Towards Ethical and Affirming Care for Intersex Children

A GUIDEBOOK FOR HEALTHCARE PROFESSIONALS IN INDIA

Intersex Children's Foundation of India

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We extend our sincere thanks to each contributor for their dedication to promoting respectful, informed, and compassionate care for our children born with somatic intersex variations.

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Your insights ensured that the information presented reflects current best practices and upholds our commitment to rights-based, person-centered care for intersex children, adolescents, and their families.

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1. Foundations of Intersex Inclusive Healthcare

1. Executive Summary

Healthcare professionals play a critical role in ensuring ethical, evidence-based, and compassionate care for all individuals. Among the diverse communities they serve, children born with somatic variations of sex characteristics have historically been marginalized and misunderstood within the medical community. These variations refer to differences in development in chromosomes, hormones, reproductive and / or sex anatomy that do not match typical definitions of male or female. They may be identified at birth, during puberty, or later in life.

Despite the majority of these variations not having any immediate threat to life or any potential future health risks, early medical interventions, including invasive and non-reversible surgeries, are often carried out more for adhering to societal expectations and avoiding social stigma. Such interventions, performed in infancy or early childhood, can result in long-term physical and psychological consequences, including loss of sexual function, infertility, chronic pain, and psychological trauma.

Today, global medical ethics guidelines and human rights organizations advocate against unnecessary medical interventions, surgical or non-surgical, without the child’s informed consent or assent. These guidelines advocate for delaying the interventions till the child is mature enough to participate in the decision-making process, unless absolutely required due to medical emergencies.

Intersex children, adolescents, and youth in India, and elsewhere in the world, have historically been overlooked in medical, psychological, and policy responses. Many continue to experience unnecessary medical interventions without their knowledge and informed consent or assent, and the psychological burden of stigma and silence that follows. There is a growing recognition today from across sectors that healthcare systems must evolve to respect and protect the dignity, rights, and well-being of intersex individuals from the earliest stages of life.

However, knowledge about variations in sex characteristics remains limited in healthcare settings across the world. Medical training often centers on a binary understanding of sex and conflation of sex with gender, leaving healthcare professionals ill-prepared to provide respectful and appropriate care to children. This lack of information, along with misinformation and stigma, increases parental anxiety and often pressures families into making immediate medical decisions without a complete understanding of long-term repercussions on the children’s bodies or minds.

A lack of accessible psychological and social support further complicates these experiences. Clinicians, many times unintentionally, may convey their personal beliefs and assumptions to parents, who often interpret this as definitive medical recommendations. Some stakeholders argue that it is important for a child’s development to have physical anatomy that aligns with current social ideas of sex and gender; that such anatomy improves the likelihood of satisfying (heteronormative) sexual relationships later in life; that ‘normalization’ will protect children from bullying or abuse at school and in the neighborhood; and that medical interventions can prevent psychological distress in both children and parents when dealing with society. However, there is no compelling evidence to support these claims.

In response to this critical need, the Intersex Children’s Foundation of India (ICFI) has developed *Towards Ethical and Affirmative Care for Intersex Children: A Guide for Healthcare Professionals in India*. This guidebook has been made possible through the generous support of the Mariwala Health Initiative (MHI), whose grant to ICFI has played a vital role in bringing this resource to life.

This guide is intended for healthcare providers, mental health professionals, medical educators, policymakers, and allied healthcare service providers looking to improve outcomes of medical interventions for intersex children through informed practice and structural reform.

Call to Action: Healthcare systems in India must urgently adopt approaches that prioritize the informed consent of parents (and the informed assent of children), defer unnecessary interventions without any therapeutic value and immediate or future health risks, and uphold the dignity and autonomy of every child.

1.2. Purpose and Objectives of the Guide

The purpose of this guide is to support the creation of intersex-inclusive healthcare systems in India—systems that recognize, respect, and reaffirm the rights, dignity, and well-being of children, adolescents, and youth born with somatic intersex variations.

Developed by the Intersex Children's Foundation of India (ICFI) with support from the Mariwala Health Initiative (MHI), this guide responds to the urgent need for ethical, rights-based, and medically sound approaches to intersex care in India. It aims to empower healthcare providers, mental health professionals, and policymakers to move beyond stigma, secrecy, and non-consensual interventions toward care grounded not only in autonomy, compassion, and informed collaboration but also backed by science and informed by empirical evidence from around the world.

