



NATIONAL STANDARDS OF CARE FOR TGIQ HEALTH

A COMMUNITY-DRIVEN UNDERSTANDING OF COMPETENT
CARE FOR TRANS, GENDER NON-CONFORMING,
INTERSEX, AND QUEER INDIVIDUALS

ABOUT RAD REMEDY

RAD Remedy, founded in 2014, is dedicated to its mission - **connecting trans, gender non-conforming, intersex, and queer folks to accurate, safe, respectful, and comprehensive care in order to improve individual and community health.** RAD's board members and team members live and work remotely throughout the United States, and members are drawn from the communities that RAD serves, making RAD uniquely qualified (and uniquely positioned) to help guide health care practitioners towards more culturally competent care as determined by members of the TGIQ communities.

RAD Remedy is a 501(c)3 non-profit organization funded through the generosity of individual donors, grants, and through sales of its health care zine series and other merchandise. For more information on RAD, please visit our website, www.radremedy.org.

AUTHORS

Eliot Colin
Rachel Hennessy
Riley Johnson
Rowan Lowden
Sarah Sloane

ILLUSTRATIONS BY ISABELLA ROTMAN | ISABELLAROTMAN.COM
BOOKLET DESIGN BY ROB ZALAS | TITANVISUALS.COM

SPECIAL THANKS TO THOSE WHO VOLUNTEERED THEIR TIME AND EXPERTISE AS BETA READERS, EDITORS, AND SOUNDING BOARDS. IT WAS TRULY A COMMUNITY EFFORT!

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CULTURALLY COMPETENT CARE - YOUR CHALLENGE

A decorative horizontal arrow pointing to the left, with a vertical line crossing it in the middle. The arrow is pink and the vertical line is light blue.

One of the most basic needs that any human being has is health care, and here in the United States, it has been a consistent struggle to adequately deliver care to every person regardless of their race, gender, financial status, and background. Yet while governmental and legal interventions over the past decade (such as the efforts by the US Department of Health and Human Services to define and describe what constitutes “culturally competent care”)¹ have minimized barriers to care for millions of Americans, tremendous challenges still exist for people in marginalized communities. As health care providers, regardless of your specialty or patient demographics, your goal is to continually provide compassionate, culturally and linguistically appropriate care to all of your patients. However, this challenge is made even more difficult because there are few, if any, guidelines to providing care that are centered on the experiences and needs of people whose gender and sex is outside of the binary.

As an organization created by and centered on Trans, Gender Non-Conforming, Intersex, and Queer (TGIQ) people, RAD Remedy seeks to provide stronger connections between people who are TGIQ and the professionals that serve them; this includes offering guidance to professionals who are attempting to create higher standards of care for their patients. By evaluating the current legal standards for non-discriminatory health care access through the lens of the communities experiences and needs, we have developed these guidelines to help professionals in all types of organizations (from single-practitioner offices to major hospitals) determine how to raise the level of care for their TGIQ patients and positively affect the ongoing health and wellness of our larger communities.

How critical is culturally competent care from a patient perspective? Let’s take a look at some statistics:

- One out of every four respondents to the largest-ever survey of Trans people reported that they did not seek medical care because of fear of mistreatment, and for good reason – the same study reported that 1 out of every 3 respondents had at least one negative experience when accessing medical care in the previous year. These experiences range from having to educate providers about basic gender information, to physical and mental harassment, to denial of care, and beyond.²
- When it comes to mental wellness, 39% of respondents in the above noted survey experienced major psychological distress in the month prior to their survey involvement (a rate nearly 8 times higher than the national average of 5%).
- 91% of Transgender respondents stated that they desired counseling, hormones, or puberty blockers at some point in their gender transition, however only 65% reported having received those critical forms of care.
- Numerous people in RAD’s most recent needs assessment survey reported that lack of appropriate patient intake forms and procedures (for example, having only two gender options, or reflecting only the legal name and not the patient’s preferred name) led to their own hesitation to continue working with the doctor or practice.

CLAS STANDARDS IN ACTION

RAD Remedy has compiled these action points to help practitioners review the efficacy of care they offer to TGIQ patients. These same guidelines can also build a wider cultural understanding of gender and sexuality for both staff and patients by presenting TGIQ identities and experiences in authentic, positive ways. Raising the visibility and understanding of TGIQ people in our daily culture has an overall positive impact on the respect offered to these community members, which can result in an even greater long-term effect on the physical and mental wellness within the TGIQ communities as a whole.

