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# NAVIGATING TRANSITION-RELATED CARE:

## A Guide for Parents and Guardians of Gender-Expansive Children and Teens

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### INTRODUCTION

If you are a parent of a transgender or gender-expansive child, chances are you have had to educate a healthcare provider about some aspect of your child's gender identity. You are not alone—one 2015 study conducted by the National Center for Transgender Equality revealed that 24% of respondents reported having to teach their medical providers about transgender care.<sup>1</sup> Such lack of knowledge is a major barrier for many gender-expansive people and their families, particularly when family members do not have this expertise themselves.

The good news is that comprehensive gender clinics are growing in number across the country. These multidisciplinary centers are often housed in larger health centers or hospitals and offer a variety of affirming providers in one location, where a treatment team might include a pediatrician, an endocrinologist, a social worker, a psychologist, and an educational specialist. These teams take somewhat different shapes depending on the size and scope of the clinic. At a clinic, patients and their families are supported by a care coordinator or patient navigator, who can ensure that care is holistic, individualized, safe, and affirming. Gender clinics are also typically able to connect patients with peer support groups and other community resources. In most cases, a gender clinic can also connect patients to outside legal services (including support with name and gender marker changes) and prepare them to navigate other areas of daily life including school and work.

Still, thousands of families of transgender youth across the country are living in areas without access to comprehensive clinics. In rural or more conservative areas, families may struggle to find even a single provider who is openly gender-affirming. For those families who manage to connect with affirming providers, they will likely shoulder the burden of coordinating their child's

care for themselves, often through their pediatrician or primary care provider. This guide will help families navigate gender-affirming transition-related care for their children—from the initial search to the delivery of services. While this resource will not offer clinical advice, it will direct you to nationally recognized resources intended to educate and advise transgender youth, their families, and their providers.

#### DID YOU KNOW?

To find a comprehensive gender clinic in your area for gender-expansive youth, visit [HRC's interactive map](#).

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**There are many paths on the journey that is gender exploration, and the most critical element of any path is parental support. Remember that gender exploration may not lead a child to identify as trans; rather, gender exploration is a healthy and critical process for *all* children, cisgender and otherwise. Because no medical interventions are part of this journey prior to puberty, parental support during this period of life means ensuring social support and facilitating social transitions for those who choose them.**

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## A NOTE ON TERMINOLOGY

The terms “gender-expansive,” “transgender,” and “trans” are used interchangeably in this publication to refer to any children or teenagers whose gender identity differs from the sex assigned to them at birth. This includes binary-identified transgender youth (transgender girls and transgender boys), as well as non-binary youth, gender fluid youth, and other youth whose gender identity falls outside of the girl/boy gender binary.

## WHEN DO WE START?

Many families hesitate to seek gender-affirming care for their children because they consider their child's behaviors and preferences to be “natural gender exploration.” Parents may suspect that their child is simply mirroring the behaviors of transgender peers they may have; they may find themselves questioning whether their child is “really” gender-expansive, or if this is simply a passing phase.

Research over the past several decades has taught us that “watchful waiting,” by which families observe their child to see if their gender expression and behaviors change over time, is not a neutral act.<sup>2</sup> All too often, gender-expansive youth are unable to access affirming services until they have been experiencing distress for many years. Both transgender youth and their gender-questioning peers (including those who are cisgender) can benefit greatly from the safe, affirming space offered by trained behavioral health providers. Establishing such a relationship early on will allow your child to explore their identity and potential transition-related needs, without any commitment to irreversible medical or surgical intervention. There is no harm done in seeking support for your child as soon as they begin to voice questions about their gender identity; actually, it is full of benefits—and there is potential for great harm if this care is postponed.

**“** *In many ways, we hated the idea of gender dysphoria being a clinical diagnosis. This isn't a disease or infliction. This being said, we have found it invaluable medically because most insurances and providers are bound by codes and recognized diagnoses when establishing medical care. Being able to give a specific name to what our kiddo is experiencing was also helpful for the school system.* **”**

**— Ashley Rhodes-Courter, mother of a transgender daughter**

## GENDER DYSPHORIA: A COMMON DIAGNOSIS

Some families report feeling a sense of clarity upon learning that their child has been diagnosed with gender dysphoria. Gender dysphoria refers to the distress a transgender person experiences when their body does not align with their internal sense of their gender, or as a result of public misgendering and mistreatment due to their transgender identity.<sup>3</sup> While not all transgender people experience gender dysphoria, it is a common requirement in accessing certain medical care, and can help some families understand their child's distress, allowing them to move forward with transition with more confidence. While the diagnosis of gender dysphoria can open doors to treatment, there are concerns that this mental health diagnosis can potentially add a layer of stigma to transgender children and many believe that access to gender affirming care should not be dependent on this diagnosis.



