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Office of the Assistant Secretary for Health
U.S. Department of Health and Human Services
Submitted via email (Adrian.shanker@hhs.gov)

RE: Request for Information on Promising Practices for Advancing Health Equity for Intersex Individuals

Dear Senior Advisor Shanker,

The Fenway Institute at Fenway Health submits this comment in response to the RFI on Promising Practices for Advancing Health Equity for Intersex Individuals. For nearly a decade, the National LGBTQIA+ Health Education Center at The Fenway Institute has been providing educational programs to health centers and other health care organizations with the goal of optimizing health care quality and eliminating health disparities for sexual and gender minority people. The Education Center is a part of The Fenway Institute, the research, training, and health policy division of Fenway Health, a Federally Qualified Health Center, and one of the world's largest health centers focused on LGBTQIA+ communities.

The Education Center is a multi-disciplinary team of clinicians, educators, and public health professionals with expertise in LGBTQIA+ health research and care. We work with a national network of faculty, advisors, and collaborators representing medical and public health universities, community health centers, and leading government and non-profit organizations. In 2020, we published a guide, *Affirming Primary Care for Intersex People*, which outlines best practices for providing culturally responsive, affirming, and clinically competent care for intersex patients. This comment is based on this guide, with updates in language. You can view the best practices guide [here](#).

Intersex is an umbrella term that refers to those with a wide range of natural variation in sex characteristics and development that falls outside traditional conceptions of female or male. For clinicians, the best practice is always to mirror the term(s) your patients use or ask them what they prefer at the onset of the clinical relationship.

The Fenway Institute uses LGBTQIA+ to refer to sexual, gender, and sex characteristic minority populations that often share affinities and common experiences, including experiences related to stigma and discrimination, and that often overlap. Experiences of stigma, discrimination, and other social and health barriers based on sexual orientation, gender identity, and sex characteristics share common roots in stereotypical assumptions and restrictive norms regarding gender. In addition, intersex populations and transgender and gender-diverse populations often share similar health needs and barriers related to gender-affirming care, as well as sexual and reproductive health care.

Medically unnecessary, nonconsensual surgeries

Starting in the 1950s, the prevailing medical approach to treating intersex infants and children emerged as an attempt to “correct” the appearance and function of atypical genitalia. Surgeries also aimed to prevent the

possibility of a child growing up to have non-heterosexual relationships.³ Unfortunately, the practice of surgical “correction” continues in some U.S. institutions and beyond.³ Often, families feel pressured to consent to surgeries on their child without being given sufficient mental health counseling, peer support, or information on alternatives to surgery.³ The majority of these surgeries are not medically necessary and can be delayed until the individual can participate in the decision. There is no evidence demonstrating the benefits of cosmetic genital surgery to a child’s long-term mental or physical health, nor is there evidence of any risk to delaying the procedures until the individual can decide if they wish to have the surgery.^{1,11-15}

Many intersex people experience multiple adverse side effects from these deferrable early genital surgeries, including scarring, chronic pain, loss of sensation, urinary and sexual dysfunction, and other complications that require repeated follow-up surgeries. Intersex people also report symptoms of post-traumatic stress disorder, depression, feelings of loneliness, and fear of intimacy due to surgeries performed on them before they were old enough to participate in the decision themselves.⁴ Furthermore, surgery performed at an early age can assign a genital appearance that does not align with the individual’s gender identity that emerges later in life.¹¹

In recent years, human rights advocates and intersex-led community organizations have made great advances in raising awareness and promoting a patient- and family-centered long-term management strategy that safely delays surgery. Multiple human rights and medical professional societies have also issued policies opposing medically unnecessary surgeries on intersex infants.¹⁶ Despite this progress, some specialists in the U.S. and other countries continue to perform medically unnecessary genital surgeries on infants and young children.^{1,11}

Unnecessary and objectifying medical examinations

Intersex people are often made to feel like medical curiosities. Adults report long-term emotional consequences from repeatedly undergoing intrusive, objectifying, and medically unnecessary genital examinations and photography as children.³ Even today, some children still undergo repetitive genital examinations which are not necessary for their medical care.³

Providers should keep in mind that even a medically necessary genital examination can re-traumatize an intersex patient. Prior to performing an exam, it is vital to first establish a warm and respectful relationship with the patient, engage them in shared decision making about their health, and use a trauma-informed approach (see below). An organ inventory may be a less intrusive and more trauma informed approach to learning information about a patient.

