TRANSGENDER HEALTH:
Improving Access to Care Among Transgender Men & Women Living with HIV/AIDS under the AIDS Drug Assistance Program: Model Policy for Ryan White/ADAPs Serving Transgender Clients

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ACKNOWLEDGEMENTS

The ADAP Advocacy Association believes that the voice of persons living with HIV/AIDS shall always be at the table and the center of the discussion – including transgender and gender nonconforming patients. In 2016, a new project was launched by the ADAP Advocacy Association to improve access to care and treatment for transgender men and women living with HIV/AIDS. The project – “Improving Access to Care Among Transgender Men & Women Living with HIV/AIDS under the AIDS Drug Assistance Program (ADAP)” – aims to raise awareness about issues confronting transgender men and women living with HIV/AIDS who also access care and treatment (or whom could benefit from such care and treatment) under ADAP, as well as provide useful resources and tools to the communities serving them.

This white paper is an important part of that project. The project is funded, in part, by grants received from Gilead Sciences, Janssen Therapeutics, and ViiV Healthcare. (Disclaimer: The findings included in this white paper do not necessarily reflect the views of the project’s funders)

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This white paper could not have been made possible without the cultural competency insights provided by the team at RAD Remedy. Special thanks to Rachel Hennessy and Riley Johnson for their significant contributions and collaboration. RAD Remedy's mission is to connect trans, gender non-conforming, intersex, and queer folks to accurate, safe, respectful, and comprehensive care in order to improve individual and community health. In 2017, RAD Remedy aims to release the first-ever national standards for TGIQ health. Based on the CLAS standards (National Standards for Culturally and Linguistically Appropriate Services in Health and Health Care) and adapted for our communities, these will establish community-driven best practices and competencies for providers to meet.
“Provider cultural competency, as well as affirming forms and systems results in better health outcomes and greater patient retention. The path to treatment adherence starts with forms, systems, and providers equipped to meet clients where they are.”
- Riley Johnson, Executive Director of RAD Remedy

“Among people with HIV using Ryan White HIV/AIDS services, transgender people are less likely, than patients overall, to remain in care (78% vs. 80%) and to achieve viral suppression (74 vs. 81%).”

Considering the overwhelming amount of transgender people at-risk for or living with HIV/AIDS, it is imperative that clinical professionals understand why this discrepancy exists and what they can do to directly impact the rates. One of the main causes for this discrepancy is the various barriers transgender people face within the public, health, and social service sectors. Per the 2015 U.S. Transgender Survey, barriers to care include actual, perceived, and fear of discrimination, harassment, and violence in public accommodation, health care, and public service settings. These stressors and events of discrimination compound and manifest into a general distrust by transgender clients of the “services/systems” and providers. The key to overcoming this distrust, increasing adherence and efficacy, and reducing transmission rates rests in comprehensive competency.

1 Highleyman, L. (2016, March). Transgender people are at high risk for HIV, but too little is known about prevention and treatment for this population. NAM aidsmap.

Background

According to the Centers for Disease Control & Prevention (CDC), transgender communities in the United States are among the groups at highest risk for HIV infection.\(^3\)

The CDC reports the following key demographic data:\(^4\)

- Highest percentage of newly identified HIV-positive test results was among transgender people (2.1%), compared to HIV-positive test results among males (1.2%), and by females (0.4%);
- Among transgender people in 2010, the highest percentages of newly identified HIV-positive test results were among racial and ethnic minorities:
  - Blacks/African Americans comprised 4.1% of newly identified HIV-positive test results;
  - Latinos comprised 3.0%;
  - American Indians/Alaska Natives and Native Hawaiians/Other Pacific Islanders (both 2.0%);
- 73% of the transgender women who tested HIV-positive were unaware of their status; and
- HIV prevalence for transgender women was nearly 50 times as high as for other adults of reproductive age.

Among male-to-female and female-to-male transgender persons, there exists a high prevalence of clinical depression (44.1%), anxiety (33.2%), and somatization (27.5%).\(^5\) The Department of Family Medicine and Community Health, Medical School, University of Minnesota concluded that the minority stress model necessitated education to “…confront social structures, norms, and attitudes that produce minority stress for gender-variant people; enhance peer support; and improve access to mental health and social services that affirm transgender identity and promote resilience.”\(^6\)

Furthermore, transgender persons experience numerous healthcare-related disparities. The extent of this barrier to health care is unknown, since “U.S. health surveillance systems infrequently include measures to identify transgender respondents or monitor the health of this underserved and marginalized population.”\(^7\)

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Why Does It Matter?