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## FINDING THE RIGHT PROVIDERS

For families that are able to access a nearby comprehensive gender clinic, a care coordinator, a patient navigator, or in some cases, a social worker will direct you to the first provider in your child's journey (typically a behavioral health specialist) and guide you along the path forward.<sup>4</sup>

If you do not have access to a nearby clinic, you may still be able to reach out to one in your region for support; many clinics receive calls from all over the country and may be able, with some research, to share resources that are accessible to you. If you are tasked with constructing your own transition care team, your “provider roadmap” can mirror the journey you would follow in a comprehensive clinic. As you research and gather your child's team of providers, it is critical that you assess each provider's knowledge and competency in gender-affirming care. Some providers may publicly advertise that they work with transgender populations—however, they may not have much experience working with gender-expansive youth. Others providers may advertise LGBT experience, but really only have experience with LGB issues (sexual orientation expertise). Consider reaching out to a provider over the phone, or visiting them without your child first, to ask a few screening questions, such as:

- Approximately how many transgender patients have you worked with in the past?
- My child identifies as [non-binary] and is [13]. Have you worked with other youth with similar identities in this stage of life before?
- Do you have general training in working with children and/or adolescents?
- How comfortable and experienced are you with helping young people like my child access physical transition-related care, like puberty blockers, hormone therapy, or surgery?
- Do you have access to a list of local gender-affirming resources or specialists in case there are elements of care you can not provide?
- How comfortable and competent is your support staff in working with gender-expansive youth and their families?
- Does your billing office have experience with submitting claims for gender-expansive patients?

**“** Last year when [our child] was struggling with depression, we looked for a therapist that could assist with cognitive behavior therapy (that wasn't available at [the hospital]), and it took me 8 months and calls/emails to more than two dozen in our area to find a good fit. Half who listed on their websites or *Psychology Today's* website claiming to work with trans folks admitted they really didn't. And most who did wanted to talk to her about her gender, almost to confirm she really is trans, rather than on the reasons we were seeking care. **”**

— Debi Jackson, mother of a transgender daughter



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With a bit of research, you'll find a wide array of Facebook groups and other online communities for families of trans youth, including [Trans Chance Health](#). These forums are a great source of local information on affirming providers and social support for parents and caregivers. If you find a highly-recommended provider who has a long waitlist, they should be able to provide you with a list of nearby resources that have their seal of approval—and local LGBTQ centers should be able to do the same. In addition, several directories of trans-affirming providers are hosted online, including [Transgender Care Listings](#) and [Trans-Health](#). It is important to note that not all providers listed in online directories have been vetted by reliable sources; you should still plan to do independent research on any providers you find in these lists. Consider visiting Seattle Children's resource on "[Choosing a Mental Health Provider](#)" for more general guidance on selecting a mental health professional.

Unfortunately, in some cases, families may not find a local clinic or affirming provider who can support their child's needs. Parents faced with this concern can consider making their initial trip(s) to access care for their child further away. For example, a family living in a small, rural community with few openly trans-affirming providers may be able to make one or two trips to a nearby city, where they can access puberty blockers or hormones and request that the prescribing specialist support their local primary care provider (PCP) in managing ongoing care. This also offers an opportunity for local providers to be educated about transgender care basics, and ultimately better support other local youth. If your child's PCP is open to learning about gender-affirming care, there are a number of options for remote and in-person trainings—including Fenway Health's National [LGBT Health Education Center](#).

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## ELEMENTS OF TRANSITION CARE

Before families can finalize their child's transition care team, they must understand the elements of transition care for gender-expansive youth. Every child, whether cisgender or transgender, has a unique set of experiences and needs surrounding their identity and expression. Many children simply require a safe space in which to explore gender—and may find that they are comfortable with the gender and sex assigned to them at birth. Others may identify strongly with a different gender and may pursue some form of social or physical gender transition.

