

# Trans and Non-Binary Youth Healthcare in The Digital Age of Medicine

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**Executive summary:** Gender-affirming care has been established as essential healthcare for transgender and non-binary (TNB) youth but many patients face prohibitive barriers when accessing this kind of care. These roadblocks span a wide array of arenas, from access to gender affirming care to digital privacy protections. Many TNB youth lack familial and community support to seek care, geographical access to specialized providers, insurance coverage sufficient to make this care affordable, and legal protections for existing as a TNB person in society. During the COVID-19 pandemic, digital technologies and health legislation expanded patients' access to out-of-state or remote care. Telemedicine in particular has the potential to reduce barriers to accessing gender-affirming care. However, without guidance and oversight in the form of concrete federal or state policies, these benefits may not be extended to those most in need of support. How telehealth providers manage the data collected using these technologies is also of great concern; this health information could be used to prevent and criminalize youth and families seeking care. We thus propose a suite of policy actions to protect and expand access to gender-affirming care for TNB youth: ensuring legal protections for data relating to gender identity and gender-affirming healthcare, establishing nationwide access to gender-affirming care via insurance waivers and support for remote care, and expanding the pool of providers trained in TNB healthcare.

## I. Introduction

The relationship between the US healthcare system and transgender and nonbinary (TNB) people has historically been greatly compromised due to dangerous transphobic practices and a lack of humane care. In the present day, gender identities and gender stereotypes are far better studied and understood (Beemyn 2014), and critical consensus has been reached that these begin to form far earlier in life than previously thought (18 to 24 months; Martin and Ruble 2010, 356). Recent studies show transgender individuals are on average younger than the US population, with youth ages 13 to 17 being significantly more likely to identify as transgender (1.4%) than adults ages 65 or older

(0.3%) (Herman, Flores, and O'Neil 2022). Therefore, new healthcare policies and practices should focus on supportive treatments for youth populations in the TNB community. LGBTQIA+ individuals experience high rates of poverty and uninsurance, and TNB individuals experience particularly high rates of discrimination in health insurance coverage (Baker et al. 2016). Many individuals from low-income communities rely on Medicaid coverage, making the program essential to TNB healthcare (Gomez et al. 2022; Rooney, Durso, and Whittington 2018). Data collected within this community show higher rates of suicidal ideations than in cisgender LGBTQ youth. In cases where TNB youth had their pronouns respected by all or most

people in their lives, the attempted suicide rate was reduced by over half (The Trevor Project 2021). Additionally, gender-affirming care that includes medical interventions, such as puberty blockers and gender-affirming hormones, has been shown to improve well-being among TNB youth in multiple studies (Tordoff et al. 2022; What We Know Project, Cornell University 2018), and is the best medical practice as stated by multiple medical organizations (Keith 2022; Harvard Law Review 2021; Transgender Legal Defense & Education Fund, n.d.). As the gender identities of trans and non-binary individuals begin to form in their youth, providing access to gender-affirming care at an early age is critical to this population's mental health and quality of life.

The advent and widespread use of electronic healthcare records (EHRs) and other digital modalities over the past thirty years have given healthcare providers a unique opportunity to expand access to care while individualizing treatment options. Many of these advancements, including the ability to collect far more data about patients, were viewed as a way to improve treatment outcomes (Evans 2016, S54). This effort is especially important for patients with historically marginalized identities ("Medicine in the digital age" 2019, 1). These technological advancements, while exciting, have the potential to exacerbate existing inequalities for TNB youth. This article will highlight existing inequities in healthcare policy for TNB youth and expand on how telehealth can ameliorate the lack of access to healthcare that plagues this vulnerable population.

## II. Legal landscape for access to gender-affirming healthcare

Federal protections for TNB youth's access to healthcare have typically lacked consistency, having been subject to change under different presidential administrations. For example, changes under the Trump administration weakened protections for TNB and LGBTQIA+ youth by removing explicit language for gender identity discrimination from Section 1557 of the Affordable Care Act, leaving only discrimination on the basis of "sex" in the text (Musumeci et al. 2020). The Biden administration has reversed course with the Department of Justice (DOJ) and the Department of Health and Human Services (HHS) indicating that refusal of medical

treatment based on gender identity may indeed violate this law (Clarke 2022; US Health and Human Services 2022). Regardless of the position of the executive branch, there are no federal protections against discrimination based on sexual orientation or gender identity in public accommodation settings, including doctor's offices (American Civil Liberties Union 2022). Without explicit language in federal laws, legal protection for TNB youth healthcare will continue to be in flux.