Statistics show an increasing need exists for HIV/AIDS services and supports directed specifically towards transgender men and women due to the alarming rate at which the disease is affecting the community. The exact number of transgender people impacted by the disease is unknown due to inconsistent transgender-inclusive recording in HIV/AIDS research; however, estimations can be gathered by various reports released in the past few years. According to a 2016 CDC publication, “findings from a systematic review (Herbst et al.) of 29 published studies showed that 28% of transgender women had an HIV infection, while 12% of transgender women self-reported having HIV.” The publication also reports that “among the 3.3 million HIV testing events reported to the CDC in 2013, the highest percentages of newly identified HIV-positive persons were among transgender persons.” While the most alarming rates target transgender women and transgender women of color, the CDC still makes note “that transgender men who have sex with men are at substantial risk for acquiring HIV.”

This finding is corroborated by the 2015 U.S. Transgender Survey released by the National Center for Transgender Equality in December 2016. Of the 27,715-transgender people surveyed, 1.4% reported living with HIV. When comparing the results to the national rate (0.3%) transgender people are reportedly nearly five times more likely to be living with HIV. Transgender women are reportedly 11 times more likely to be living with HIV (3.4%) and black transgender women are 65 times more likely (19.0%) when compared to the national rate. To put these statistics further into perspective, 34% of the U.S. adult population gets tested for HIV. Therefore, it is a high probability that these rates are even higher. It is uncertain how many of the 66% untested U.S. adults identify as transgender, however, it is imperative that healthcare spaces are not fostering barriers to allow these individuals to access the care they need. The remainder of this paper will further address common barriers that exist within various public systems, actions that can be taken to address barriers, best practices, and recommended competencies for transgender-inclusive care.

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Healthcare as a System

Immediate barriers to care. First impressions are key to creating a transgender-affirming space, including healthcare environments. There are nuances that transgender individuals note within the first few moments starting at greeting. Some of the major barriers are as follows:

- **Assumption of gender pronouns**; “Mr/Ms” or “he/she” from staff either on the phone or during the first visit
- **Perceptions of an absence in “friendliness” and competence** among medical clerical staff
- **Lack of deference to client autonomy** (i.e., “preferred name” field on forms/systems and staff using legal not preferred name)
- **Lack of intake forms’ ability to accurately communicate client gender** (i.e., “sex” or “gender” field only relating to “male” or “female” rather than comprehensive listing or additional fields: e.g., “sex assigned at birth,” “legal gender/gender on insurance,” “pronouns,” and the inclusion of gender options such as Female-to-Male [FTM], Male-to-Female [MTF], Intersex, Gender Non-conforming [GNC], and Agender)
- **Up to date coding competency for billing**; some systems still use ICD-9 rather than ICD-10 thus causing patient portals to show internal codes labeled “transvestism” rather than “gender identity disorder”

Forms and systems recommendations. Adjusting to transgender competencies does not happen in one step. It can take time and minor goals to start the momentum. A simple first step is to create a Community Advisory Board comprised of the populations you serve. Use them as a resource for feedback on proposed changed, new initiatives, etc. Take their recommendations and devise a realistic time-oriented plan to turn the feedback into action.

Also, consider the technology and the EMR/EHR systems that are used. Select a system that handles legal vs. chosen name, birth gender, current legal gender (as designated on insurance), current gender (as designated by client), and pronouns used. One vendor that currently meets this need is AthenaHealth.  

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You also want to be sure that the system includes the ability to search by chosen name and institute this as formal intake practice for all clients (not just transgender people). If this system is not possible due to finances, consortium agreements, etc., form a committee comprised of staff, CAB members, and providers to consider possible workarounds using the current system.

Have a clear, succinct feedback process for all patients, including the ability to have a direct connection to someone in the weeks after the visit. A clinic, for example, could institute a practice where patients would submit a very brief survey at the close of each visit. It would yield valuable data on their client demographics and needs. This practice can later be used for program decisions and further appeals, but more importantly, it would provide a standard and a consistent opportunity for ongoing feedback. A clinic could also provide contact information in case additional issues came to light in the days following a visit. This approach is highly recommended as some patients have a lot of trauma around seeking care and it can take some reflection before choosing to submit feedback.

Transgender-specific data are limited. Currently, many federal, state, and local agencies inaccurately collect data about individuals’ sex and gender. Using a two-step data collection method - asking for sex assigned at birth and current gender identity - can help increase the likelihood that transgender people will be accurately identified in HIV surveillance programs.