For children, pre-adolescents and early adolescents, gender transition is mainly a social process and many times a legal process as well. For those in the early stages of puberty, puberty blockers may be the first medical intervention. Future elements of gender transition for your child may include gender-affirming hormone therapy and various surgeries. **There is no one set way for a child to transition and it varies from child to child.** To learn more about the most common steps in gender transition, see the chart below and visit HRC's resource, "[Supporting & Caring for Transgender Children](#)."

**“** *We do not have a multidisciplinary gender clinic in our area so we have pieced providers together. This took quite a bit of work. Right now our team consists of a psychologist, psychiatrist, pediatrician, and endocrinologist. It takes quite a bit of effort to coordinate our child's care among these providers and it is up to me to coordinate their care. I keep a notebook with me at all times and take detailed notes. I ask for copies of their medical notes so I can share with all of the providers involved in our child's care. Our child's mental health providers are very good about communicating with the medical providers and they have written us letters for name and gender marker changes.* **”**

— Sarah Watson, parent of a non-binary teenager



## COMMON STEPS IN GENDER TRANSITION

	Examples	Ages	Reversibility
<b>Social transition</b>	Adopting gender-affirming hairstyles, clothing, name, pronouns, restrooms and other facilities	Any	Reversible
<b>Puberty blockers</b>	Gonadotropin-releasing hormone analogs such as leuprolide and histrelin	Early Puberty	Reversible
<b>Gender-affirming hormone therapy</b>	<ul style="list-style-type: none"><li>▪ Testosterone (for those assigned female at birth)</li><li>▪ Estrogen plus androgen inhibitor (for those assigned male at birth)</li></ul>	Adolescents (as appropriate)	Partially Reversible
<b>Gender-affirming surgeries</b>	<ul style="list-style-type: none"><li>▪ “Top” surgery (to create a male-typical chest shape or enhance breasts)</li><li>▪ “Bottom” surgery (surgery on genitals or reproductive organs)</li><li>▪ Facial feminization surgeries</li></ul>	Adolescents (as appropriate) and Adults**	Not Reversible
<b>Legal transition</b>	Changing gender and name recorded on birth certificate, school records and other documents	Any	Reversible

\*\*Note: Surgery protocols are evolving, and age of eligibility for surgical procedures may vary widely based on the surgeon’s and insurance company’s requirements. While some surgeons may offer surgery for gender-expansive people as young as 13, insurance will likely not cover the procedure until the individual is around 18 years old. Whenever possible, consider consulting with a few surgeons to determine who best fits your child’s needs and your insurance coverage.

### ◆ Behavioral Health Specialists

Behavioral health specialists (including licensed clinical social workers (LCSWs), psychologists, psychiatrists, marriage and family therapists, among others) are a critical piece of the journey toward gender affirmation for gender-expansive youth. Many interdisciplinary gender clinics will require that younger children, in particular, spend numerous sessions with a behavioral health specialist (often a child psychologist) before beginning to consider future physical intervention.

The responsibilities of behavioral health specialists in gender-affirming care for trans youth include:

- Creating a safe and open environment for youth to express their authentic feelings about their gender, and to share any distress they may be experiencing;
- Assessing the young person’s situation to determine their needs and readiness for intervention—but also to assess the function of the family, and what level of support a young person is receiving at home;
- Working with the youth and family to discuss different paths forward in social and/or physical transition. This can help ensure that a young person has realistic expectations for the outcome of blockers, hormones, and surgery;



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- Working with families (both with their children, and with parents alone) to help them better understand their children's experience, improve their responses to it, and to shift from worry or concern, when evident, to acceptance and from acceptance to active support;
- Assessing the young person's other behavioral health needs and concerns, particularly given the disproportionate impact of mental health concerns among gender-expansive youth;<sup>5</sup>
- Guiding the patient and their family through strategies for addressing roadblocks in other aspects of life, including school, friendships, overnight trips, etc.;
- Working with older teenagers to assess readiness for any desired gender-affirming surgeries, and, if appropriate, providing a letter of support to a surgeon and the family's insurance carrier.

#### ◆ Primary Care Provider (PCP)

If your PCP is affirming and trained in basic transgender care, there is a great deal they can do to support your child on a regular basis. PCPs can prescribe and manage hormones, offer referrals for surgeons, hair removal providers, behavioral health providers, and social support networks, and provide routine care.