Providers must also avoid asking intrusive questions not directly relevant to the patient’s presenting health concerns. Such questions reinforce shame, stigma, and feelings of difference, and can exhaust a patient who is tired of educating their providers. Importantly, providers should not expect a patient to serve as a teacher and should never ask a patient a question simply to satisfy their own curiosity.

Finally, although it is important to teach students to care for intersex patients, providers must respect a patient’s refusal to be observed by trainees and should never invite others to observe the patient unless medically necessary and specifically consented to by the patient.

Non-disclosure

Another common practice that has harmed intersex people and their families is the concealment of information from patients about their bodies.⁴ Unfortunately, concealing information from intersex people (including youth) delays the process of self-acceptance and increases shame and stigma. When an intersex person eventually learns the truth, they may ask: “Why did they hide this information from me unless there was something shameful about my body?” Secrecy also perpetuates the myth that variations in sex characteristics are extremely rare. In contrast, sharing information in an age-appropriate manner enables people to process the information and access peer support.¹⁷

Patients and their families need full disclosure of medical information and options so they can make informed decisions that are appropriate to the child’s developmental stage. Behavioral health providers and intersex-affirming peer support organizations can help families learn to disclose information to their child in age-appropriate ways, and to share information with extended family, babysitters, and others who would benefit from learning about the child’s variations. For adult intersex persons who only recently learned of their diagnoses, primary care providers can help them access medical records, understand their medical history, and engage with mental health professionals and peer support as needed to adjust to their new reality.

Overview of affirming care

The good news is that primary care providers can provide affirming and compassionate care for intersex patients and their families. To practice cultural humility in interactions with intersex patients, it is important for clinicians to listen with sensitivity to their patients and acknowledge that:

- Sex development, like gender identity, exists on a continuum
- Human fetal development is complex; variations in sex characteristics are an expected and natural outcome of sex development
- An individual born with variations in their sex characteristics may or may not identify as intersex or as part of the LGBTQIA+ community

While primary care providers are not expected to be intersex specialists, they still require education in the basics of intersex care.

Specific medical needs

While many intersex people do not need any specialized medical care, some require care at specific developmental junctures, and others have lifelong needs related to their individual variation. An intersex person seeing a specialist may experience discomfort or trauma, particularly if they have seen a specialist provider from a young age. Primary care providers can help individuals and families find trusted referrals and navigate specialized care.

Some common medical specialty care needs include:

- Steroid replacement for individuals with combined adrenal gland/gonadal conditions
- Gynecologic, urologic, and sexual health care, particularly to address any complication created by prior surgical procedures
- Hormone therapy to:
 - induce secondary sex characteristics, as desired by the individual
 - affirm gender identity if sex assigned at birth does not correspond with gender identity

- replace sex hormones after surgical removal of gonads
- Prevention and treatment of osteoporosis
- Cancer surveillance of internal gonads; some individuals/families may elect to surgically remove the internal gonads or gonadal streaks if there is elevated risk of malignant transformation relative to the general population
- Reproductive endocrinology

Making referrals

Ideally, intersex patients and their families with specialty care needs will have access to an integrated multidisciplinary team of intersex-affirming medical and behavioral health clinicians who do not condone medically unnecessary surgeries on infants. Unfortunately, finding clinicians who are aware of the needs of intersex populations, who are sensitive to intersectional cultural identities, and who have relevant expertise is often challenging. Before referring patients to specialized centers, first inquire as to whether the facility affirms patient autonomy by delaying medically unnecessary interventions on intersex individuals until the individual can meaningfully participate in the decision. If the facility performs interventions absent patient consent, attempt to find alternative centers. If none are available, employ a harm-reduction approach to inform the patient and/or their family of their rights.

To find referrals, it can be helpful to reach out to local and national leaders in the intersex community to ask about specialists in the area (see interactadvocates.org/resources/intersex-organizations). Once a referral is made, it is important to check in regularly with the patient/family to determine if they are satisfied with their specialty care or need further assistance.