This guide has five core aims:

Promote Evidence-Based, Ethical Medical and Mental Healthcare for children with somatic Differences in Sex Development [DSD]: Provide correct, up-to-date information on variations in sex characteristics, and advocate for a shift away from unnecessary and irreversible medical interventions without any immediate or potential future risk to the child's life or any other therapeutic value, toward child-centered, evidence-based healthcare practices. All information provided in this guide is from already implemented and validated best practices across the world.

Clarify the Distinction Between "Sex" and "Gender": This distinction is critical when caring for intersex individuals, whose bodies exist outside of typical binary notions of male or female. The conflation of sex and gender often leads to harmful assumptions and medical decisions, such as unnecessary surgeries or gender assignments based on rigid societal norms. A truly affirming and ethical approach in healthcare must acknowledge biological diversity, uphold bodily autonomy, and center the voices and lived realities of those most affected, while also recognizing culturally relevant identities.

Ensure Informed, Non-Coercive Decision-Making: Equip healthcare professionals to communicate clearly and sensitively with parents and young people, ensuring that any medical decisions are fully informed, consensual, and guided by the best interests of the individual, and especially minors [below the age of eighteen]. Multidisciplinary Teams need to brainstorm amongst themselves and create "consensus statements" to ensure uniform communication with intersex children and their parents.

Strengthen Interdisciplinary, Holistic Models of Care: Encourage collaborative approaches across medical and psychosocial disciplines—including pediatrics, endocrinology, surgery, mental health, and social work—to support the full spectrum of intersex health and well-being.

Advance Communication, Advocacy, and Systemic Change: Offer practical tools to enhance respectful dialogue with intersex children and their families and support broader advocacy efforts aimed at inclusive policy reform, institutional accountability, and medical education.

By fulfilling these aims, this guide aspires to contribute to a healthcare environment where intersex children and youth are not pathologized but supported to grow, thrive, and lead lives of dignity and self-determination.

1.3. A Global Snapshot on Legal and Policy Approaches

A critical review of intersex laws and healthcare protocols across the globe gives us some perspectives on how laws and policies are being amended to protect intersex children from harmful and non-consensual procedures. Juxtaposing them against the scenario in India clarifies the direction that we should be taking to protect the future generation our our nation.

