-centered care model.

# § American Psychological Association (APA)

The APA is a scientific and professional organization representing psychologists in the United States that offers information and reliable research around matters related to LGBTQ mental health.

# § Lesbian, Gay, Bisexual, and Transgender Health (Centers for Disease Control and Prevention)

A website hosted by the Centers for Disease Control and Prevention (CDC) that offers an overview of LGBTQ health issues, national health reports, journal articles on health disparities, data and statistics, news stories and resource lists for LGBTQ individuals.

#### **FOR FAMILIES**

Family members juggle the responsibility of seeking out care and emotional support for the youth in their lives while seeking support of their own. Providers should be able to direct families to support groups, legal resources and sources of further information around transgender and non-binary identities and issues.

#### § PFLAG

PFLAG is made up of LGBTQ individuals and their family members and friends who identify as allies. The organization aims to end discrimination against LGBTQ people through advocacy and activist efforts. The organization's website hosts information about the many chapters of PFLAG across the country, and also offers news, a list of PFLAG events and resources for finding support.

#### § Transgender Law Center

Based out of Oakland, California, the Transgender Law Center aims to incite legal change in order to better the lives of transgender and gender non-conforming people.

#### § Lambda Legal

Lambda Legal is the oldest and largest national legal organization whose mission is to achieve full recognition of the civil rights of LGBTQ people and those living with HIV/AIDS. Lambda Legal does not charge their clients for legal representation or advocacy.

### § Family Acceptance Project

A research-based initiative working to end discrimination against LGBTQ youth in the context of their families, cultures and faith communities. Their website features this research, as well as publications, trainings and family videos intended to increase awareness, acceptance and allyship.

# § Human Rights Campaign (particularly the Transgender Children and Youth page)

HRC's Transgender Children and Youth page includes resources for families, community members, school officials and more.

# § Trans Youth Equality Foundation

Trans Youth Equality Foundation provides education, advocacy and support for transgender and gender-expansive young people and their families. Programs include support groups, camps and retreats, and a popular Tumblr blog for youth.

# § Trans-Parenting

The Trans-Parenting website provides answers to frequently asked questions about transgender and gender non-conforming children and youth.

# § TransYouth Family Allies

TransYouth Family Allies partners with service providers, educators and communities to create supportive environments in which gender can be expressed and respected. TYFA's FAQ for parents answers basic questions about raising a transgender and gender-expansive young person.

#### **FOR TRANS YOUTH**

## § The Trevor Project

Created with the goal of preventing LGBTQ youth suicide, The Trevor Project offers immediate, 24/7 support for LGBTQ youth in crisis, as well as trainings for youth workers, a comprehensive list of local resources (including resources on LGBTQ youth health care), and an active blog and event page.

#### § Trans Lifeline

A non-profit offering resources and support to transgender people, with the goal of preventing self-harm. Their hotline is intended for those in crisis, including those who are questioning their gender identity, and is run entirely by transgender volunteers.

#### § GLBT National Help Center – National Youth Talkline (25 and Under)

The GLBT National Help Center's private hotline for one-on-one chat and email peer-support, servicing those up to age 25. Call for support related to coming out, relationship concerns, bullying, workplace issues, HIV/AIDS anxiety, safer sex information, or any other issues faced by transgender and gender-expansive youth.

#### **BASIC INFORMATION ON TRANS IDENTITIES**

#### § National Center for Transgender Equality (NCTE)

NCTE offers a comprehensive introduction to transgender issues, including basic terminology, stories of transgender people, statistics, steps to take as a trans ally and FAQs regarding the treatment of transgender people in the United States. The organization also offers opportunities to get involved with fighting anti-trans legislation.

#### § Gender Spectrum

Gender Spectrum offers information and resources to help families, schools, professionals and organizations better understand gender identity and expression and advocate for transgender and gender non-conforming youth. Their website also features information on current issues around gender identity and how to connect with other adults who are working to become advocates for transgender and gender non-conforming youth in their environments.

#### **CONFERENCES**

Conferences are popular environments for family members and professionals alike. They offter a way to learn about and discuss transgender and non-binary identities as they relate to various personal and professional experiences and best practices. The conferences listed below include professional tracks for providers and are also useful points of contact for families of transgender or non-binary youth who may be seeking community and/or more information.