At the state level, legal access to gender-affirming healthcare for minors is narrow and diminishing under recently proposed legislation. There are only 24 states that have explicit mandates protecting individuals from insurance discrimination based on gender identity (Movement Advancement Project 2022). This leaves an estimated 44% of LGBTQIA+ individuals with state-level protections that may be interpreted to exclude them. State-administered Medicaid programs are either silent on TNB access to gender-affirming care (19 states) or have explicit bans on coverage (13 states) with the most recent being Florida's Rule 59G-1.050, effective August 2022 (Movement Advancement Project 2022). Between January and November 2022, 20 states have proposed legislation banning any access to best-practice healthcare for TNB youth (Freedom for All Americans 2022). The proposed legislation includes penalties for healthcare providers that provide gender-affirming care to TNB youth, including fines, revoking of licenses, and even felony charges. Some bills have gone as far as proposing criminal child abuse charges for parents seeking gender-affirming care for their TNB children (Dawson, Kates, and Musumeci 2022). With almost half of states proposing restrictions on TNB youth healthcare, this leaves a dangerous picture for access to essential health services for TNB youth.

## III. Digital medicine as a tool for trans and non-binary youth healthcare

### *i. Risks of digital data to TNB youth*

Since the advent of EHR, new barriers to effective, gender-affirming care have arisen. The lack of adequate data collection for a patient's correct name, pronouns, gender identities, sex assigned at birth, and anatomy could harm TNB patients. EHR systems need to be updated and monitored to better serve vulnerable patients (Sequeira et al. 2020, 502;

Imbler 2021). The dramatic increase in digital data requires careful management and better protection for all patients' sake (Nicholson Price II and Glen Cohen 2019, 37). However, given the unique vulnerability of TNB patients in the current political climate, the need for such protections has grown especially sharply for this community.

Certain states may seek to acquire digital data, whether from healthcare providers or other sources, in order to prosecute parents and youth for pursuing gender-affirming healthcare. This scenario has already occurred in cases where patients sought and received abortions. Authorities in Nebraska filed for private conversation data from Facebook between a young woman and her mother (Nix and Dwoskin 2022). Facebook has also taken private patient data from many of the biggest hospital systems in the United States by placing ads and extracting data from behind password-protected patient portals (Feathers et al. 2022). The lack of protection for digital data represents an alarming vulnerability for digital health technologies and TNB youth targeted by hostile state legislation. To ensure that TNB youth benefit from the opportunities presented by digital medicine, policy interventions are needed to eliminate the potential for discriminatory use of their digital data.

### *ii. Opportunities to expand access to gender-affirming healthcare via digital technologies*

Telehealth provides a unique platform for addressing inadequacies in gender-affirming healthcare for TNB youth. The emergence of telehealth, from a fringe form of medical care to a more legitimate practice, was driven by the need for remote doctor visits during the COVID-19 pandemic. Moving forward, telehealth will likely remain a common part of the public's access to healthcare (Hamnvik et al. 2022, 113). TNB patients commonly experience fear of exposure, discrimination, or being misgendered at clinics and hospitals (Kattari et al. 2020, 2; Kcomt 2018, 211). Telemedicine could allow these patients to choose their healthcare providers and set specific parameters for their safety. Telemedicine allows TNB youth to access expertise that may not exist in their local communities and to do so without the cost of travel or concern for exposure (Downshen & Lett 2022). For some of these young patients, gender-affirming care might not be available in certain states at all

(Dawson, Kates, and Musumeci 2022). As the pandemic restricted in-person visits in 2021, nearly all state medical boards waived the restrictions on telehealth and allowed patients to see doctors out of state ("COVID-19 Telehealth Coverage Policies" 2021). These flexible policies were encouraged by the Centers for Medicare and Medicaid, which began to provide significantly more reimbursements for telehealth services (Hamnvik et al. 2022, 114). Given the increasing acceptance of telehealth and the flexibility it provides, this service presents an opportunity to expand access to gender-affirming care for TNB youth.