#### ◆ Endocrinologist

Some families may find that their child is best supported through visits to a pediatric endocrinologist who has experience working with gender-expansive youth. Endocrinologists can assess how far along your child is in puberty, (based on the development of their secondary sex characteristics),<sup>6</sup> and if appropriate, prescribe puberty blockers or hormone therapy. Most importantly, they will be able to sit down with your family and talk through physical and emotional impacts of hormones, which changes will be reversible, and what impact such intervention will have on fertility and reproduction. Note that not all gender-expansive youth seeking hormone-related intervention need to work with endocrinologists. Some PCP's, adolescent medicine physicians and OB/GYNs are trained to prescribe and manage hormone regimens.

*“ I had reservations in the beginning of the medical interventions and I still do. I worry about side effects and long term effects and any surgeries she may have to experience and the pain in recovery...the only peace of mind that I have in making the decisions to move forward at each level of care is that my daughter is happy to align her mind and body, and doesn't have to worry about her body changing in ways that could be traumatic for her. ”*

— Amy D'Arpino, mother of a transgender daughter

*“ Our child was in the middle of puberty when they came out to us as a transgender boy. After seeking advice from a mental healthcare provider, we made an appointment with an endocrinologist to talk about suppressing puberty. We had no idea that this was an option. Stopping the periods and further permanent body development gave our child quite a bit of relief from their dysphoria and gave us time to develop a thoughtful path forward. ”*

— Sarah Watson, mother of a non-binary teenager



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## WHO GIVES CONSENT?

In most circumstances, youth and their families can access puberty blockers and hormone therapy through a process of informed consent (without a letter from a behavioral health provider). If your child is under the age of consent, this process will look different between different health centers: some will only require the informed consent of one parent or guardian, while others might require the consent of both. Parents do not always agree that their child should receive medication to aid in the transition process. If your family confronts this issue and finds that the dissenting parent cannot be swayed, the best path forward is to engage a family therapist who is experienced in gender identity, and can alleviate the impact of stress on the child. In some cases, when parents cannot agree, and work with a family therapist has not been effective or is not possible, legal services may need to be sought out to ensure optimal gender care for a child or youth.

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## PARENTS AND MEDICAL PROFESSIONALS: A TEAM APPROACH

Many parents will find themselves working with providers who are open to supporting transgender youth, but who have little experience doing so. This may mean that they need more information on the clinical aspects of transgender care,—but they also may be more prone to misgendering your child or making other social errors (even if well-intentioned).

Fortunately, there are many resources for healthcare providers who are looking to learn more. These resources can provide doctors, nurses, and front-line staff with training on the road map of transgender care, and offer a more exhaustive introduction to transgender identities and health disparities. Many health centers that do not have much experience working with openly transgender youth will find they will need to modify their Electronic Health Records (EHR) systems to accommodate trans patients, particularly regarding gender markers, pronouns, and chosen rather than given names; —they can find the resources to do so [here](#).

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## NAVIGATING INSURANCE COVERAGE

For many families of gender-expansive youth, the greatest hurdle in accessing gender-affirming care is discovering that their insurance will not cover the medical and potentially surgical interventions. Because health insurance is regulated independently by each state, navigating the process can be complex and individualized; what your family will find available to you may differ based on your location. While it is illegal for insurance carriers to discriminate against transgender people, they are given license state-by-state to decide if they will cover medical costs for part or all of the transition process.

Fortunately, there are numerous resources for those in need of support. The National Center for Transgender Equality offers a [comprehensive guide](#) on getting health care covered, along with a helpful [“know your rights” resource](#).



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If your attempts to have procedures covered are a result of a “coding error”—for example, if your transgender son finds that he is denied coverage for routine gynecological care—there may be an easy fix. Your provider will likely use Code 45 to indicate a “sex mismatch” for refusals of this kind.<sup>7</sup> However, when transition-related services are denied, you have a number of options:

1. If your child has not yet undergone the services for which you're seeking coverage, you should submit a preauthorization request for the intervention(s). If approved, this will give you peace of mind.
2. If your child's services are denied, your provider should be prepared to send an appeal letter; if this still does not lead to approval, the physician or provider can have a phone call with the insurance carrier's medical director. This can provide a critical opportunity for education, as your provider can inform your insurance carrier on transgender health law and policy, as well as [WPATH standards of care](#), of which they may be unaware.
3. If your family has the option to seek coverage with an alternative insurance carrier, the U.S. government [hosts information](#) on patients' rights with marketplace coverage and how to apply.