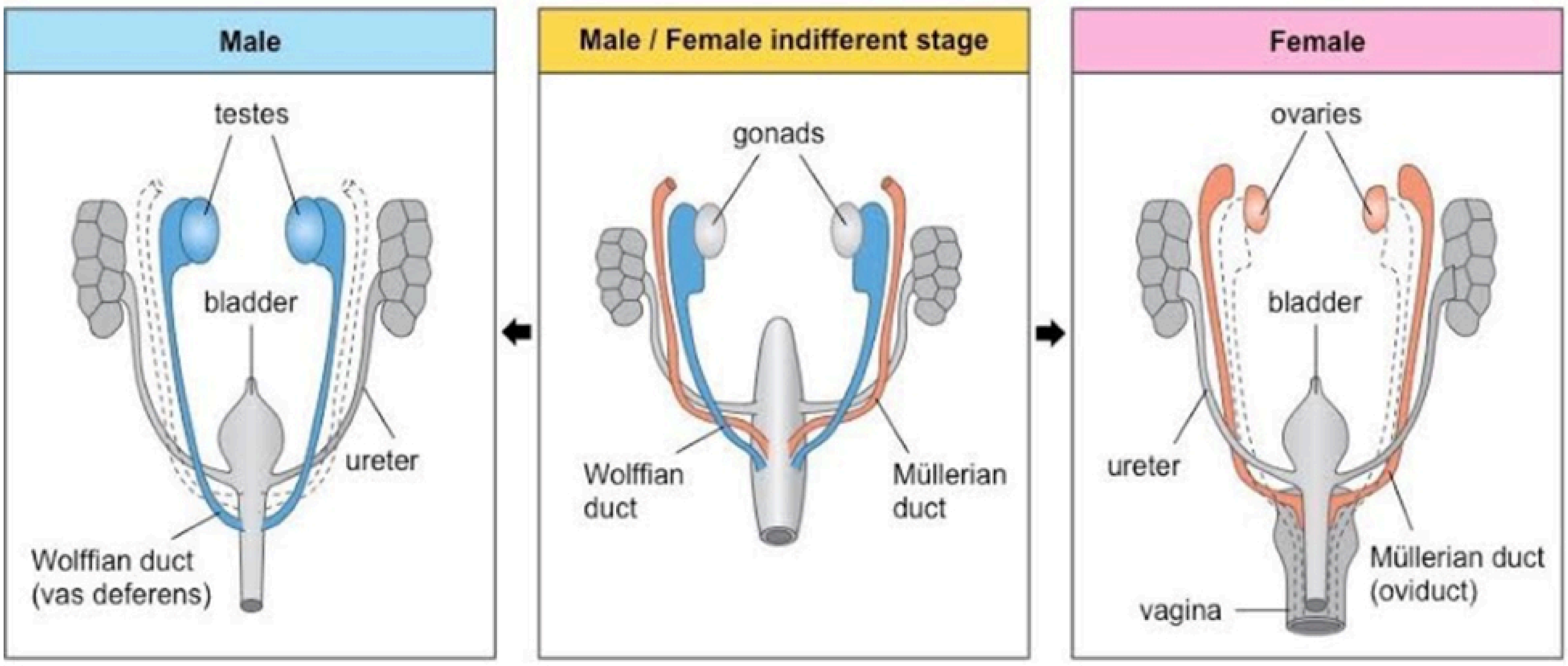
Country	**Key Legal/Policy Provisions**
Albania	2020: Medical protocol issued (non-binding); includes MDT approach but uses pathologizing language; lacks legal ban.
Austria	2018: Constitutional Court ruling affirms intersex rights; allows non-binary registration; prohibits unnecessary surgeries with binding punitive measures for non-compliance.
Brazil	2023: Working group formed; intersex infants may be registered without sex marker; pending 2025 policy report.
Chile	2023: Health Ministry circular bans non-consensual surgeries; backed by Law 21,430, prohibiting discrimination by sex characteristics.
Colombia	Court rulings restrict non-essential surgeries, thereby affirming the child's right to bodily autonomy. No clear age for consent is defined.
Uruguay	Law No. 19580 bans unnecessary medical procedures on intersex minors; supports name/gender change rights.
Germany	2018: Legal recognition of non-binary gender; 2021 law bans surgery under 14 years of age, unless medically necessary; mandates intersex-competent counseling.
Spain	2023: Prohibits all non-essential genital surgeries on children under 12; violations incur serious administrative/criminal penalties.
Greece	2022: Prohibits non-therapeutic surgeries under 15; requires court and expert committee approval; penalties for unauthorized procedures.
Iceland	2019: Ban on permanent changes to sex characteristics under 16 without consent; expert committee involvement mandated.
Malta	2015: First country to ban sex assignment surgeries on minors without consent; interdisciplinary team + parental agreement required in exceptions.
Portugal	2018: Law bans non-necessary sex assignment procedures under 16; implementation gaps due to lack of training and oversight.
Kenya	2024: Intersex Persons Bill prohibits harmful practices; allows intersex registration; lacks clarity on procedures for infants.
India	Madras (2019) and Kerala (2023) High Court rulings prohibit non-consensual surgeries, unless there is an immediate threat to life or future health risks, Advocates for Multi-Disciplinary Committees. There is no national legal ban or protocol for medical management of intersex variations. Intersex is conflated with Transgender in the law.

1.4. Understanding Intersex: Definitions and Biology

Intersex is a term used to describe a range of somatic variations in a person's sex characteristics—such as chromosomes, hormones, internal reproductive organs, or external genitalia—that do not align with typical medical definitions of "male" or "female" bodies.

Undifferentiated gonadal tissue develops along one of two pathways:

- In typical male development, the Müllerian ducts regress while the Wolffian ducts develop into male reproductive structures.
- In typical female development, the Wolffian ducts regress while the Müllerian ducts develop into female reproductive structures.



If the duct system does not fully regress or mature as per either of the above-mentioned pathways, this can lead to variations in sex characteristics.

These variations may be visible at birth, appear during puberty, or later in life. They may also remain undetected without medical testing.

It is important to note that while most intersex variations do not pose any health risk, or cause any dysfunction, some may require medical attention immediately or later in life. Yet historically medical science has viewed intersex variations or differences in sex development as a **"disorder",** thereby leading to non-consensual interventions aimed at "normalization" and erasure of the intersex identity.

These interventions often result in lifelong medical problems for the intersex person, not because of the intersex variation, but because of the medical intervention received to **'correct'** it.