### *iii. Barriers to equitable expansion of TNB youth healthcare via digital medicine*

While recent waivers have allowed more patients to use telehealth, the full ability of digital medicine to expand TNB healthcare access may be suppressed by high out-of-state care costs and limited provider training in this care. 56% of patients seeking surgery as part of their gender-affirming care had to travel out of state and experienced a higher cost burden for doing so (Downing et al. 2022, 799). While special waivers issued by state medical boards during the COVID-19 pandemic allowed patients to be seen by out-of-state providers, these have since lapsed in some states (Alabama, Louisiana, Arizona). Other states (California, Illinois, Massachusetts) maintain the waiver policy only if the Federal Public Health Emergency status (currently extended until January 2023) remains in effect (American Speech-Language-Hearing Association 2022). As it stands, while TNB youth may be able to connect with providers remotely via telemedicine, for those needing to look outside of their state for providers specializing in gender-affirming care, doing so may still be financially out of reach.

Additionally, while advances in digital technologies may expand access to many types of care, including gender-affirming care, if these technologies are used by medical providers without sufficient training in TNB healthcare, they may present new risks to these patients. Within the limited literature, it has been highlighted that medical training for TNB healthcare is currently insufficient (Dubin et al. 2018, 377). Many providers feel underprepared to serve these patients and many TNB patients report having to educate providers on their care needs (Newcome

and Gilmer 2021, 317; Kattari et al. 2020, 4). On average, training for medical students only includes one to two lectures that are encompassed by larger discussions about the entire LGBTQIA+ community (Dushyant Utamsingh et al. 2017, 161-162). This is an issue if the goal is for providers to be truly clinically competent when treating TNB patients. We have already discussed the unique health issues and barriers to healthcare that TNB youth face. For these reasons, TNB healthcare should be taught separately from broader LGBTQ+ topics. When surveyed, medical trainees stated that their comfort and knowledge of providing care to transgender patients was much lower than patients in the broader LGBTQ+ community (Liang et al. 2017, 900-905). Additionally, there is no evidence that such limited and short-term training leads to benefits in terms of clinical competency or patient outcomes (Dubin et al. 2018, 384-385). Inequities in TNB youth healthcare access are in part due to insufficient provider training and an in turn limited pool of providers with expertise in this care.

To ensure that TNB youth benefit from advances in digital medicine, policy interventions are needed to prevent harmful use of their digital data and eliminate barriers to telehealth utilization and remote care access. As telemedicine evolves, healthcare providers who offer telehealth services should take great care in building and monitoring their platforms so that they do not exacerbate existing inequalities that plague this patient population. Ensuring all providers are properly trained and licensed, that medical information is adequately protected, and that guidelines for care are established for this population is essential to solidify the longevity of telemedicine in TNB healthcare. Specific policy suggestions for the federal and state governments will be outlined below.

#### **IV. Recommendations**

We recommend the federal adoption of a regulatory framework that leverages the opportunity telemedicine provides and preempts state-imposed vulnerabilities. We also describe actions that additional stakeholders, including state governments, healthcare institutions and providers, and data management companies can take to promote and uphold access to TNB healthcare while accounting for risks posed by digital technologies. It

is important to note that these recommendations are not exhaustive but are provided to highlight policy priorities and considerations.

##### *i. Address risks of digital data to TNB youth*

###### *Enact federal policies to prohibit the collection and use of data relating to gender identity and TNB healthcare access for discriminatory purposes*

Protections for TNB healthcare usage and gender identity should be codified in the language of federal laws and consistently and explicitly upheld across federal agencies and offices. One of the most urgently needed policy interventions to protect TNB youth may now be enhanced data protection laws. We recommend that policymakers seek to establish more extensive data protection laws surrounding HIPAA and healthcare privacy as certain states take aim at individual rights and prosecute through digital information. At the state level, California has recently enacted multiple pieces of legislation introducing data privacy safeguards specifically concerning reproductive status and trans health data (Schwartz 2022). These laws exempt trans health data from law enforcement sharing mandates and bar providers from releasing information pertaining to a patient's use of gender-affirming care in response to criminal or civil action against a person (Schwartz 2022). We recommend federal adoption of such laws. We additionally recommend that employers, internet service providers (ISPs), social media services, and law enforcement be prohibited from collecting or sharing personal data related to the usage of gender-affirming care.

###### *Take initiative at private institutions to support TNB youth by adopting data policies that preempt discriminatory use*

Even in the absence of recommended federal level data protections, employers, ISPs, social media services, and similar entities can support TNB employees, affiliates, and clients by implementing data policies at the organizational level that bar collection of data related to TNB health. By electing not to collect this data, these entities can preempt its potential for discriminatory use in states that have laws restricting access to gender-affirming care.