In general, the TGIQ communities want medical professionals to respect and affirm their identities and support their right to determine their own needs and their own care plans, while also treating them accurately for their presenting issues without bias or shame. We have ample studies that show that when health care professionals fail to offer culturally competent care to TGIQ people, these patients tend to avoid all medical care - including general health care and emergency care. Similarly, when TGIQ people seeking a medical transition cannot access transition-related medical care that is respectful and free from bias or shame, they will often avoid other medical care as well.

The following are steps that should be taken, involving all levels of patient care, in order to create an environment that is safe and affirming for TGIQ people. This gives them the needed support to be able to trust the professional guidance and treatment offered by practitioners, which gives them the confidence to build relationships with medical care providers on an ongoing basis, thus improving any treatment adherence and overall wellness.

PATIENT / PRACTICE INTERACTIONS

From the moment that a patient receives a referral to a provider, and throughout their interactions with the practice in person and via phone or online, the patient should feel respected, welcomed, and empowered. These guidelines offer a structure for interactions that ensure that TGIQ patients feel safe and heard.

- Patients should be given copies of HIPAA regulations that include gender identity and sexual orientation-affirming language.
- Creation of a community advisory board that includes diverse community representation from trans, gender non-conforming, intersex, and queer communities and organizations should be considered, especially in larger practices and facilities, (note: traditional LGBT organizations may not effectively cover the needs and experiences of TGIQ people, so additional organizational engagement may be necessary).
- Patient surveys should offer language to help patients note both positive and negative experiences, and use open-ended questions to create room for patient to give feedback fully and accurately regarding their experience. Surveys should also allow for distinct ratings of personnel (intake, provider, other staff etc.)

- Patients' bill of rights should include sexual orientation and gender identity-specific language, and the practice's grievance/complaint/feedback procedures should clearly encompass issues specific to TGIQ individuals and be transparent in their process and easily accessible and understandable by laypeople.
- Patient's preferred name, gender, pronouns, and other terminology should take priority over any other names, pronouns, or terms used by family or friends of the patient. The patient's preferred names and terminology should also take precedence over the name or gender marker on any legal identification, except when necessary for insurance billing purposes. Additionally, the patient's living conditions, personal values, and cultural needs should directly inform any treatment plans, and those plans should be developed cooperatively with the patient, including the prioritization of any treatments.
- All patients should be addressed by the pronoun that they choose; if you don't know the correct pronoun, please use "they", "them", or "their" until you have an opportunity to confirm the patient's pronoun with them directly. Once they have stated their pronoun, please ensure that it is recorded on charts and intake forms in a way that allows other staff who interact with the patient to address the patient correctly.
- As whole people, TGIQ patients have additional identities - such as race, disability, socioeconomic class, HIV status, etc. - and staff should be comfortable providing competent care for all of their varied identities, in order to more effectively support the wellness of the patient.
- Due to numerous factors including poverty, discrimination, and harassment, a substantial percentage of trans and gender non-conforming people currently engage (or have engaged in the past) in sex work and street-based economies (current studies show over 10% of trans people have engaged in sex work, and the rates are significantly higher for trans feminine people and trans people of color). Providers should be able to offer non-judgemental, affirming, and professional care to these patients, including using a harm reduction, client-centered framework for treatment, and offering resources that support the patient's choices.³

“ Multiple medical professionals have misgendered me, denied to me that I was transgender or tried to persuade me that my trans identity was just a misdiagnosis of something else, have made jokes at my expense in front of me and behind my back, and have made me feel physically unsafe. I often do not seek medical attention when it is needed, because I'm afraid of what harassment or discrimination I may experience in a hospital or clinic. ”

- In caring for minor patients, parents and guardians should be strongly encouraged to engage in consent-based, affirmative, collaborative care plans that are driven by the needs of the minor child, including the child's decisions and wishes; this should include delaying any non-critical non-reversible surgical interventions (especially relating to genital alterations) until the child is old enough to take part in those decisions, and/or

using hormone blockers or hormones to halt or initiate puberty. Parents and guardians should be given resources that are appropriate to their child's diagnosis or wellness, including support groups, professional referrals, and scholarly works. Practitioners should receive training on how to work with parents and children in collaboratively creating affirming care.

- Patients whose point of contact / emergency contact is a non-marital relationship or distant legal relative should be offered information on ensuring health care decisions are being made by the person that they designate, rather than deferring to the closest legal relative. This may include offering HIPAA waivers to all patients, as well as counseling patients on obtaining permanent waivers to ensure that their point of contact is able to legally obtain their health records and advocate for them.
- Interpreters that work with patients should be able to communicate with appropriate language and terminology to and about TGIQ patients.
- Patient handouts should include images and language that is inclusive of trans, gender non-conforming, intersex, and queer patients; this should include general information handouts, as well as those specific to particular illnesses, treatment plans, and self care education. [RAD Remedy has a helpful zine series that may assist in this regard.]
- Referrals to other practitioners (specialists / paramedical treatment providers) should confirm that the specific referred practitioner demonstrates a commitment to culturally competent care for TGIQ patients, including understanding of risk factors that may influence these patients.

PAPERWORK

All forms that relate to patient care, from intake forms to insurance billing, must acknowledge and respect the patient's identity. These forms can help staff throughout the practice use appropriate language and terminology, clarify differences in how insurance billing should be handled, and ensure that the patient does not have to consistently correct staff or otherwise advocate to be treated in the manner in which they deserve.

- Please select an EMR/EHR system that offers preferred name options within the patient's file; if your EMR/EHR system does not include this feature, an in-system alert should be created to provide the patient's preferred name for use by staff when calling the patient in the waiting room and providing treatment. Additionally, notifying EMR/EHR system developers of the importance of this feature when communicating update and bug fixes will help ensure that this option is more widely available.
- All patient forms, including those accessible by staff, should include the patient's name, any preferred name(s), pronouns, and specific terms that the patient uses for their body. These should be highlighted in some way to assist staff in ensuring that the patient's name and affirming terms can be used exclusively.

“ My general practitioner’s office (billed as the go to office for trans people in Pittsburgh) frequently sends mail with my legal name as opposed to preferred name, leaves reminder messages with legal name versus preferred name. I addressed these concerns with my doctor and felt dismissed by her explanation that it’s just the way the system works. ”

- Assigned sex at birth may be listed on the medical forms, but should not be used other than in medical history and to inform treatment.
- For insurance and billing, note the gender marker that is to be used for billing purposes (as that may be different than the patient’s gender identity).
- Recognition of nonmarital relationships should be included, especially in cases where the patient’s visitors may be limited.
- Any gendered language on intake forms should be removed and/or changed to reflect gender inclusive language.
- All methods of demographic information collection should include options (including open-ended or fill-in-the-blank options) for sexual orientation and gender identities, as stated above. Gender selections should at minimum include binary as well as multiple non-binary options (such as “gender non-conforming”, “genderfluid”, and “agender”). If the EMR/EHR or other recording system does not provide for multiple non-binary options, then an open-ended field for gender should be present.

“ My positive experiences have come from providers that didn’t confront me about my identity, but rather made it obvious that they want to hear about what I experience. It’s given me a sense that they’re trying to see how they can help me and it keeps me from feeling combative. I’ve also greatly appreciated when providers have given me the room to update how I’m identified as my identity evolves. I feel comfortable knowing that there’s no pressure to be one thing or another and that my needs are still valid. ”

- Demographic information collection questions should offer an option for the patient to select that does not force them to disclose their gender or sexual orientation. These designations have been used in the past to deny coverage to patients based on their trans status, and in some cases have led to the patient being asked intrusive and unnecessary questions about their bodies and relationships. Prioritizing patient privacy by giving an “opt out” choice helps build trust between the patient and the practice.
- Demographic information should be expanded to allow more than one selection in each group (for example, a patient may identify their gender as “male” and “trans”, or their race as “Black” and “Latinx”).

- Practitioners should be mindful that documenting their patient's trans status beyond the disclosure of their legal gender may cause unforeseen challenges, such as insurance coverage, claim denials, and unintentional legal and personal consequences due to disclosure of this information. Consider the ramifications of documenting the patient's trans status and discuss with the patient prior to noting it in their file.

OFFICE/PRACTICE REGULATORY ACTIONS

The regulatory standards of therapeutic care must be inclusive of a range of gender and sex identities. This involves not only ensuring that non-discrimination statements are in place, but that they are demonstrated in the internal guidelines concerning care for all patients.

- Sexual orientation and gender identity should be added to non-discrimination regulations for both patients and employees. This should be noted on the practice's website, in common areas, at admission and discharge offices, in employee work areas, during orientation, and as part of ongoing staff trainings.
- Current insurance regulations dictate that insurance plans must provide no more restrictive limitations on treatment for mental conditions; this includes treatment for diagnoses such as gender dysphoria or gender identity disorder.
- HIPAA states that patient care should not violate confidentiality. Pronouns, bathroom usage, room assignments, and family visiting rights should accurately reflect the patient's gender.
- All patients should receive clear verbal and written information on how to request copies of and/or otherwise access their medical records, and should be encouraged to review these records to ensure accuracy and treatment history. Patients that request medical records should be offered an opportunity to ask follow up questions of the doctor or office staff in order to fully understand any notes or comments.

/// I was consistently misnamed and misgendered throughout my hospital stay. I passed a kidney stone during that visit. On the standard 1-10 pain scale, that's somewhere around a 9. But not having my identity respected, that hurt far more. ///

- Access to and use of patient's personal items that assist their gender presentation (including makeup, clothing, items for binding, packing, tucking, and padding) should be permitted, unless there are specific medical reasons that would make such use adverse to the patient's health. If so, providers should be transparent about the concern and collaborate with the patient to find alternatives/prioritization, so that the patient's needs can be respected while medical issues are addressed.

- Gender-affirming bathrooms should be available in both public areas as well as in employee-only areas.
- Vendor control and/or vendor partnership agreements should require stated non-discrimination policies on the part of the vendor. Any vendors who engage in patient contact should demonstrate cultural competency with regards to TGIQ patients or clients and their families.
- The facility or practice should utilize health research and community needs assessments, as created by TGIQ community-driven organizations and institutions, in responding to ongoing changes in the community and in further developing cultural competency. It should also be noted that the general LGBTQIA community is not always the best source of information for and about TGIQ needs, as it can lead to the inaccurate conflation of gender and orientation.

HUMAN RESOURCES

Human Resources guidelines are not simply in place to ensure that staff are treated equitably, but also to ensure that diversity is present within the staff of the practice or hospital. Having a diverse workforce can create a more culturally-aware practice through representation, through adding their own experiences to the practice on all levels, and by advocating for patients from a position of personal awareness and understanding.

- EEO information in job postings and on website should include gender identity and sexual orientation, and all applications and other pre-hire paperwork should include this statement. Additionally, specific HR liaisons should be designated to assist employees who transition while employed by the practice.
- Questions regarding experience with trans, gender non-conforming, intersex, and queer communities and individuals should be addressed during the initial screening and interviewing process.
- Employment orientation should include basic competency training for working with TGIQ patients, including non-discrimination advisories and CLAS-aware language and actions. In addition, this training should incorporate cultural competency training for other identities (such as race, disability, age, etc.) to ensure that TGIQ patients are treated appropriately in all of their intersectional identities. HR staff that conduct these orientations should undergo cultural competency training at least annually.
- A grievance / complaint process should be in place for staff who have experienced (or witnessed) discrimination based on gender identity or sexual orientation, whether affecting patients or other staff; this can be an extension of current HR grievance processes, but should be clearly delineated during training and in internal guidelines.
- Due to the specific and heavy discrimination faced by TGIQ folks, there should be a TGIQ-identified liaison to work with patients during this grievance process, especially in larger facilities and organizations. All grievance personnel should have a deep understanding of TGIQ competency issues and their long-term impact.

- Any staff governance / oversight committees should seek to include a diverse range of experiences, including utilizing TGIQ community-based organizations, in their meetings and during the decision making process.
- Staff regulations should ensure that the organization attracts and retains a diverse LGBTQIA staff by offering health care plans that offer coverage for transition care (including surgeries) as well as coverage for family and dependents, equal access to FMLA utilization, TGIQ-friendly life insurance, personal leave time, gender transitioning process guidelines, etc.
- All staff (at minimum: all staff that engage in client / patient contact) should receive periodic training in cultural competency, with specific focus on gender identity, sexuality, and relationships. This training should occur at minimum once per year, and be reinforced as needed based on changes in staff, organizational focus, or as a result of related incidents.
- All practitioners must include ongoing professional development in cultural diversity, research updates with regards to medical transition, understanding of health-related benefits and cultural values, disease incidence and prevalence in affected communities, and treatment efficacy, as is appropriate to their role.
- Assessment methods used by hospital or practice to review staff's competence should include cultural competency inclusive of gender identity, sexuality, and relationships. This can be done through post-training testing, return demonstration, or use of simulation.
- Billing and insurance liaisons should be trained on working with insurance issues, especially regarding transgender and intersex patients, including gender-specific service claims and managing claim resubmission.

“ Be creative with insurance coding to expand our access to health procedures that may be technically excluded but with some creative coding could allow us to gain access to medically necessary care. Most doctors seem to be aware that we need access to care but it is social discrimination and insurance policies that keep us from this care that would be provided to cis patients. ”

- Trainings may be offered in person (by competent and qualified staff or external educators) or online. Staff should also engage with local and national LGBTQIA-focused conferences to enhance their understanding of current challenges within the community landscape.
- The governing body (including managing partners, board of directors, and senior staff) should be required to participate in the above trainings, to enable them to more fully guide the direction of the practice or facility.

MARKETING / COMMUNITY ENGAGEMENT

A medical office or hospital does not exist in a bubble; it's a member of the surrounding community, and contributes far more than simply access to medical care. It is important for the practice's activities to extend to its interactions with both the local community that it serves, and to the TGIQ community through event participation, referrals, and marketing.

- The practice or facility should participate in or provide sponsorship to LGBTQIA community events, including festivals, organizations, charities, and fundraisers, in order to reach out to many TGIQ people and their families (who often attend these events).
- Community outreach efforts should include events that reach out specifically to TGIQ patients, such as HIV testing and counseling or "ask a doctor" booths at TGIQ-centered events.
- Human Resources should engage in LGBTQIA-focused job fairs by either tabling or providing information, in order to attract and retain competent staff who are familiar with or a part of the community.
- Advertisements for the hospital or practice should include diverse images that are gender and queer inclusive, and language on advertisements should be evaluated for cultural literacy and affirmation.
- Partnerships should be sought with local LGBTQIA-run organizations, and members of those organizations should be invited to participate in community advisory boards.

****Note: LGBTQIA community, centers, events, etc often are umbrella organizations that INCLUDE TGIQ people, but do not necessarily center them. It is important to be mindful of this when looking with ways to connect with the TGIQ community and note that LGBTQIA community centers, organizations, events, etc, are a good starting point, but should perhaps not be the only source.***

CITATIONS

Survey data: James, S. E., Herman, J. L., Rankin, S., Keisling, M., Mottet, L., and Anafi, M. (2016). The Report of the 2015 U.S. Transgender Survey. Washington, DC: National Center for Transgender Equality.

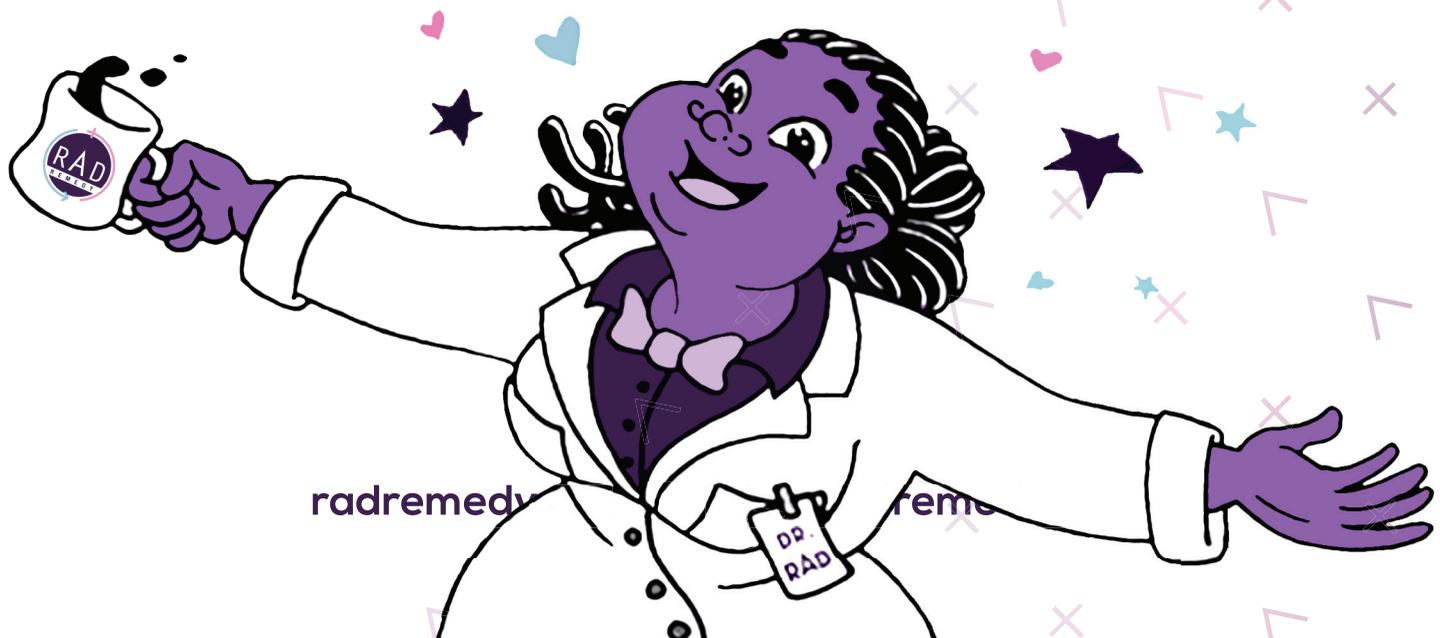
Patient quotes taken from "In Our Words", 2015 U.S. Transgender Survey, and from RAD Remedy's 2015 Needs Assessment Survey.