This guide advocates for care that respects the autonomy, dignity, and lived realities of intersex children and adolescents. Health professionals are urged to avail training on intersex issues through consultations with the intersex community to provide such care.

Recommended Reading: *Grabham, Emily. (2007). Citizen Bodies, Intersex Citizenship. Sexualities. 10. 29-48. 10.1177/1363460707072951.*

1.5. Intersex Terminologies - Why Language Matters

Terminology refers to precise technical words that help us communicate complex concepts accurately and consistently within a particular field or context. However, beyond the technical benefits of terminologies, they also shape feelings and emotions.. Some medical terms once used are now rejected by intersex individuals and human rights experts as dehumanizing or inaccurate. Healthcare professionals are urged to use supporting language and center individuals' preferences. The most ethical approach is one rooted in informed choice, respect for self-identification, and a commitment to listen, learn, and do no harm.

Avoid These Terms	**Use These Terms**
“Hermaphrodite”	***“Intersex Variation”*** **/ “Differences of Sex Development” / “Variations of Sex Characteristics”** – widely embraced by the intersex community as an umbrella term affirming diversity. It is always advisable to check with the intersex people what term, if any, they would prefer to be referred by.
*“**Disorders** of Sex Development (DSD)”*	The continued use of the term “Disorders of Sex Development (DSD)” promotes a pathologizing framework that stigmatizes bodily diversity. This framing has historically led to irreversible and non-consensual medical interventions aimed at “normalizing” intersex bodies, often without regard for the individual’s autonomy, well-being, or identity. To support a more ethical, respectful, and rights-based approach to care, this term should be strictly avoided. For the purpose of continuity where the acronym “DSD”, since it is widely in use within medical settings, the term **“Differences** of Sex Development” may be adopted instead. This reframing emphasizes variation without implying defect or disorder. Additionally, the term **“intersex”** is widely accepted by intersex individuals and advocacy groups globally, and should be recognized as valid, especially in communication with intersex children and their parents.
“Diagnosis”	The word “diagnosis” implies that an intersex variation is a disease or a disorder that must be “fixed”, which can pathologize bodily diversity and add unnecessary stigma. Many intersex traits do not lead to any dysfunction. The term **“Identified”** can be used in medical notes. This is also more comforting and less daunting for parents of intersex children.
“Patient”	Instead of using the term “patient” in clinical records and treatment settings, using **person-first and child-centered language** helps uphold human dignity and emphasizes that an intersex children (and all children in general) are not defined by medical treatment alone.

Intersex Terminologies - Why Language Matters Contd.

Avoid These Terms	Use These Terms
"Sex assignment"	"Sex assignment", when used casually, implies an active decision rather than a descriptive observation. **"Sex registration," "Recorded sex", and "Observed sex at birth"** might be more precise for the purpose of documentation. Adding "Gender of Rearing" along with this would be a scientific approach towards decoupling sex and gender.
"Suffer from…" (e.g., "She suffers from AIS")	The word "suffering" implies that the variation always causes suffering is pathologizing and stigmatizing. For many intersex traits there is no sufferance involved. Phrases with **"Has…" or "Lives with…"** can be used as alternatives.
"Corrective surgery" / "Normalization surgery"	"Corrective surgery" / "Normalization surgery" implies the child is incorrect or abnormal and must be "fixed." **"Surgical intervention" or "surgical process"** can be used instead. Although ideally it is better to just describe the procedure factually, explaining the medical reason, if any.
"Condition"	The term "condition" can imply that an intersex variation is an illness or abnormality that inherently needs medical treatment or correction. This can unintentionally reinforce a medicalized or pathologizing view of natural bodily diversity. "Condition" might be acceptable only when describing a specific health issue that causes medical problems and needs treatment (e.g., hormonal imbalance causing metabolic issues), but for all other times, usage of **"variations"** is a neutral and non-pathologizing word.
"Abnormal,"/"Abnormality,"/ "Malformation"	"Abnormal,"/"Abnormality,"/"Malformation" suggest that the body is faulty, causing unnecessary shame. Advisable to use **"Variation", "Difference" or "Non-Normative development"**, **or "Variant Development"** (carefully).

1.6. Navigating Intersex Person's or Parental Preference for the Term "DSD"

While many human rights organizations and intersex advocates prefer affirming language such as "intersex variations" or "variations in sex characteristics," some families and healthcare providers — especially in clinical settings — may be more familiar or comfortable with the term "DSD" (Differences of Sex Development), and that is acceptable.

Without getting overly caught up in debates over terminology at the expense of compassionate care and clear communication, it is suggested that healthcare professionals adopt a flexible, child-centered approach that respects both human rights standards and the individual family's comfort level, without reinforcing pathologizing narratives.

The priority should always be to ensure that families and young people feel informed, respected, and empowered to make decisions that protect the child's health, dignity, and autonomy.

Best Practice Approach:

- Start by using affirming, non-stigmatizing language such as "intersex variations" or "bodily diversity."
- If a parent or child uses the term "Disorder," ask gently: "I hear you're using the term Disorder—would you prefer to use "Differences", or would you like us to use a different term like intersex or variation in sex characteristics?"
- Clarify that language choice is theirs and that your goal is to use terms that feel most comfortable and respectful to them.
- If using "DSD" in clinical documentation, use it as "Differences" and not "Disorder", and pair it with affirming explanations in discussions. For example: "This is sometimes called a DSD in medical language, but we prefer to focus on supporting your child's unique needs."

By respecting parental or child preference without losing sight of inclusive principles, healthcare professionals can build trust, reduce anxiety, and create a safe space for ongoing care and conversation.

1.7. Distinguishing Intersex from Transgender Identities

A common source of confusion, both in public discourse and within healthcare systems and policy frameworks, is the conflation of sex and gender. This misunderstanding frequently leads to inaccurate assumptions and misguided interventions that not only affect both intersex and transgender people differently but also might end up causing more harm than benefit.

The divergence:

- Sex refers to a person's biological characteristics, such as chromosomes, hormones, reproductive anatomy and external genitalia, which are often labeled male, female, or intersex.
- Gender, on the other hand, refers to an individual's deeply felt sense of identity (e.g., woman, man, non-binary, genderqueer, agender, or other diverse gender identities) and how they express that identity in social and cultural contexts.

The confluence:

- Transgender people typically have sex characteristics aligned with what is medically labeled male or female, but their gender identity differs from the sex assigned to them at birth. Their primary concerns may include social recognition, access to gender-affirming care, and protection from discrimination. However, for some transgender people, gender identity is closely linked to their physical body and biological sex characteristics, and hence while many parts of gender, such as role and expression may be considered as social constructs, there are biological aspects as well (in terms of hormones, anatomy etc.) which also shape their intrinsic sense of identity.
- On the other hand, while intersex people are born with biological variations in sex characteristics, they may identify with any gender (e.g., woman, man, non-binary, genderqueer, agender, or other diverse gender identities) just as transgender people. Their primary concerns often relate to bodily autonomy, consent to medical interventions, and protection from unnecessary medical interventions, including non-reversible and non-consensual surgeries. However, they might also need gender-affirming care basis their intrinsic sense of gender identity and expression.

Understanding Sex, Gender, and Sexuality: Why distinction between transgender and intersex people is critical?

Intersex and transgender experiences each highlight the deeply interwoven nature of sex, gender, and sexuality, and challenge the rigid binaries often used to categorize human identity. While sex is commonly viewed as biological and gender as social or psychological, in reality, they are mutually informing and shaped by a range of biological, cultural, and personal factors. Research has consistently shown that these elements do not exist in isolation but instead influence one another in complex ways.

It is critical for healthcare providers to move beyond simplistic dichotomies. People may identify as cisgender, transgender, agender, nonbinary, queer, or through culturally rooted identities such as hijra, kinnar, thirunangai, or aravani. These identities reflect diverse lived experiences that cannot be reduced to binary frameworks of male/female or man/woman. Similarly, sexual orientation — whether heterosexual, gay, lesbian, bisexual, asexual, pansexual, or otherwise — is a distinct yet often conflated aspect of identity that must be understood and respected on its own terms.

Intersex, Hijra and transgender are distinct identities. A person may identify with one, two or all three, but they are not interchangeable and come with unique lived experiences and challenges.

Conflating them leads to policies, healthcare protocols, and social messaging that overlook these distinct needs. Clear differentiation ensures that each community's rights, autonomy, and well-being are protected through specific, context-appropriate approaches in law, healthcare, and social support.

Recommended Reads:

- Fausto-Sterling, A. (2000) - "Sexing the Body: Gender Politics and the Construction of Sexuality"
- Joel, D., & Fausto-Sterling, A. (2016) - Beyond sex differences: new approaches for thinking about variation in brain structure and function. Philosophical Transactions of the Royal Society B: Biological Sciences, 371(1688), 20150451. https://doi.org/10.1098/rstb.2015.0451.

1.8. Addressing Healthcare Practitioners’ Internal Biases

Most healthcare professionals are trained and socialized within systems that reflect the broader norms of a cisgender, heteronormative society. As such, sex and gender are often understood in binary terms — female/male and woman/man. Moreover, sex and gender are often conflated and used interchangeably. In clinical settings, this worldview may influence the default response to assign newborns a binary sex and the corresponding gender identity, even when there may be natural variations in the child’s sex characteristics or uncertainty about their future gender identity.

This tendency is rooted in longstanding societal beliefs, including what scholars refer to as sex essentialism, that is, the idea that biological sex deterministically shapes gender identity (Hemmingham & Jones, 2019). However, the lived realities of intersex, transgender, and non-binary individuals challenge this assumption, highlighting the need for a more nuanced and person-centered approach to sex and gender.

It is important to recognize that many individuals’ gender identify do align with the sex assigned to them at birth. Yet, this fact alone should not negate the diversity of human experience or reinforce rigid binaries, especially in cases where biological development does not conform to standard definitions of male or female.

Healthcare practitioners, therefore, are encouraged to reflect on how implicit biases — shaped by culture, training, and social expectations — might influence clinical decision-making.

By engaging in self-reflective practice, seeking out education informed by the lived experiences of people with diverse sex and gender identities, and remaining open to dialogue, practitioners can better support families navigating uncertainty. This includes guiding parents toward a gender-neutral and open approach to caregiving in the absence of a definitive binary sex assignment and avoiding premature medical interventions aimed at conforming to normative expectations.

Rather than framing this as a matter of fault, it is more constructive to see it as an opportunity for growth through continuous learning. Ultimately, fostering an affirming, ethical, and rights-based approach begins with the willingness to question assumptions and create space for each child to grow into their own identity, on their terms, and in their own time.

2. Medical and Psychological Care Guidelines

2.1. Initial Identification Medical Tests, and Long-Term Care (Age-specific guidelines)

Newborns and Infants (0 to 2)

Identification: Intersex traits may be noticed at birth or shortly after through physical/clinical examination. Immediate diagnostic testing should be limited to essential assessments that affect urgent health, such as checking for life-threatening presentations and/or structural anomalies that can cause immediate or future health risks (e.g., urinary obstruction, menstrual flow, adrenal insufficiency, gonadal malignancy).

Testing: Genetic and hormonal tests, along with imaging studies, may be conducted if medically necessary, but only with clear communication to parents or guardians about the purpose, risks, and implications.

Parental Support and Counseling:

- Provide immediate, clear, and compassionate communication to parents about their child's intersex variation, focusing on correct, non-alarming information, using non-technical and non-pathologizing terminology
- Multidisciplinary Team (MDT) members should collaborate to develop clear, consensus-based communication guidelines for what information is shared with the parents or guardians. This ensures that messages are accurate, consistent, and delivered in a supportive, reassuring manner that promotes trust and understanding.
- Ensure counseling services are available and easily accessible to help parents/guardians process their emotions, including any confusion, fear, or grief, and to reduce feelings of isolation or stigma.
- Guide parents on how to create a nurturing, positive environment at home that supports their child's well-being and overall development. Conversations and decisions around assigning sex for the purpose of identity documentation and gender of rearing (either / both of which may change in the future), need to be managed with parents.
- Provide resources such as support groups, community connections, and educational materials to help parents build knowledge and emotional resilience.
- Emphasize the benefits of delaying any irreversible medical interventions until the child is older and able to take part in decision-making, unless there is an urgent medical threat to the child's life.
- Encourage ongoing psychological support for parents as their child grows, to help them advocate effectively for their child's rights and needs.

Care Focus (0–2 years): Support parents or guardians in understanding their child's body by providing accurate, clear, and compassionate information, along with mental health counselling to help them navigate social and familial concerns. Discuss any potential future medical interventions only with full, informed parental consent, and stress the importance of respecting the child's bodily autonomy and delaying any non-essential procedures until the child can participate in decision-making, where possible.

Care during this stage should be integrative and family-centered, considering not only the child's immediate physical health but also their future emotional well-being, the parents' mental health, and the broader social environment that may influence decisions and experiences.

Avoid early medical interventions, including surgery, unless there is an immediate threat to life (like surgery to remove urinary obstruction or steroid supplements for Salt Wasting CAH). Decisions about irreversible procedures should be postponed until the child can take part in the decision-making process and provide informed assent.

Children (2-9 years)

Identification: Added testing may be needed if the intersex variation becomes clearer between the ages of 2 and 10 years or if health concerns arise (e.g., related to growth or developmental milestones).

Testing: Any tests performed should be minimally invasive and conducted with the child's informed assent (if the child is above the age of 7 years) alongside the parents' or guardians' informed consent.

Parental Support and Child Counseling:

- **Informed assent of the child should be mandatory if they are 7 years of age and above**, along with the informed consent of their parents / legal guardians. Every attempt should be made to help the child understand the implications of the medical interventions on their body in the immediate, near, and far future.
- All efforts should be made to see to the child's comfort and non-verbal cues and to minimize any distress or discomfort.
- Surgeries required to address immediate life-threatening presentations or to preserve vital organ functions, for example, repair of an irreducible or obstructed hernia containing a gonad, or management of a urogenital sinus to prevent recurrent infections and kidney damage, should be performed without delay through minimally invasive methods like laparoscopy / cystogenitoscopy.
- Transparent communication with the family about the necessity, risks, benefits, and alternatives of testing is essential to uphold ethical standards and respect for the child's emerging autonomy.
- Psychological Counseling and Support should be made accessible for Intersex Children and Parents / Guardians. In case the parents are from an economically weaker section, then they should be referred to free counseling services and peer support groups of intersex adults or parents of intersex children.
- Use child-friendly approaches such as play therapy, storytelling, or art-based methods to help children express feelings and develop positive body awareness.
- Support parents with counseling and education about intersex variations, helping them to manage their own emotions and reduce stigma or anxiety.
- Guide parents on how to communicate openly and supportively with their child, fostering healthy psychological development and emotional resilience.
- Encourage ongoing family-centered counseling if and when needed, help nurturing relationships and open dialogue within the family while respecting the child's pace and comfort. Equip parents with practical tools and guidance to navigate and advocate for inclusive support systems at home, in schools, and in other public spaces.

Support For Parents If Informed Assent of Child Is Not Available:

- When a child is too young (that is, less than 7 years of age) or is unable to meaningfully understand or provide an assent, healthcare providers must rely on the informed consent of parents or legal guardians.
- **Even in cases where the child's informed assent is not available, all efforts should be made to see to the child's comfort and non-verbal cues and to minimize any distress or discomfort.**

Care Focus (2 to 9 years): Check physical and psychological development. Foster an environment where the child feels safe and cared for. Provide age-appropriate education about their body, encouraging open dialogue.

Delay irreversible "cosmetic" or "normalizing" surgeries, that are not instigated by risks to life and health, till the child is cognitively mature to express personal preferences and/or provide informed assent.

Adolescents (10-18 years)

Identification: This period may bring changes, such as puberty, that reveal or complicate intersex traits. Ongoing evaluation of physical and emotional health is critical during this phase.

Testing: Hormonal assessments and imaging might be necessary to guide care decisions related to not only puberty but overall health. While legally in India consent of a minor [below eighteen years] is not mandatory, it is advisable that informed assent is taken directly from the adolescents, thereby respecting their bodily autonomy and fundamental human rights.

Psychological Counseling and Support for Intersex Children and Parents / Legal Guardians