Changes such as those outlined above provide various benefits to agencies. First and foremost, it eliminates “atmospheric” barriers such as a perceived “hostile” environment, thus allowing for an opportunity to welcome a wider clientele. Secondly, it allows agencies to remain compliant with federal guidelines. The Health Insurance Portability and Accountability Act (HIPAA) guidance included in the final rule of Affordable Care Act (ACA) 1557 states that “failure to comply leaves an agency open to liability.” It is also worth noting that the ACA allows for a wider range of client suites for failure to comply. In short, the lack of transgender-inclusive competencies has the potential to result in legal ramifications. Finally, there's “only one chance to make a first impression.” There is a high probability that many clients may not return if there is a blatant or subtle lack of inclusion/competency even if the medical care is considered “critical.” Therefore, by a simple act of omission, agencies directly or indirectly turning away individuals who are need services.

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“Customer Service”: Non-Provider Medical and Non-Medical Staff Interaction

Secondary barriers to care. It is equally as important to have staff trained in gender identity-affirming customer services as it is our professional medical and non-medical staff. The individuals working behind the front desk and answering the phones are normally the front line of client interaction. They are the ‘first impression’ from an agency standpoint. A first step is having a conversation with these individuals about gender pronouns and gender-neutral greeting options. If need be, agencies can create a gender script for phone conversations until new policies become habit. No client is a “clean slate,” all clients come with history of personal experience. Self-preservation places experiences of discrimination, harassment, and violence at the forefront. Because of these experiences, some clients may approach health care settings from a place of defensiveness or “on the defense”. Trauma informing experiences are not limited to medical services. Twenty percent of transgender individuals avoid accommodation settings due to fears of being harassed, assaulted, and denied services. Fourteen percent of those surveyed in the 2015 U.S. Transgender Survey reported being denied services in places of public accommodation due to transgender identity; 24% reported being verbally harassed in places of public accommodation. These numbers are the exact reason why transgender individuals go into new situations hyper-vigilant. A well-trained front line can help diffuse this hyper vigilance within the first interaction.

Overcoming barriers. To learn more about creating a safer environment within your organization RAD highly recommends referring to their “10 Tips for Working with TGQI (transgender, gender non-conforming, intersex, and queer) Patients” [attached]. This document was created with the intent to help diffuse the barriers TGQI patients face when attempting to access care. Though the research on transgender health disparities is somewhat limited, between the two U.S.-based Trans Discrimination Surveys as well as RAD Remedy’s own community needs assessment, many of the barriers are apparent. This document offers concrete steps for providing competent care.

The most prominent barrier for TGQI people to seek care is feeling like they will be unable to access safe and affirming care. A majority, if not nearly all, of TGQI people have faced discrimination in medical and care settings. According to, the U.S. Trans Survey, 28% of transgender individuals reported overt discrimination (e.g., verbal and/or physical harassment), while 15% reported experiencing such discrimination in the past year. Nineteen percent of respondents reported that they have been refused care within their lifetime, 11% within the past year, due to their transgender identity. Fifty percent of the respondents reported covert discrimination (e.g., misnaming, mis-gendering, and/or a lack of provider competency around their care) within their lifetime, and 24% experiencing within the past year. This widespread, and, frankly, anticipated, discrimination creates a situation that makes many TGQI people averse to seeking any care at all. In fact, 23% of transgender people reported avoiding seeking medically necessary care within the last year because of a fear of discrimination.

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14 RADRemedy utilizes the acronym “TGIQ” to denote the most inclusive language and reach with regard to the spectrum of gender identity
Personal stories from RAD Remedy’s needs assessment mirror these statistics. Some of the responses include:

"My [doctor] doesn't treat me like a person.”
"I have had a provider tell me they couldn't serve me because I was trans."
"I once had to pull out my own catheter because a nurse didn't want to touch me."
“[I’m] tired of putting off visiting the doctor for fear of bad care.”
"Searching [for providers] and testing each place is draining and exhausting."
"[My] experiences have made me distrust the medical and mental health care systems."

A combination of provider competency and mindfulness to create affirming care spaces will help to solve many of these issues. Respect and understanding goes a long way in this regard. RAD Remedy’s “10 Tips” serves as an easy and actionable starting point to providing competent safe, affirming, and accessible care for TGIQ individuals. RAD Remedy’s National Standards for TGIQ Health (to be released in 2017) will provide a solid understanding of what a provider and institutional competency is, as determined by the community directly impacted.

