

Proposal:
GUIDE (Gender Understanding, Identity, and Expression) Center

Vanessa Jensen, Psy. D., Program Director (pediatric psychology)
Laurie Tsilianidis, M.D., Medical Director (pediatric endocrinology)

Presented below is a proposal for the establishment of the GUIDE (Gender Understanding, IDentity, and Expression) Center. The GUIDE Center will serve as a multi-disciplinary patient-centered medical home specializing in the comprehensive health care needs of trans and gender-nonconforming youth within Cleveland Clinic Children's.

Defining Transgender Health Care and the Need for Trans-Specific Services

Comprehensive transgender health care encompasses both primary care and health care specific to transgender and gender nonconforming (TGNC) individuals. Similar to the needs of other populations, primary care includes routine healthcare screening, diagnosis, symptom assessment, and management of various acute illnesses and chronic diseases, with these services provided in a "trans-affirmative" manner by professionals with sensitivity to and competence in TGNC issues. Primary care also incorporates preventative medicine, risk reduction, and referrals for other health and psychosocial concerns, including those related to mental health, educational needs, and family functioning, whether specific to TGNC or not. While these primary care services are not exclusive to transgender populations, there is currently a lack of health care professionals that are educated about and sensitive to the ways in transgender status may complicate health care.

TGNC specific services include specialized psychological evaluation and treatment as well as medical and surgical interventions provided by specialists and subspecialists with expertise in addressing the needs of young TGNC patients. Patients seeking transition may require a number of services related to the process of transitioning toward their affirmed gender identity. Providing competent transgender health care entails awareness of the diversity of ways in which trans individuals identify and the many paths gender transition may take. This includes people who undergo medical interventions, such as hormone suppression, cross sex hormone therapies, and/or surgeries, as well as those who transition socially without receiving medical or surgical treatment.

As more youth are disclosing their gender identify, the need for pediatric and adolescent specific services has increased significantly. Hormone suppression, a reversible treatment option, is now considered a best practice for eligible TGNC youth as early as the onset of puberty. Such intervention significantly decreases the psychological distress many TGNC youth experience related to the physical changes that occur through puberty, changes that are consistent with their natal sex but strikingly inconsistent with their internal gender thus interfering with gender exploration. Timely suppression may also prevent the development of irreversible secondary sex characteristics, thereby decreasing cost and risk associated with later stages of transition. Cross-sex hormone therapy has also been shown to profoundly increase the quality of life for transgender individuals, and is often critical to achieving mind-body gender identity congruence. Integral components of hormone therapy include assessing the patient's psychological and physical health status, needs, and values, as well as prescribing appropriate hormones and monitoring potential short- and long-term side-effects. Some transgender individuals (typically adults) undergo surgical procedures to bring the body more in-line with their affirmed gender, all

requiring additional monitoring and evaluation. Given the inherent complexity of providing health care for transgender individuals, coordination of care and provision of comprehensive health care services in a patient and family friendly atmosphere is key to ensuring patient satisfaction and positive health outcomes.

Transgender individuals often experience severe social inequities, underscoring the need for culturally competent TGNC health care professionals. Many transgender people are economically and socially vulnerable and experience multiple forms of oppression and discrimination. Particularly at risk are transgender people of color, immigrants, and those who have a gender expression that is fluid or outside the typical conceptualization of gender as automatically meaning only male or female. Transgender and gender nonconforming youth constitute a particularly vulnerable population due to their age (including dependence on parents and potential lack of fully mature coping skills). These youth may not have full family and social supports and often do not have access to essential health care services. It is important that providers take into consideration the constellation of life factors which may impact patients' health and wellbeing.