*ii. Address barriers to equitable expansion of TNB healthcare access via digital technologies*

*Implement state-level policies to make telehealth and out-of-state care affordable*

We recommend that states adopt permanent physician licensing laws that allow patients to access specialized care (i.e., gender-affirming care) that is not available within their own borders. Achieving national physician licensing that allows flexibility in access to care throughout the country would be ideal. However, medical licensing is currently determined at the state level. Healthcare advocacy groups recommend that waivers implemented by states during the COVID-19 era to expand the reach of telehealth be continued permanently or incorporated into laws to help address access inequities (Pifer 2022). Additionally, we recommend states require insurance plans to include coverage for the cost of travel to access gender-affirming care, recognizing that a high proportion of patients are burdened with seeking care out of state. For the same reason, we also recommend that this care be covered at in-network rates regardless of care location. Finally, to address the lack of access due to internet or device affordability on a national level, policymakers could seek to expand the Affordable Connectivity Program and make permanent COVID-19 era waivers requiring insurance coverage for audio-only telehealth appointments via phone calls (US Health and Human Services 2022).

*Expand TNB care training at healthcare institutions*

We recommend the adoption of requirements for distinct clinical training in TNB care for healthcare workers. While new requirements should ultimately be implemented by accreditation organizations (e.g., the American Medical Association or Association of American Medical Colleges), medical training institutions can and should individually institute and advocate for the following policies to support TNB youth. Classroom instruction about TNB health trends, barriers to healthcare, and best practices for treatment should be disaggregated from larger discussions on LGBTQIA+ patient care. This allows time to discuss unique aspects of TNB health factors and treatment. Distinct training for this population can also allow for greater discussion on ways to alleviate current inequities, notably with the use of telemedicine and considerate electronic medical records intake processes. These practices and

long-term retention of this information should be implemented not merely in didactic learning settings, but importantly in pedagogical clinical settings. Implementation of this requirement is critical since roughly only half of surveyed colleges had any TNB training involving patient interactions (Dushyant Utamsingh et al. 2017, 163). While there are many challenges to implementing new medical education practices, the largest hurdle is likely the lack of educators at institutions that are already skilled enough to teach TNB healthcare practices (Dubin et al. 2018, 379-380). For this reason, we also recommend that institutions dedicate effort to training and developing educators in TNB healthcare. In time, medical schools and organizations should implement training requirements for licensing that include distinct clinical training for best-practice healthcare for TNB youth.

Finally, we recommend that any effort to create policy that supports the TNB community, and especially youth, should include mechanisms for involving this community in the policy development process. These efforts should ensure that “TNB individuals or groups are not put at increased risk of harm or raise their public profile in a way that could lead to backlash” and include “thoughtful consultation with TNB individuals and groups before and throughout any engagement designed to support them and their priorities” (US Agency for International Development 2021). This could involve meeting and requesting guidance from members of transgender community organizations, advocacy groups, and support services groups. Additionally, dedicated institutional offices could be created and tasked with ensuring consistent opportunities for TNB community members to privately and safely communicate feedback, and advisory groups led by TNB community advocates could be formed to ensure consistent community oversight of institutional policy efforts.

## **V. Conclusion**

Access to gender-affirming care from an early age is critical to the mental and physical well-being of TNB youth. Despite being a newer form of healthcare with limited regulation, this article argues that telemedicine provides an opportunity to help this vulnerable population. There is a lack of explicit, permanent legislation prohibiting discrimination in

medicine for TNB youth on the federal level, and the tone of the administration in power changes with each election cycle. State-level legislation concerning access to gender-affirming care varies widely, with some states offering explicit protections, some refraining from implementing any protections or bans, and others actively prohibiting gender-affirming care. Digital medicine can help break barriers to access for TNB youth, but shortcomings within this relatively new medical practice must be addressed so that telemedicine does not exacerbate existing inequalities. Expanded

access to digital healthcare services during the pandemic gave a sense of greater legitimacy to telemedicine. Medicare and Medicaid, along with state medical boards, issued waivers allowing for out-of-state medical visits facilitated by telemedicine. This key trend must be codified into state and federal healthcare policies. This article offers a suite of recommendations for various groups as there are multiple players in this field that can all offer something in service to TNB youth.

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