

# >OVERVIEW

As part of NASTAD's cooperative agreement (U69HA26846) with the Health Resources and Services Administration's HIV/AIDS Bureau (HRSA/HAB), the following issue brief provides AIDS Drug Assistance Programs (ADAPs) with considerations to develop systems, policies, and procedures that are responsive to the needs of transgender people who are living with HIV. This brief will highlight opportunities to leverage insurance purchasing programs, ADAP formulary compositions, and the collection of sexual orientation and gender identity data to implement meaningful programming for the transgender community. Please contact Britten Pund, Joe Caldwell, or Kelsey Donnellan if you have any questions or comments.



Facing the Facts: Emphasizing the Importance of ADAPs •

ADAPs across the nation hold the key to better, more equitable health outcomes for transgender people living with HIV.



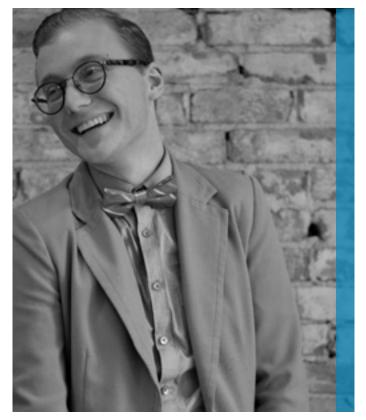


A growing body of empirical evidence has concluded that the transgender community is disparately impacted by HIV. Moreover, studies have found that Black transgender women are further disproportionately impacted by HIV with an estimated prevalence of 50% of women currently experiencing seroconversion of the disease. Recognizing this trend, the National HIV/AIDS Strategy (NHAS), updated to 2020, guides all pertinent stakeholders to implement interventions targeted at the transgender community as a necessary pathway to prevent new HIV cases in the United States. As programs mobilize to respond to this important challenge, it is imperative that ADAPs ensure that their interventions are informed by a robust understanding of the unique personal, societal, and structural barriers that impede access to care and treatment for transgender people.



### Setting the Space: Ensuring Trans Inclusivity (>)

From front-line staff to provider interactions, ensuring a safe space for transgender and gender nonconforming clients is essential in ensuring equitable health care.



### > BACKGROUND

The disparate impact of HIV on transgender people of color requires ADAPs to acknowledge the intersection of race and HIV and how this disease serves as an indicator of inequality.. To this end, salient statistics from the National Transgender Discrimination Survey include the following. The full report can be found here.

#### **EMPLOYMENT**

- The transgender community experiences double the rate of unemployment as the general population.
   Transgender people of color are exponentially impacted, with three and four times the rate unemployment compared to the national average for Hispanic and Black communities respectively.
- Of the employed transgender population, 90% report workplace harassment and discrimination.

#### FAMILY LIFE

- More than half (57%) of survey respondents reported experiencing family rejection based on their transgender identity.
- Nearly half (45%) also reported their relationships ending after they came out to their partner.
- Nineteen percent (19%) reported experiencing domestic violence by a family member because of their transgender or gender non-conforming identity.

### **IDENTIFICATION DOCUMENTS**

Of people who had already transitioned from male to female or female to male:

- Only one-fifth (21%) have been able to update all of their IDs and records with their new gender and one-third (33%) had updated none of their IDs/records.
- Fifty-nine percent (59%) reported updating the gender on their driver's license/state ID.
- About half (49%) reported updating the gender in their Social Security record.

### **HEALTH**

- Survey participants reported that when they were sick or injured, they postponed medical care due to discrimination (28%) or inability to afford it (48%).
- Refusal of care: 19% of our sample reported being refused care due to their transgender or gender non-conforming status, with even higher numbers among people of color in the survey.
- Harassment and violence in medical settings: 28% of respondents were subjected to harassment in medical settings and 2% were victims of violence in doctor's office.

Proper use of language and terminology is important when talking and writing about transgender people, their identity, and experience. In this document NASTAD uses a variety of terms related to gender as they are defined by National Center for Transgender Equality, to see full definitions please click here.



### **Understanding Gender Identity and Sexual Orientation** ( )

This video takes a deeper dive into gender variance and signals the importance of gender affirming and confirming care *inside* and *outside* the binary.