Unfortunately, some families will find that their insurance company continues to refuse to cover transition-related care, even after multiple appeals. Some families are able to pay out of pocket for these expenses; others may be able to raise money through crowdfunding efforts, or with the help of other families with trans youth in their networks. However, for patients who can get insurance coverage only for doctor's visits themselves, gender-affirming providers can still do a lot to support trans youth socially, including—managing other mental health concerns, and affirming youth in their identities and struggles. Although it is less than ideal for transgender youth to go without necessary transition-related services, the behavioral health support of a strong provider can go a long way, reminding the youth that although stalled, everyone is working to move their care forward.

Always remember to keep detailed documentation of all communication with insurance companies—the better documented your fight, the better prepared you will be to take further action against them if necessary. For more information on navigating healthcare laws and policies, explore the Transgender Law Center, [which does focused work around health law and policy](#) and offers a helpful [resource](#) on how to appeal your health care denial if necessary. Families can also find information on their rights using the [Lambda Legal fact sheet](#) available on the organization's website.

**“ We eventually got in to see an endocrinologist who specialized in transgender affirming care, but insurance denied the puberty blockers several times. This was probably the most stressful time during our journey because by then we knew what our child needed, but we could not afford to purchase the blockers on our own. After several appeals and a lot of negotiating, we were able to get the insurance company to cover the blocker. ”**

**— Sarah Watson, mother of a non-binary teenager**





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## PUTTING THE PIECES TOGETHER: COORDINATING CARE AND THE OUTSIDE WORLD

If you are not able to access a comprehensive gender clinic, you will likely find yourself doing the work of coordinating multiple providers. By the time your child is a teenager, if they are undergoing hormone therapy and seeking gender-affirming surgeries, they will likely be working with a behavioral health provider, a primary care provider, and/or an endocrinologist, and a surgeon.

If you anticipate that your child will be working with multiple providers in various locations, you should consider informing each provider's front desk staff that there will be frequent requests for medical records from other health centers and specialists. Ensuring you understand the process of sharing these files, and signing releases ahead of time for this information, should help save time and stress later on.

**“** *The barriers to affirming care got a bit more complicated when our child came out as nonbinary. When our child was identifying as a transgender boy, our endocrinologist was supportive of discussing and introducing cross hormone therapy at a future date. The endocrinologist, who was relatively new to transgender affirming care, was conflicted about the course of our child's treatment because she thought that my child needed to pick between identifying as a boy or a girl. She could not wrap her head around treating a nonbinary child with cross hormones. She ended up referring us to someone else and my child is much more affirmed.* **”**

— Sarah Watson, mother of a non-binary teenager

### NON-BINARY GENDER IDENTITIES AND CARE

Although non-binary and gender fluid people have existed throughout time, the majority of physicians and providers may not understand how best to navigate transition services for non-binary and gender fluid youth. We are taught that gender dysphoria requires that a young person's identity be “insistent, persistent, and consistent.” However, if your child is non-binary or gender fluid, this criteria may not apply as accurately as with a child who identifies as a trans boy or trans girl. This can create barriers in access to care.

Parents of non-binary and gender fluid children will likely have to do additional background research on potential providers. Those who do provide affirming care, but who are not familiar with the unique needs of non-binary and gender fluid youth, can be referred to WPATH guidelines on caring for young people outside of the binary. Similar best practices have been adopted by comprehensive gender clinics around the country,<sup>8</sup> and trainings and informative publications are available through the National LGBT Health Education Center at Fenway Health.

Typically, even if a patient's gender identity and/or expression shifts over time, the medical interventions needed to treat or decrease that patient's dysphoria are clear. In these cases, it may help parents to refer back to their child's diagnosis of gender dysphoria or the documentation of their child's gender stress or distress in order to understand the importance and urgency of treatment—even if aspects of that medical transition may be permanent.



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## CONCLUSION

As transgender care is integrated into medical school curricula across the country, more and more gender-expansive children and teens are at last accessing the comprehensive care they need. However, even in areas without publicly gender-affirming providers, families of gender-expansive youth need not feel alone in their fight to access care. Thanks to countless community and legal advocacy organizations, online forums and support groups, and healthcare training centers, there are many roads enabling social and physical affirmation for trans youth. In embarking on your own journey as a parent of a gender-expansive child or teenager, you will continue to spread critical knowledge and awareness, paving a path forward for countless trans youth to come.

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## ENDNOTES

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