**Medical Competency Tools**

Various organizations have created resources to aid in the process of developing and implementing competency trainings and policies. The ADAP Advocacy Association recommends the following organizations for medical competency training resources:

- AETC programming ([http://aidsetc.org/searches/transgender](http://aidsetc.org/searches/transgender))
- WPATH Global Education Initiative ([http://www.wpath.org](http://www.wpath.org))
- RAD Remedy ([http://www.radremedy.org](http://www.radremedy.org))
In 2017, RAD Remedy will be launching the provider Competency Project that can be broken down into four parts:

**National Standards for TGQI Health (early 2017):** based on the U.S. Department of Health and Human Services CLAS standards (National Standards for Linguistically Appropriate Services in Health and Health Care) and adapted for transgender, gender non-conforming, intersex, and queer communities. These will establish community driven best practices and competencies for providers to meet.

**Provider Training Calendar (2017):** RAD Remedy will assemble an independent, nationwide training database mapping existing trainings to the National Standards, creating a learning structure for providers and identifying gaps in existing training. Whenever possible, the project will prioritize asynchronous webinars as they provide flexibility in timing and location for all who desire training, aiding in accommodating a provider’s busy schedule and the unique needs of rural providers.

**Provider Training Curriculum (Late 2017/Early 2018):** RAD Remedy will be adapting the CLAS standards and existing trainings into a comprehensive curriculum that can be delivered to health science and other care providers. The goal of this project is to work within existing educational structures to ensure that care providers in training receive comprehensive cultural competency trainings.

**RAD Certified (2018):** providers will supply evidence of continuing education they have taken or taught on topics related to TGQI populations (mapping to the National Standards), and in turn, RAD Remedy will provide a badge on the provider’s listing on their national database and optimize search results for users.

Another important aspect within medical competencies is medication interactions. There is limited information on drug-to-drug interaction between hormone replacement therapy (HRT) and antiretroviral therapy (ART). As a medical professional, it is best to stay informed and keep watch for developing information as it becomes available. It must be noted that often transgender clients may prioritize transition-related care (e.g., hormone replacement therapy) over HIV related care (e.g., antiretroviral therapy) and that is okay. For many transgender people, gender affirmation is as critically important to survival as HIV management, if not more so. As a provider, you must allow a patient to assign care prioritization.

Given individual prioritization of care needs vary from client to client, expanded formularies that include coverage for transition-related care (i.e., HRT) may not only incentivize transgender clients to remain in care who may otherwise be hesitant to seek and maintain services, but increase overall access to and engagement in comprehensive care. Certain HRT regimens are already included in limited ADAP formularies, i.e., testosterone in NY ADAP formulary can be written to treat wasting. Because HRT also requires regular monitoring through labs (some of which overlap with ART labs), inclusion in ADAP formularies, in theory, consolidates client need to reach multiple providers and expand efficacy of care, leading to improved adherence in both HRT and ART regimens and further improved health outcomes.

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Non-Medical Facilities Competency

Clients often rely on providers as primary access points for information regarding additional services. In order to facilitate client comfort in requesting additional services and referrals, clients may rely on subtle signs of inclusive atmospheres such as signage, literature competency, and employee familiarity with affirming guidance and rules. Signage in agency and provider facilities should meet all OSHA and ADA compliance (i.e., restroom signage). For best practices recommendations refer to Fenway, WPATH, Whitman Walker, and other technical assistance from Federal government (i.e., HRSA’s TAC, and AETC). The CDC is expected to release updated standards of care for HIV positive transgender clients later in 2017, make sure to conform accordingly. This past year, 2016, was a landmark year for agency rulemaking and guidance with regards to transgender competencies. Some of these rules/guidance may impact wrap-around services (i.e., HUD expanded guidance to include appropriate placement for transgender persons in single sex facilities)\textsuperscript{20}.

“Back End” Competency: Human Resources for Employees/Students

Best practice within Human Resources, related to the work place or academia almost identical to best practice of “forms and systems” within a medical environment, sans HIPAA compliance. Be sure to utilize an HR or academic record system that is equipped to appropriately document the intricacies of an individual’s transgender identity (e.g., legal name, chosen name, birth gender, legal gender [as designated by gov’t ID], gender identity [as designated by client], and preferred gender pronouns). Be sure said system has the ability to search for a client by chosen name rather than legal name and institute this as formal clerical practice regardless if a client does or does not identify as transgender. If this is not possible, in the same fashion as the medical realm, form a committee comprised of stakeholders to consider possible workaround using the current system.