The Health Resources and Services Administration (HRSA) encourages ADAPs to purchase insurance for clients provided that the coverage meets two criteria: (1) the plan formulary includes at least one drug in each class of core ARVs from the HHS Clinical Guidelines, and (2) purchasing the plan is more cost-effective in aggregate as compared to directly purchasing medications.

As of 2015, the majority of the ADAPs in the United States engage in some type of insurance assistance. For transgender clients, insurance coverage represents an opportunity to access both HIV services, and gender-affirming care and treatment.



### Moving Forward: Insurance Coverage Reforms ( )

How are recent Affordable Care Act reforms affecting the insurance coverage landscape for transgender individuals?

## ASSESSING PLANS FOR GENDER-AFFIRMING CARE AND TREATMENT

The Affordable Care Act (ACA) includes specific protection and market reforms that aim to promote the equitable access of insurance coverage for historically marginalized communities, including transgender people. These protections include:

- Section 1557 of the ACA prohibits discrimination on the ground of race, color, national origin, sex, age, or disability under for the vast majority of the health care system. It protects transgender people and is the first federal civil rights law to prohibit sex discrimination in health care.
- Section 2702 of the Public Health Service Act (PHSA) requires that the majority of large group plans, including Qualified Health Plans (QHP), issue policies regardless of health status, medical condition (including both physical and mental illnesses), claims experience, receipt of health care, medical history, genetic information or disability.
- Section 1302 of the ACA extends access to ten essential health benefits for the vast majority of the private insurance market. This benefits apply to all eligible enrollees, regardless of sex and gender.
- Section 1311 of the ACA applies all of the aforementioned protections to QHPs and Marketplaces.

### > INSURANCE PURCHASING AND COVERAGE

Medication adherence among transgender people is heavily dependent on the availability of gender-affirming health services and continued hormone therapy. Although the extent to which members of the transgender community may avail themselves of various gender-affirming health services changes by the individual's experience, it is integral for ADAPs to assess plans to include coverage of care and treatment for the needs of transgender people. According to the Center of Excellence for Transgender Health, common treatment regimens for transgender people include: Estradiol, Progesterone, Spironolactone, Testosterone, Finasteride, and Monoxidil. In addition to prescription drug coverage, it may be useful to assess plan provider networks to ensure that they include transgender-friendly providers.

### NAVIGATING SEX-SPECIFIC UTILIZATION MANAGEMENT

As of September 2015, 49 ADAPs provide premium and/or prescription drug cost-sharing assistance to ADAP clients. While QHPs include myriad consumer protections provided by the ACA, there are still a number of insurance practices that may impact the speed at which transgender people can access gender-affirming services along with their HIV care and treatment. As this brief previously noted, transgender people often experience difficulty with ensuring that their identification documents reflect their gender identity rather than their sex at birth. Incongruence in documentation may trigger some insurance company system protocols to temporarily deny access to gender-affirming health services or for a healthcare provider to question the validity of a patient's gender identity. This insurance provider protocol is a type of sex-specific utilization management (UM). For example, sex-specific UM could occur if a transgender individual whose gender identity is that of a man, yet whose sex at birth was female tries to seek coverage for a testosterone treatment. Testosterone is medication typically prescribed to cis-gender men, which prompt some insurance companies to temporarily deny access to Testosterone and/ or seek clarification from the prescribing provider. QHPs and other insurance companies are not required to report sex-specific UM, however, they may elect to disclose their practices prior to enrollment. Contacting a prospective insurer to ascertain their sex-specific UM during insurance navigation for a transgender client is a good practice for ADAPs seeking to maximize enrollment opportunities for the transgender community.



The World Professional Association for Transgender Health (WPATH) regards comprehensive insurance coverage for those pursuing sex reassignment as essential:

The medical procedures attendant to sex reassignment are not "cosmetic" or "elective" or for the mere convenience of the patient. These reconstructive procedures are not optional in any meaningful sense, but are understood to be medically necessary for the treatment of the diagnosed condition. [See: Victoria L. Davidson v. Aetna Life & Casualty Insurance Co.] Further, the WPATH Standards consider it unethical to deny eligibility for sex reassignment surgeries or hormonal therapies solely on the basis of blood seropositivity for infections such as HIV or hepatitis.