# **9** Philadelphia Trans Wellness Conference (A Program of Mazzoni Center)

The mission of PTWC is to educate and empower trans individuals on issues of health and well-being; educate and inform allies and health service providers; and facilitate networking, community-building, and systemic change. The conference content is categorized into a General Track for families and the lay public and a Pro Track for health and legal professionals. Pro Track sessions are dedicated to medical care, behavioral health and legal concerns faced by transgender, gender non-conforming and non-binary people. Continuing education credits may be available.

#### § Gender Conference East

Using collaborative principles, the organizers of GCE seek to shape the event as the needs of families, providers, partners and young people evolve over time.

# § Gender Odyssey

Held in Los Angeles and Seattle, Gender Odyssey empowers transgender people and their families and allies to live full and authentic lives and educates those who serve them on how to best facilitate that authenticity.

#### § GLMA Annual Conference on LGBTQ Health

GLMA's Annual Conference is the premier, interdisciplinary LGBTQ health conference and the world's largest scientific gathering devoted to LGBTQ health issues and concerns. Continuing education credits are available for medical providers and nurses.

# **§** National Transgender Health Summit

The National Transgender Health Summit (NTHS) is a program of the Center of Excellence for Transgender Health at University of California, San Francisco. NTHS presents cutting edge research and evidence-based education sessions across many disciplines.

# Various conferences offered by the World Professional Association for Transgender Health (WPATH)

WPATH offers the Global Education Initiative (GEI), a series of certified training courses to increase access to knowledgeable care providers for transgender people by training healthcare providers globally in the context and principles described in the WPATH Standards of Care and their implementation into practice. The educational topics include foundations in transgender health, advanced medical treatment, advanced mental health and a variety of workshops. Continuing medical education credits are available.

# **APPENDIX - HRC GENDER CLINIC WORKBOOK**

This workbook is designed to help you develop the business model, care plan, and protocols associated with your gender clinic. This workbook is intended to assist the Gender Clinic planners in organizing and mapping their assets, strengths, weaknesses, opportunities, and threats as they create their pediatric gender service in their community.

You can download an editable version of this workbook at: hrc.im/ComprehensiveCareClinics

Mission, Vision, Self-Assessment			
What is your Clinic's Goal or Mission Statement?			
Ke	Questions to Ask:	Response:	
1.	What is our goal for creating the service?		
2.	Who are the stakeholders in our community who should participate in our service development?  a. Are community members involved in the assessment and planning of this service?		
3.	<ul> <li>Who are the potential patients?</li> <li>a. Demographics (age, sexual orientation, gender identity, race, sex, etc)</li> <li>b. Insurance status (private, public, under/uninsured)</li> <li>c. Connectedness to care – do they have an existing PCP, transgender health hormone provider, surgeon, behavioral health provider, HIV care, PrEP provider, etc</li> <li>d. Are the potential patients willing to change providers?</li> </ul>		
4.	<ul> <li>Staffing and Services</li> <li>a. What clinical services do we have capacity for? Who/what are our strengths, assets and resources?</li> <li>b. What services are already provided in the community? Who is our competition (if any)? How will we be perceived in comparison to their services?</li> <li>c. What are the prioritized needs of our client/patients? (medical, surgical, mental health, social, legal, etc). Do we have capacity to meet their needs?</li> <li>d. What services are we not able to provide initially? What services are we not able to provide at all?</li> </ul>		

#### 5. Growth and Development

a. What will be the estimated patient volume growth over the next 3 years?

#### 6. Partnerships and Referrals

- a. If we cannot provide a service for a client/ patient need, who can we partner with (internally or externally) to provide that service?
- b. What will be the sources of our client/patient referrals?

# 7. Clinical Space and Service Timing:

- a. Where will the services be held (physical location)? Is this an existing used/unused space? Do we need to acquire a new space? Build out shell space?
- b. Does the space have the resources we need for the clinic?
  - i. Reception area/waiting room
  - ii. Restroom(s)
  - iii. Lab
  - iv. Counseling space
  - v. Office/work area
  - vi. Meeting space
  - vii. Other need
- c. When is the clinic's hours of operation?
  - i. Business hours (8:00 AM 5:00 PM)
  - ii. Afternoon/Evenings (5:00 PM 9:00 PM)
  - iii. Weekends (Saturday AM or PM sessions)

8. Clinical	Clinical Team:	Medical Director:
	<ul><li>a. Who will be on the clinical team?</li><li>b. What are the roles and responsibilities of each team member?</li></ul>	Administrative Champion:
		Medical Provider (MD, DO, PA, NP):
		Behavioral Health Provider (MD, DO, PA, NP):
		Specialty Providers:
		Clinic Navigator:
		Nursing:
		Social Work:
		Child Life:
		Parent/Family/Sibling/ Patient Support Group:
		Other:

# 9. Patient Interface (Forms, Registration, and Interactions):

- a. How are gender identity and pronoun use addressed currently in the organization?
- b. How do providers/staff demonstrate their pronouns? (e.g. pronoun buttons, stickers, pins)
- c. How do providers/staff affirm the client's pronouns?
- d. How are health records maintained to allow for the patient's pronoun and affirmed name?
- e. What staff training has been/will be done to prepare staff (registrars, medical assistants, nursing, social work, providers and all others with patient/family contact) on interacting with transgender patients and best practice communications?
- f. How will the care team address calls from pharmacies and other interactions regarding patient care prescriptions, denials, prior authorizations?
- g. What diagnoses will providers use to code for their services? How will this be communicated with patients/families?
- h. What is the patient care workflow between providers and specialists?
- i. What model of care for hormonal care will providers follow (triadic therapy vs. informed consent)?

#### 10. Clinical Protocols

- a. What clinical protocols will we use/follow?
- b. Are these protocols new or modified from other clinics?
- c. Develop a flowchart of how patients move through the program and address the following key issues in clincal management:
  - i. What is the first step after the first call/referral?
  - ii. What provider does the patient see in the 1st appointment?
  - iii. How/when does the patient interact with other providers/specialties as the patient flows through the program?
  - iv. How do the providers interact with each other in an interdisciplinary model of care? I.e. through regular meetings, providing patient care simultaneously in a shared clinical space?
  - v. Will verbal or written consent be required from one or more parent/legal guardians for puberty suppression and/ or gender-affirming hormone therapy?
  - vi. Will the mental health providers be involved in the decision making of puberty suppression and/or gender-affirming hormone therapy? If so, how will this take place?
  - vii. If treatment will not covered by insurance, what steps can be taken to appeal to the insurance or provide alternative treatment options?
  - viii. How frequently will patients be seen?
  - ix. What labs/imaging studies will be done regularly?

#### 11. Workflow Protocols

- a. How do patients get appointments?
  - i. Call Center/scheduler
  - ii. Office number
  - iii. Web-based appointment interface
  - iv. Drop-in/walk-in
- b. Referrals
  - i. How are internal/external referrals handled?
- c. How are patients transferred for care once they "age out of the system?"
  - i. Referral to internal provider(s)
  - ii. Referral to external provider(s)
  - iii. No referral needed care is part of a health care service for all ages.

#### 12. Budget:

- a. Staffing
  - i. Provider Time/Salary
    - A. Medical/Hormonal
    - B. Behavioral Health
    - C. Surgical
  - ii. Nursing
  - iii. Social Work/Case Management
  - iv. Med Technician/Phlebotomy
  - v. Laboratory
  - vi. Other
- b. Overhead
  - i. Space owned vs. leased
  - ii. Utilities, start-up fees, licenses
- c. Supplies
  - i. Laboratory supplies
  - ii. Basic medical supplies saline, dressings, etc.
  - iii. Sharps, syringes
- d. Medications
  - Will you administer testosterone to patients?
     (Multivial stock vs. unopened patient supply).
  - ii. Truvada Patient Assistance forms/link: https://www.gileadadvancingaccess.com/

#### 13. Advertising/Marketing/Public Relations

- a. What budget is available for marketing this service?
- b. Is it a standalone service or part of a larger service line?
- c. How do you stand out from others in your community offering similar services?
- d. Do you participate in community LGBTQ events/youth-focused events?
- e. Can you co-sponsor any educational events/LGBTQ health awareness with other organizations and agencies?

#### 14. Academia & Research

- a. Is the clinic formally or informally associated with any schools of medicine, nursing, physician assistant training, residency training, or schools of public health?
- b. Do you collaborate with any of these programs or institutions already by lecturing/ teaching LGBTQ health topics?
- c. Is there interest in offering students and health professional trainees limited, intermittent to longitudinal LGBTQ health education experiences at the gender clinic? (Shadowing opportunity
  - college/university elective course)
- d. Who are your teaching faculty?
- e. What have you identified as your learning objectives and reading/learning materials?
- f. Are you conducting research/do you wish to conduct research on LGBTQ topics at the gender clinic?
- g. With whom have you partnered with/would you like to partner on your research endeavors?
- h. Is the community you serve involved in some advisory capacity in your research activities?

Items in italics are included but may pertain to services geared toward more mature clients of a gender clinic.

## **ENDNOTES**

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