Community Health Needs

A critical step in establishing effective transgender health services involves a community health assessment to identify the health needs of the local community, the resources that are available, and the state of current programs. We are currently in the process of establishing ties to community organizations such as the LGBT Community Center of Cleveland, Transfamily, and the Northeastern Ohio chapter of GLSEN (Gay, Lesbian, and Straight Education Network), as well as the PRIDE Clinic at Metrohealth Medical Center. These organizations offer various transgender-related services and supports, and we intend to collaborate with them order to enhance community-wide participation in the delivery of relevant health services. In addition, these institutions will be in the critical position to refer patients to the GUIDE Center for services not presently available through other organizations. Currently there are very limited services specifically addressing the needs of for transgender youth in the Northeast Ohio area; as such, the GUIDE Center at Cleveland Clinic Children's will be offering a unique set of services to support the region.

Proposed Program: Health Care Services and Community/School Connections

With rising medical and cultural attention to gender variances, many gender non-conforming youth and their families are beginning to seek medical advice and assistance at younger ages, only to find limited options for health care professionals familiar with and able to support and care for such youth. Cleveland Clinic Children's GUIDE (Gender Understanding, IDentity and Expression) Center aims to improve the health and wellbeing of this vulnerable population through establishment of a multi-disciplinary, comprehensive health clinic for TGNC youth, adolescents, and young adults. The GUIDE Center aims to integrate primary care, basic psychosocial services, hormone management and surgical expertise to address the broad health and transition-related concerns faced by TGNC youth. This program will involve a collaborative team of general pediatricians, pediatric psychologists, endocrinologists, gynecologists, urologists, surgeons, and other providers committed to improving transgender health care. As such, the GUIDE Center will serve as a patient-centered medical home that coordinates the various health needs of transgender youth and their families. A key component of this program involves education, not only for individual patients and families but also for the broader community, particularly schools. Each situation is unique and often close communication with school administration and staff is necessary. Assisting schools in

proactively addressing issues around gender and gender transition will better prepare a school community in their journey.

The GUIDE Center model will be based on the WPATH (World Professional Association for Transgender Health) *Standards of Care for the Health of Transsexual, Transgender, and Gender Nonconforming People* and similar guidelines (e.g., the Endocrine Society), as well as the most current research findings and feedback from both national and local programs and services. The clinic will accept professional, family, and self referrals for trans youth ages 2-21. Upon referral to the clinic, patients will receive an initial psychological assessment in order to determine the best course of care management. Due to the multiplicity of biopsychosocial profiles of gender nonconforming youth, the clinic will utilize flexible, individualized care plans based upon a general care path that considers both patient/family preferences and professional recommendations.

The behavioral health professional will play a critical role throughout course of care, and will support the patient and their family in psychosocial exploration of living in their affirmed gender (“social transition”) before and throughout any medical or surgical transition. Gender Affirming waiting and continual assessment and support by the behavioral health professional and endocrinologist will allow early detection of signs of pubertal development, at which point eligible patients may consider hormone suppression therapies. Eligible patients may later undergo cross sex hormone therapy, which may be followed by surgery if and when appropriate. Medical and mental health monitoring will be conducted throughout each stage of treatment. In addition to this transition-specific treatment patients will be offered primary care and continuing mental health services by knowledgeable, trans-affirmative care givers. Collaboration and networking with regional trans-affirmative practitioners and community organizations will allow referral to support and other relevant services, particularly for those living outside the Northeast Ohio region. Due to the paucity of trans-affirmative care options, the GUIDE Center will continue to provide care for patients until a natural transition point to an adult care program is reached or when the patient reaches age 25. *(NOTE: GUIDE staff are working closely with an adult health care team that is in early stages of creating a similar program for lesbian, gay, bisexual, and transgender patients).*

Patient Referral and Intake

Professional referrals to the GUIDE Center will involve completion of pre-determined questions. Family or self referrals will be screened through a series of scripted questions. Upon referral to the center, patients will first be scheduled for a psychological/behavioral health consultation, which includes assessments of gender-related and other psychological concerns, as well as assessments of social, emotional, cognitive, and family functioning. If the GUIDE Center is deemed the best care option for individual patients, future directions for care will be established in accordance with the general care path.