An academic institution, for example, may only allow legal names within their system. One enrolled student may have a name change pending while preparing to start an online class. If the student is worried that his birth name would automatically populate on the roster and out him, a transgender-competent staff member at the institution may seek to make it so that the university would allow the student to instead use first initial of his legal first name and last name (e.g., J. Smith instead of Jane Smith). This would allow the student to say, “I go by David” and sign online posts at himself rather than being forcibly outed by an administrative system.

Aside from the committee, designate a specific liaison for TGQI, and LGBA, individuals. This person would help employees/students navigate the complexities of various transgender-related concerns such as familial benefit coverage, transition processes, and interpersonal/conduct concerns (e.g., transphobia or homophobia). Having a transgender-competent liaison would help foster an environment in which TGQI employees/students feel more comfortable coming out, transitioning on the job or at school, and reporting discrimination.

In addition, have a clear HR procedure for general inquiries as well as formal and informal complaints. This procedure should include the designation of a specific culturally competent HR employee to process LGBTQIA complaints/grievances.

Advocate for transgender-inclusive insurance offerings in institutional benefit packages, including full spectrum reproductive health, hormones, and transition-related surgical coverage. If this proves impossible under your current system, a possible workaround is a health and wellness stipend given from the agency each pay period. The employee can use this stipend for a gym membership, saving for surgery, or other health goals.

It is also important to making a point to hire TGQI peoples when possible, including HR positions. TGQI patients/student/employees feel significantly more comfortable in environments where share identities with staff, faculty, and coworkers. This hiring practice also allows for increased institutional cultural competence due to these individuals’ lived experiences and the way they already interact with the world, including other employees. Some entities should also be aware of their federal contractor status, as federal contractors (i.e. accepting Medicare/Medicaid grant monies) are prohibited from discriminating on the basis of sexual orientation and gender identity in hiring practices.21

Another way to ensure that transgender competency becomes an agency practice is to include TGQI competence and procedures in any new hire orientations. In the same respect, make sure that those leading the trainings are up to date. Have HR staff members, specifically any liaison or people designing/leading orientations, received regular TGQI competency training.

All in all, “practice what you preach.” Regardless of personal gender identity be an ally within your system. Peer advocates create an open and welcoming environment for transgender clients. At the same time, it allows for a level of visibility that reinforces a sense of safety. Internal competencies mechanisms help reinforce this mentality by provided employees for best practice framework that can be applied in social and work conversations. Finally, clients talk. Internal referrals within the transgender community are a common practice. Agency/provider perception within the served and surrounding communities helps to ensure effective outreach, referrals, and retention of clients. In short, be a “positive presence”.

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Conclusions

**Comprehensive competency.** Competency needs to be comprehensive. Transgender specific barriers and concerns are directly compounded by the intersection of the client’s various identities. Thus, the various barriers-to-care directly impact clients that each their intersecting identities face. Take note that clients may not prioritize identities in the same way. For example, some clients may see themselves as a “transgender, black, heterosexual woman” while another client may see themselves as a “white, gay, transgender man”. Comprehensive competency recognizes compounded barriers to care with regards to a person’s identity.

**Ongoing concerns.** Most the research regarding trans health and HIV surrounds transgender women, and it provides an opportunity to learn. Considering that their rates of infection are exponentially higher than trans men, the focus is logical. Transgender men’s sexual health, however, has been understudied. Additional research is needed to understand HIV risk behavior among transgender men, especially those who have sex with men. A 2016 review found only 10 quantitative studies (all in North America) with laboratory-confirmed HIV serostatus among trans masculine people. Among these, documented HIV seroprevalences were 0%, 2.2%, 3.0%, and 4.3% (1 of 23 individuals)\(^\text{22}\). There exists few HIV infection data about non-binary people. Those individuals are underrepresented in current clinical and epidemiologic research.

**Becoming your client’s “advocate”**. A healthcare provider is often trusted with the most intimate details and developments in a person’s life. That information is powerful in allowing a provider to advocate for individual patients in meaningful and individually impactful ways (e.g., insurance coverage, appeals, governmental policy advocacy, and otherwise addressing the individual and community needs of clients). Utilize your role within your own agency and profession to create change in policy, practice, and in your clients’ lives.

**Community involvement.** Be visible as a competent provider, participate in community organizations and events as allowed by agency policy. Reinforce positive perception of your agency within community spaces and events.

**Client retention.** Finally, Gender Affirming Care in HIV care settings is critically important to client retention and achieving positive health outcomes.

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References:


