



Affirming Primary Care for Intersex People 2020

INTRODUCTION

For nearly a decade, the National LGBT Health Education Center 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. Recently, we and our parent organization, The Fenway Institute, Fenway Health, have come to recognize the imperative to more actively include the health of intersex people in our mission and training programs. Therefore, all of our programs now use the acronym LGBTQIA+, which refers to lesbian, gay, bisexual, transgender, queer, intersex, asexual, and all sexual and gender minority people. As part of our commitment to supporting the health of all LGBTQIA+ people, we have written the following community-informed clinical guide on primary care for intersex people. The guide provides an overview of intersex terms and concepts, the health concerns of intersex people, intersex-affirming practices, and resources for further learning.



NATIONAL LGBTQIA+ HEALTH
EDUCATION CENTER

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TERMS AND CONCEPTS

What is Intersex?

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. Although biological sex has traditionally been seen as binary (female or male) in many cultures, the reality is more complex. Variations may occur in the chromosomes, external genitalia, gonads (testes or ovaries), hormone production, hormone responsiveness, internal reproductive organs, or any combination of these, among others.¹

How Many People Are Intersex?

The percentage of people who are intersex depends on how intersex is defined. If all variations of reproductive or sex characteristics are included in the definition, experts say that approximately 1 in 58 people, or 1.7% of the population, is intersex.¹ The frequency of specific intersex traits varies widely; some traits are more common in certain areas of the world.

Terminology

Language related to intersex health is complex. Currently, the medical field uses the terms differences of sex development (DSD) as well as intersex.² The

term diverse sex development has also been cited in the literature.³ The DSD acronym originally referred to disorders of sex development, but intersex community members have made it clear that the term disorders is pathologizing and demeaning.^{1,2} The outdated terms hermaphrodite, pseudohermaphrodite, and ambiguous genitalia are experienced as stigmatizing and hurtful; these terms should be avoided unless an intersex person asks you to use them. Clinicians should also avoid terms that describe a person's anatomy as defective or abnormal.

While some people in the community use the terms intersex or difference of sex development, other people in the community prefer to use the specific name of their diagnosis.^{1,2} 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.

Common Intersex Variations

There are at least 40 recognized variations in sex characteristics.⁴ Not all variations are associated with a specific diagnosis. Some of the more common intersex variations are shown in **Table 1**.

Table 1. Common Intersex Variations

| Features of Common Intersex Variations | CAIS (Complete Androgen Insensitivity Syndrome) | Swyer Syndrome (a form of Gonadal Dysgenesis) | CAH (Congenital Adrenal Hyperplasia) | Klinefelter Syndrome |
|---|---|--|---|--|
| Karyotype | XY | XY | XX | XXY |
| Gonad Type | Internal testes | Streak | Ovaries | External testes smaller than average; Infertility is common |
| Sex Hormones Naturally Produced at Puberty | Testosterone from testes is average to high-average for typical male; high for typical female | None | Estrogen from ovaries; Above average testosterone from adrenal glands | Below average testosterone from testes; Average amount from adrenal glands |
| Response to Androgen | Convert to estrogen and feminize | Virilize | Virilize | Virilize; Some breast development is common |
| External Genital Appearance* | Typical labia; May have vagina that is short | Typical labia | At birth may have a range of genital variation | Often typical penis Smaller than average testes |
| Estimated Frequency for Live Births | 1 to 2:100,000 ⁵ | 1:80,000 ⁶ | 1:15,000 ⁷ | 1:1300 ⁸ |

We reference genitalia in this table for clinical purposes only. As discussed later in this guide, it is particularly important to avoid pathologizing intersex people by focusing on genital appearance.

The “I” in LGBTQIA+

Increasingly, intersex is included under the LGBTQIA+ umbrella. The alliance of these communities arose from a shared experience of discrimination based on harmful assumptions about gender and biology. These communities are also understudied in medical and behavioral health research.⁹

All people, regardless of their sex characteristics, have a sexual orientation and a gender identity. In other words, sexual orientation, gender identity, and sex development are distinct concepts. Sexual orientation refers to how a person characterizes their emotional and physical attraction to the same and/or other genders. Gender identity refers to a person’s inner sense of being a girl/woman/female, boy/man/male, or something else. Intersex describes a range of variations in sex characteristics and development.

A majority of intersex people identify as heterosexual and cisgender (for definitions of LGBTQIA+ terms, see [Glossary](#)).¹⁰ However, research suggests that people born with variations in sex characteristics have an increased likelihood of identifying as a sexual minority (e.g., gay, lesbian, bisexual, pansexual, queer) or a gender minority (e.g., transgender, non-binary, gender fluid).^{11,12} Some intersex people who are heterosexual and cisgender still identify as part of the LGBTQIA+ community based on common marginalized and/or stigmatized experiences. Like transgender people, intersex people may have a gender identity that does not correspond with their sex assigned at birth or gender of raising. In addition, because intersex people have sex characteristics that transcend typical notions of female and male bodies, they may experience barriers similar to transgender people in accessing affirming health care that respects their bodies, gender identities, and physical needs.

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HEALTH-RELATED ISSUES AND NEEDS

Initial Recognition of Intersex Variations

While some intersex variations are noted prenatally or at birth, many intersex traits do not become apparent until puberty or later in life. Below are common points at which an intersex variation may be identified:

- During a prenatal ultrasound
- At the time of child's birth, if genital variation is identified
- During care related to an inguinal mass/hernia that leads to the discovery of internal testes
- At time of puberty, if pubertal changes do not occur, or if there are unexpected physical changes (e.g., virilization of an individual assigned female sex at birth)
- Incidentally during a laparoscopy for another medical concern
- During evaluation of an adult for infertility

Medical Trauma and Psychosocial Health Needs

Medically unnecessary cosmetic 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}

In actuality, many intersex people experience multiple adverse side effects from 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.¹¹

In recent years, 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).

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 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.

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Compassionate, Trauma-Informed, and Affirming Care

Overview of affirming primary 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. Resources for further learning are provided at the end of this publication.

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. 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 variations
- 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; however, cancer risk may not be present; make sure to check updated recommendations.

Making referrals

Ideally, intersex patients and their families with specialty care needs 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 culturally sensitive clinicians with 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, 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 a 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 to suggest an alternative, such as a self-swab, to resist re-traumatization.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

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+ 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)

Specific recommendations across the life course



When caring for intersex infants, children, and their families:

- Discuss in a warm, positive, and matter-of-fact manner that intersex experience is more common than people think
- Recognize that families may have experienced medical trauma during or immediately after the delivery of their child
- Stay positive about the child's health and future happiness
- Do not be overly focused on the child's intersex features or genital appearance, but also do not avoid discussion of intersex characteristics altogether
- Ask what pronouns to use when discussing the child
 - Use gender-inclusive terms like "your baby/child" if pronouns are not yet chosen
 - Do not choose a pronoun for the child, and never use "it"
- Assist families in finding and interacting with intersex-affirming tertiary care centers or independent specialists, such as pediatric endocrinologists and behavioral health professionals
- Support families in their decisions to refuse medically unnecessary surgeries and other interventions until the child is mature enough to provide fully informed consent
- Help families access peer support
- Recognize that gender assignment is provisional
 - As a child matures, their gender identity may or may not correspond to their sex assigned at birth
- Do not assume the child's gender expression will align with societal gender norms, but also do not assume it will not



When caring for intersex adolescents through adulthood:

- Anticipate the potential for strong emotional reactions from the family and patient if an adolescent's body does not develop as anticipated at puberty
- Recognize that due to medical trauma, intersex youth are even more likely than other youth to distrust medical providers, miss appointments, and question medications
- Acknowledge that patients may feel anxiety if attending their first medical visit without a parent/guardian
- Be mindful that in some families, parents almost always accompany their adolescent and young adult children
- Encourage patients to ask questions and be curious about their bodies
- Explain that a wide range of sexual activity is normal and enjoyable
- Do not assume the patient desires to have heterosexual relationships
- Promote patient-driven goals regarding gender-affirming care
- If a patient is concerned about confidentiality:
 - Explain why the information is relevant to the patient's care
 - Explain clearly how medical information is kept confidential to the extent required by law
 - Do not convey the message that information regarding sex characteristics is inherently shameful and should be hidden from others
- Do not assume a patient menstruates
- Discuss fertility preservation with patients who may be interested in having biological children
- Recognize that fertility options for some intersex patients may be less available than options for non-intersex patients and acknowledge other available family building options
- Screen for anxiety, depression, substance use, and suicidal ideation
- Refer to intersex-affirming behavioral health care, peer support groups, and other resources as needed



Intersex-Affirming Health Care Environment

Health centers can make simple yet valuable changes to the health care environment that will make for a more intersex-inclusive health care environment.

Anti-discrimination policies

- Add language to policies to prohibit discrimination on the basis of intersex status, intersex traits, differences of sex development, or diversity in sex characteristics

Patients' Bill of Rights

- Empower patients to make autonomous decisions about their care
- Protect patients' rights to privacy
- Protect patients' rights to refuse being examined, treated by, or observed by learners or trainees when the primary purpose is educational or informational and not therapeutic, without their right to care being jeopardized
- Protect patients' rights to access their medical records and to be told the truth about their intersex status, intersex traits, and any related medical information, including any history of medical or surgical intervention¹

Patient forms and questions

- Review patient forms and questionnaires for inclusivity and sensitivity
- Include questions on sexual orientation, gender identity, chosen names, and pronouns on registration forms¹¹
- Remove section headers for “female only” or “male only” that assume certain anatomy or physiology
 - Questions should be open to all patients, with the option to check “not applicable” For example, “if you menstruate, date of last period”
- Use intake forms that are then reviewed by the provider and patient to discuss their existing external and internal reproductive organs in order to create an anatomical inventory
- Avoid binary depictions of bodies
 - Illustrations, such as pain diagrams, can be designed as a human outline without anatomical sex characteristics
- Revise questions that make assumptions about gender in relationships
 - Ask about the gender(s) of sexual partners; include options for transgender, non-binary, and additional genders
 - Use gender-inclusive terms like “spouse” instead of “husband or wife,” and “parent” instead of “mother and father”
- Include questions about sexual desire and function
- Include a “not applicable” option for questions on menstruation and contraception
- Provide opportunities for patients to indicate an interest in family building options, such as adoption, surrogacy, or fertility counseling and treatment

RESOURCES

Clinical Training and Tools

After decades of inattention, intersex-focused resources are being developed at a rapidly increasing pace. Recommended resources include:

- American Association of Medical College's teaching videos: [Teaching Differences of Sex Development](#)
- interACT Advocates for Intersex Youth [guidance books and brochures](#), such as [Intersex-Affirming Hospital Policies](#) and [What We Wish Our Doctors Knew](#)
- National LGBT Health Education webinars: [Caring for Intersex Patients at Health Centers](#) and [Affirming Care for People with Intersex Traits](#)
- Recommendations for social workers: [Applying Social Work Values to the Care and Treatment of Intersex People](#).

First-person individual and family accounts of the intersex experience are recommended for clinicians interested in learning more about the personal impact of issues facing intersex people:

- K.M. Zieselman, [XOXY: A Memoir](#). Jessica Kingsley Publishers, 2020.
- S. and E. Lohman, [Raising Rosie: Our Story of Raising an Intersex Child](#). Jessica Kingsley Publishers, 2018.

In general, when seeking trainings and resources, consider whether the material was authored or co-authored by intersex-identified individuals, and/or whether an intersex-led organization provided organizational oversight. Much as it would be inappropriate to produce a women's care resource without consulting any women, intersex-focused materials must reflect the voices of intersex people. To answer specific questions and provide vetted resources, many advocacy groups like [interACT: Advocates for Intersex Youth](#) have medical advisory boards with trained professionals.

Peer and Family Support Groups and Tools

[AIDSSD.org](#) (All intersex variations; changing name to "InterConnect")

[HEAInfo.org](#) (Hypospadias and Epispadias)

[BeautifulYouMRKH.org](#) (MRKH)

[Supporting your intersex child: A parent's toolkit](#) by [OII Europe](#)

[What We Wish our Parents Knew](#) (All intersex variations)

SUMMARY

Intersex refers to the nearly two percent of the population with a natural variation in sex characteristics that falls outside traditional conceptions of female or male bodies. Some, but not all, intersex people identify as part of the LGBTQIA+ community. Many intersex people have experienced trauma from medical interventions, including surgeries and repeated genital exams performed on them as children without their consent or even knowledge of their own variation. Providing affirming and compassionate primary care to intersex patients and their families therefore requires using a trauma-informed approach and following inclusive communication strategies, as recommended for all LGBTQIA+ populations. In addition, providers can educate themselves in the basics of intersex care, and provide well-vetted referrals to behavioral health providers, peer support groups, and medical specialists, as needed.

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