Hormone Intervention Protocols

The GUIDE Center will provide patient-specific hormone suppression and cross-sex hormone therapies in accordance with the most recent clinical guidelines from the Endocrine Society and WPATH, as well as relevant research findings. For transgender youth, reversible hormone suppression therapy allows extended exploration of gender identity and prevents significant distress caused by pubertal development, particularly in cases of recognized gender dysphoria. The most up-to-date protocols suggest administration of GnRH analogues (preferred) or related alternative treatment to eligible individuals during Tanner stages II-IV; eligibility is assessed

through specific criteria and suggests that the patient have appropriately explored living in the preferred gender role. If the desire for further transition persists through age 16, cross-sex hormone therapy may be advised for eligible individuals. Cross-sex hormone therapy is often a significant part of gender transition, and allows transgender individuals a sense of congruity between internal understandings of gender identity and the physical body. In general, hormone therapy is best administered in the context of a comprehensive care approach that includes primary care and coordinated psychosocial services. However, we do not recommend a “one size fits all” approach for transgender patients. Instead, such medical care should be flexible, taking into consideration each individual’s preferences, goals, and values. Likewise, decisions regarding treatment with specific hormones and dosages will be informed by patient medical circumstances. Baseline protocols will be modified to address changing conditions, emerging issues, and developing clinical research.

Location

Until establishment of a standalone, monthly or bimonthly clinic location, health care providers will continue to see GUIDE Center patients in their regular office space. However, the collaborative nature of the program will allow streamlined patient care among specialists on the team, saving both the patient and provider unnecessary time and hassle.

Funding/Resources

Initial stages of the GUIDE Center will not require outside funds, as services will be integrated into the current patient care system at the Cleveland Clinic. However, it is important for providers to inform patients of issues related to insurance coverage and potential out-of-pocket costs of specific treatments. It is advised that the program have a financial counselor able to answer questions regarding costs and insurance coverage of transgender specific care. As the program continues and begins to hold regular clinics at a specified location, additional costs may be incurred, at which time formal funding and philanthropy will be critical.

At this time, the GUIDE Center does not require extensive additional support. However, in order to produce effective marketing materials, collaboration with the Cleveland Clinic marketing staff and services may be required. A trained individual or group of individuals is essential to ensuring a smooth intake process for incoming patients.

Program Evaluation

GUIDE Center evaluations will aim to determine the success of our services, identify unmet needs, and characterize the health and other needs of our patients. We intend that the evaluation process seek both formal (survey) and informal (patient-provider communication) feedback from patients at multiple points of involvement with the GUIDE Center. Furthermore, we propose that the evaluation method solicit active community participation, allowing for vocalization of any unmet health needs of transgender youth in the community. Utilization of the evaluation process can further train and empower health care providers and community members alike, and can contribute to the sustainability of our program by ensuring community investment.

Future Directions and Sustainability

Our goal is that the GUIDE Center ultimately be centered with community pediatrics; however, at this time, team members/practitioners will continue to see patients through their current

departments and locations. As the developing adult LGBT program at the Cleveland Clinic becomes a reality the GUIDE Center plans to collaborate with this team, helping youth patients in the transition to adult care.

In the development of this program it is imperative to consider how to secure and maintain funding, ensure continual improvement and increasing community participation, and sustain collaborative partnerships with other organizations and service providers. We believe that incorporating a community-based, peer-driven model will promote high standards of care for the GUIDE Center. A network of advocates and peer organizations has been identified in order to create safe and healthy environments for TGNC people while providing a base for public and private support and funding for transgender-specific services. As such, community supports will be invaluable in directing patients to receive our unique services and ensuring continual improvement through collaborative communication.

Over time, we hope to obtain funding to establish a stronger educational component, addressing the education of professionals and the overall community. Linking with local public schools may also be an important facet of our outreach program.

Submitted by:

Vanessa K. Jensen, Psy.D.
Rachel K. Jensen
Laurie Tsiliannidis, M.D.