Trauma-informed care

Because many intersex patients have experienced medical trauma and the need to educate providers, they may have a high level of anxiety and distrust when visiting a health care provider. A trauma-informed approach to care can help put the patient at ease and reduce traumatic responses to health care. Trauma-informed care means that providers: are aware that many patients have a history of trauma; understand the impact of trauma on health and behaviors; recognize the signs of trauma; help with recovery from trauma; access care for themselves to prevent secondary trauma; and resist re-traumatization of the patient.¹⁸ An example of trauma-informed care would be to recognize that an intersex patient may experience a Pap test as traumatizing. Ask the patient for permission before performing the exam, and offer modifications to the patient (e.g., changes to the positioning or self-insertion of the speculum) or alternative screening modalities (e.g., self-administered HPV swab) to increase patient agency and place the locus of control with the patient.¹⁹

Supporting psychosocial health

In addition to providing trauma-informed care, primary care providers can support the psychosocial health of intersex patients and families by connecting them to intersex affirming mental health counseling and peer support groups. Professional counseling can help patients identify traumas and alleviate anxiety and depression due to previous medical care. Counseling may also help intersex patients explore their concepts of self, bodily integrity, sex, and gender. This process can then support patients in making well-informed decisions about their medical care and possible intervention choices. Peer support groups can help normalize the experience of having an intersex variation, provide guidance on patient-empowered decision-making, and help patients and

families cope with and overcome stigma. Peer support and psychosocial interventions can also help families communicate more openly and provide developmentally appropriate information to their child as they mature.⁹

Here are some additional resources for families:

- <https://www.nyc.gov/site/doh/health/health-topics/intersex-health.page>
- <https://www.iglyo.com/wp-content/uploads/2018/10/Supporting-Your-Intersex-Child.pdf>
- <https://interconnect.support/>

Inclusive communication

A critical aspect of affirming care is to use inclusive language when communicating with all patients. Communication strategies include the following:

- Ask patients for their sexual orientation, gender identity, names, and pronouns^{20,21}
 - Document the information in electronic health records
 - Use a person’s chosen name and pronouns consistently across the health center
 - Recheck frequently, as this information may change
- Mirror the terms patients use to describe themselves, their body parts, and their diagnoses
- Use gender-inclusive language and avoid gendered terms. For example, instead of asking “Do you have a boyfriend?” ask “Are you in a relationship?”; instead of requesting “Please remove your bra and panties,” say “Please remove your undergarments”
- Only ask questions relevant to the patient’s current health needs. Ask yourself: “What do I know? What more do I need to know to treat this patient? How can I ask for the information I need to know in a sensitive way?”²²
- Ensure that communication is two-way, authentic, and active
- Examine one’s own implicit and explicit biases about gender identity, gender expression, and anatomy²³
- Participate in training sessions on LGBTQIA+ affirming health care to ensure you are using current communication strategies and following up-to-date protocols for LGBTQIA+ health care

Using a cultural humility approach

- Remain aware of the impact of trauma on the patient’s ability to engage with medical providers
- Acknowledge the potential hardship of failing to find specialists in intersex-affirming care
- Emphasize comprehensive informed consent when recommending any procedure or treatment
- Do not assume clinical training makes one an expert in the lived experience of an intersex person
- Respect the patient’s (or their family’s) right to refuse examination, observation, or treatment, including observation by trainees when the primary purpose is educational
- Access current literature and continuing education opportunities on intersex health. See resources such as:
 - <https://interactadvocates.org/wp-content/uploads/2015/12/BROCHURE-interACT-Doctors-final-web.pdf>
 - <https://www.interfaceproject.org/>
 - <https://www.intersexjusticeproject.org/intersex-for-medical-students.html>

We thank you for the opportunity to provide this information. Should you have questions or require more information, please contact Sean Cahill, Director of Health Policy Research, at scahill@fenwayhealth.org.

Please consider the National LGBTQIA+ Health Education Center, The Fenway Institute, and Fenway Health resources as you continue the important work of providing guidance on affirming, culturally responsive and clinically competent care for intersex patients.

Sincerely,

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