For additional information and links to organizations and other online resources for professionals and consumers, please visit our website, www.RADremedy.org

RAD Remedy is a community-led 501(c)3 non-profit organization dedicated to connecting trans, gender non-conforming, intersex, and queer folks to accurate, safe, respectful, and comprehensive care.

As part of our mission, RAD Remedy offers consulting and training for professionals who serve these communities, to help them better serve their TGIQ clients and their families.

For more information, please visit us at RADremedy.org or email info@radremedy.org



10 TIPS FOR WORKING WITH TGIQ* PATIENTS

* *trans, gender non-conforming, intersex, and queer*

1

Ask, don't assume! Just because someone "looks like" a particular gender doesn't mean they identify that way. Ask them what name and pronoun they prefer to use, note their preferred name and pronouns on intake and medical history forms - and use it consistently.

2

Don't ask unnecessary questions about their bodies or genitals. If you're treating a sprained arm, focus on their arm. Respect the privacy of the patient, and ensure that they are treated professionally and compassionately.

3

Describe people by features, rather than perceived gender. "The person in the blue coat" or "the patient with a red scarf" is more accurate than "that man over there".

4

Many (but not all!) TGIQ people have complicated relationships with their body. Asking them **what terms they prefer to be used for their body and/or body parts**, and then using those terms, can help them feel empowered and affirmed.

5

Remember that TGIQ patients are more likely to have been harassed, shamed, and even assaulted in medical offices, so **ask permission before touching them** and give them clear information about any procedures that you need to perform. Respect that due to those traumatic experiences, they may also react to other kinds of interactions, and focus on providing them with safe, responsive, affirming treatment.

6

Ask BEFORE bringing additional personnel into the room (including other doctors, medical students, or nursing staff) - treating your TGIQ patients like "examples" can feel like you are de-personalizing, shaming, or harassing them.

7

Respect that TGIQ will often **bring a "safe person" or patient advocate** into their appointments with them, and be open to this. If you absolutely have to deliver something where another person cannot be in the room, such as a Domestic Violence screener, simply be clear about the fact that they will need to step outside for just a moment. TGIQ patients may also benefit from work with a patient advocate, so make advocate contact information easily available in your practice.

8

Have literature, pictures, etc that are applicable to the TGIQ population in your lobby and patient rooms. **Seeing their lives represented and affirmed** goes a long way towards making TGIQ people feel comfortable

9

No transition is the same. **Medical transitions are deeply personal**. Some TGIQ folks don't medically transition at all and some do; some medical transitions may or may not include surgeries. Don't assume anything about how medical transition relates to their identities - respect that their personal transition is critical to their health, and ask about their desires in a supportive, solution-focused manner.

10

In all work with TGIQ patients, **focusing on patient-guided care is critical**; patient's needs and desires should direct treatment goals and methods. Coordinating medical care with various specialties (such as endocrinologists and therapists) should be a priority, in order to effectively treat the whole person in an affirming, empowering manner.

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radremedy.org // info@radremedy.org



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