In order to allow for a medically-supported cross-sex transition through insurance coverage, transgender or gender-nonconforming individuals must be diagnosed with "gender dysphoria," which is described further when clicking here. Following revised language used in both Diagnostic and Statistical Manual of Mental Disorders 5th Edition (DSM-V) and the International Classification of Diseases Tenth Edition (ICD-10) criteria for Gender Identity Disorders (GID) which includes "transsexualism" both entities responsible for the creation of such guidelines have recognized that usage of the term "dysphoria" over "disordered" removes the connotation that the patient is somehow abnormal while still supporting access to effective treatment options. While "gender dysphoria" may not be the preferred nomenclature to summarize the experience of transgender or gender nonconforming individuals, the term is important in realizing the process for medically necessary treatment. In reference to sex, or gender, reassignment being beneficial for the treatment of gender dysphoria the World Professional Association for Transgender Health (WPATH) expresses that:

Sex reassignment plays an undisputed role in contributing toward favorable outcomes, and comprises Real Life Experience, legal name and sex change on identity documents, as well as medically necessary hormone treatment, counseling, psychotherapy, and other medical procedures. Genital reconstruction is not required for social gender recognition,

and such surgery should not be a prerequisite for document or record changes; the Real Life Experience component of the transition process is crucial to psychological adjustment, and is usually completed prior to any genital reconstruction, when appropriate for the patient, according to the WPATH Standards of Care. Changes to documentation are important aids to social functioning, and are a necessary component of the pre-surgical process; delay of document changes may have a deleterious impact on a patient's social integration and personal safety.

These medical procedures and treatment protocols are not experimental: decades of both clinical experience and medical research show they are essential to achieving well-being for the transsexual patient. For example, a recent study of female-to-male transsexuals found significantly improved quality of life following cross-gender hormonal therapy. Moreover, those who had also undergone chest reconstruction had significantly higher scores for general health, social functioning, and mental health.

### > ADAP FORMULARY CONSIDERATIONS

ADAP formulary composition presents another opportunity to promote transinclusive care and treatment. Beyond the provision of ARVs, ADAPs play a critical role in supporting the availability of medications for many co-occurring needs of PLWH, including transgender transition-related medications. The Ryan White HIV/ AIDS Program Section 2616(c)(6) of the Public Health Service Act and HRSA policies require that (1) ADAP formularies must include at least one drug from each class of HIV antiretroviral medications; (2) ADAP funds may only be used to purchase medications approved by the Food and Drug Administration (FDA) or devices needed to administer them; they must be consistent with the Department of Health and Human Services' (HHS) Adolescent and Adult HIV/AIDS Treatment Guidelines; and all treatments and ancillary devices covered by the ADAP formulary, as well as all ADAP-funded services must be equitably available to all eligible/enrolled individuals within a given jurisdiction. ADAPs' inclusion of treatment medications for co-occurring needs demonstrates a commitment to addressing the full physical and mental health of the clients they serve. As of December 31, 2015, 16 ADAPs cover one or more FDA-approved transgender transition-related medications on their formulary.

All services must be provided by a physician or under the supervision of a physician or other qualified/licensed personnel.



### **ADAP Formulary Coverage: Hormone Treatments** ( )



The composition of a state's ADAP formulary may be a barrier to care for many transgender individuals. Watch here to see if your jurisdiction's ADAP is providing essential treatments for masculinizing or feminizing procedures.

Endocrine, or hormone, therapy is a common form of treatment to suppress the secretion of endogenous hormones based on the person's biological sex while maintaining the ideal secretion range of sex hormones for the person's desired gender. All transgender people hoping to pursue cross-gender transition must take anti-androgens, then either feminizing or masculinizing drugs. If the patient has been diagnosed with HIV, many providers will prescribe hormone replacement therapy alongside an ARV treatment regimen. While short-term and midterm studies on the safety of hormone therapy and antiretroviral therapy (ART) have shown the combination to be generally safe for patients, providers should be aware of the longterm risks of the dual therapy regimens. Long-term hormone therapy may increase the risk for some cardiovascular diseases, certain cancers, hepatic complications, and erectile dysfunction. Providers opting to provide hormone therapy alongside ART often choose to do so to encourage daily treatment adherence. Since the hormonal range must be maintained daily, coverage of these medications may be essential to ensure ART adherence as well.



# > ADAP FORMULARY CONSIDERATIONS

TRANSGENDER WOMEN	TREATMENT	ADMINISTRATION
FEMINIZING DRUGS	Estradiol Cypionate (Depa-Estradiol)	
	Estradiol Valerate (Delestrogen)	Intramuscularly
	Medroxyprogesterone acetate (DepoProvera)	
	Estradiol (Estrace)	
	Conjugated estrogens (Premarin)	Orally
	Micronized progesterone	
	Estadiol transdermal patch	Transdermally
TRANSGENDER MEN MASCULINIZING DRUGS	TREATMENT	ADMINISTRATION
	Testosterone Cyplonate	Intramuscularly
	Testosterone Enanthate	
	Testosterone Gel (Testim or Androgel)	Topically
	Testosterone Patch (Androderm)	Transdermally
ANTI-ANDROGENS	TREATMENT	ADMINISTRATION
	Spironolactone (Aldactone)	
	Flutamine (Eulexin)	Orally
	Finasteride (Proscar or Propecia)	
	Dutasteride (Avodart)	
	Cyproterone acetate (Andracur)	Orally or injectable

Please note: dose ranges for hormone administration vary based on the needs of the patient. The Center of Excellence for Transgender Health at the University of California San Francisco lists suggested prescription ranges for applicable hormones once a patient has elected to pursue cross-sex transition and undergone appropriate pre-assessment and monitoring protocol. To see the suggested prescription ranges, please click here.





A national movement is afoot to collect inclusive and comprehensive data related to a person's sexual orientation and gender identity (SOGI). Along with updated reporting standards, the Centers for Disease Control and Prevention (CDC) and HRSA have started to include SOGI information on national health surveys. The CDC collected SOGI data on the flagship National Health Interview Survey and starting with the 2014 Behavioral Risk Factor Surveillance System, while HRSA included SOGI information and sex at birth on the 2014 ADAP Data Report (ADR). The ADR uses a three pronged approach by asking whether a person's current gender, if they indicate transgender they are asked for more detail and lastly for their sex at birth. See page 19 of the ADR Manual for the specific wording and system logic.

Beyond reporting, medical staff can use these sections to properly identify patients. Social support among openly transgender people is critical within the medical setting, many of whom seek services from trans-inclusive clinics, hospitals, and/or providers. Trans-inclusive services should be gender-affirming and mindful of the medically necessary services based on the person's biological sex. WPATH has published Standards of Care for providers of transgender people, which can be referenced here. Community-based organizations (CBOs) are great frontline resource for many individuals who may have had negative experiences with staff at larger medical establishments. Some CBOs and clinics develop targeted messaging for transgender



## Sexual Orientation and Gender Identity Data Collection: Best Practices ( )

Accurate gender identity and sex-at- birth data is important to understand the impact HIV has on transgender individuals. What can your jurisdiction do to ensure that your clients' gender identity is accurately recorded?

individuals, [click on the posters in the frame above to see more targeted messaging] which may help to ensure a safe and inclusive environment. Apicha Community Health Center in New York released a messaging campaign to promote pelvic exams for transgender men, who they refer to as men of the trans experience. See their presentation materials here. For best practices from the Center of Excellence for Transgender Health at UCSF related to culturally competent and trauma-informed client engagement, click here.

When collecting sexual orientation or gender identity data it is important for providers to gauge whether questions are potentially harmful to the patient, clinically relevant for data recording, and if they provide a holistic view into the patient's identity and needs. The National LGBT Health Education Center released the top ten actions that can help create an inclusive health care environment for transgender, gay, lesbian, and bisexual people, click here to see their recommendations.

# > ACTION STEPS

ADAPs and providers are uniquely positioned to align with the goals of the NHAS by:

- Including transgender-specific considerations into insurance purchasing plan assessments, being mindful of plan policies and practices
- Including gender-affirming treatments on ADAP formularies
- Promoting the collection of sexual orientation and gender identity data
- Including transgender-inclusive considerations on forms, communications, and publications
- Partnering or contracting with organizations that are run by transgender people, or are majority staffed by transgender people.
- Supporting syringe exchange services for clients who are injecting hormones or silicone, for feminization or masculinization, without medical supervision.

ADAPs and providers must directly engage transgender and gender nonconforming people in order to understand the systemic and day-to-day barriers many experience when attempting to engage in health care services. While cultural and gender-based training for staff can be a step in the right direction, intentional and direct input from transgender individuals is essential to create a support system that is safe and inclusive of all. The goals in NHAS 2020 will not be achieved if we do not bring the voices of those most impacted to the table.

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