- **Informed assent should be mandatory for children above 7years of age** along with informed consent of their parents or legal guardians. Every attempt should be made to help the child understand the implications of the medical interventions on their body in the immediate, near, and far future.
- Even if the child concerned may have provided their informed assent, efforts should be made to look out for verbal or non-verbal cues to minimize any distress or discomfort.
- Healthcare providers should prioritize the least invasive procedures necessary and defer any non-urgent interventions until the child can take part in decision-making.
- Transparent communication with the children and their families about the necessity, risks, benefits, and alternatives of testing is essential to uphold ethical standards and respect for the child’s emerging autonomy.
- Psychological counseling and support should be made accessible for Intersex Children and their Parents / Guardians. In case the parents are from an economically weaker section, then they should be referred to free counseling services and peer support groups of intersex adults or parents of intersex children.
- Counseling, tailored to both adolescents and their parents, should be made easily accessible to address the complex emotional, social, and identity-related challenges during this critical period.
- **For adolescents:** A safe, positive space should be provided where they can explore their feelings about their body, gender identity, and social experiences without judgment. Age-appropriate therapeutic approaches, including individual therapy, peer support groups, or family sessions should be used, as needed. Peer Groups are especially beneficial for adolescents in reducing the sense of isolation by affirming diverse experiences.
- Encourage joint sessions with parents, whenever possible, to improve understanding and strengthen family bonds, while respecting the adolescent’s privacy and autonomy.
- **For parents:** Clear education about intersex variations and practical guidance on supporting their child’s physical and emotional well-being should be provided. Counselling should help parents process their own emotions, address feelings of guilt or anxiety, reduce stigma, and build effective communication skills to foster a supportive and affirming family environment.
- Parents should also receive accurate information about important medical considerations, including:
    - o The possibility of infertility (if any) due to under-functioning gonads (which may result from histological disarray).
    - o The potential risk of malignancy and the importance of appropriate monitoring.
    - o The need for ongoing renal health assessments (if relevant).
    - o The chance that intersex traits may appear in future offspring, and what that may mean for the family planning.
- Connecting parents with peer support groups, comprising other parents of intersex children, can be highly beneficial. Such groups provide a safe space to share experiences, reduce feelings of isolation, learn from others’ coping strategies, and gain practical advice on navigating social and medical challenges.

Care Focus: Focus should be on supporting adolescents in understanding their bodies and identities. Providing mental health counseling tailored to issues like body image, gender identity, and social challenges should be prioritized. Potential medical interventions should be discussed, with emphasize on the importance of bodily autonomy and delaying non-essential procedures.

Delay irreversible “cosmetic" or “normalizing” surgeries, that are not instigated by immediate risks to life and health, till the child is cognitively mature to provide informed assent.

Adolescents (10-18 years) Contd.

Understanding and Supporting Menstruation in Intersex Children

- **Not all intersex children menstruate**, and among those who do, experiences may vary widely depending on individual anatomy and hormonal profiles.

- **Menstruation should never be assumed or enforced as a marker of "normalcy" or gender identity**. Some intersex adolescents may menstruate unexpectedly due to retained or under-acknowledged reproductive anatomy.

- **Healthcare providers should offer non-judgmental, age-appropriate information** about menstruation—including what it is, what to expect, and how to manage it with dignity and hygiene.

- **Emotional and social support is critical,** especially if the child's body and identity have been previously medicalized or pathologized. Menstrual experiences may trigger anxiety, shame, or confusion if not addressed with care and compassion.

- **Privacy and consent must be upheld** when discussing menstrual health, whether with the child, parents, or in medical records.

- **Avoid using menstruation to justify invasive procedures** such as hysterectomy or vaginal construction unless there is a clear and urgent medical need, supported by full informed consent from the parents and written informed assent from the adolescent, if they are above 7 years and below eighteen years of age.

- **Encourage referrals to counselors or support groups** experienced in working with intersex and gender-diverse youth, especially during puberty.

Addressing Future Reproductive Abilities with Sensitivity and Respect

- **Reproductive potential in intersex individuals vary** depending on the underlying variation in sex characteristics and must be assessed individually, without assumptions or bias.

- **Respect for bodily autonomy is paramount.** Reproductive decisions should not be made on behalf of a child unless there is an immediate and unavoidable medical risk.

- **Avoid irreversible procedures (e.g., removal of gonads, hysterectomy)** that eliminate future fertility unless medically essential and life-saving. **Preservation of reproductive tissue and function should be prioritized where possible.**

- **Provide accurate, age-appropriate information to the child and family over time, not in a single overwhelming conversation.** These discussions should evolve alongside the child's understanding and developmental stage.

- **Do not frame infertility as a deficiency.** Instead, support diverse understandings of family-building, including assisted reproductive technologies, adoption, or choosing not to parent.

- **Document decisions transparently,** ensuring that any choices about reproductive health are made with the fullest possible informed understanding, and ideally with assent from the child as they mature.

- **Engage multidisciplinary teams,** including mental health professionals, reproductive endocrinologists, and peer support resources, to ensure holistic care.

Young Adults (19–25 years)

Navigating Transition and Independence: For intersex youth, the years between eighteen and twenty-five (18–25) represent a profound transition - not only in terms of legal adulthood but also in moving from a more protected home and school environment into the wider world of higher education, work, relationships, and independent living.

This stage often involves:

- Moving from school to college, vocational training, or employment.
- Increased exposure to new social networks and romantic relationships.
- Greater independence in managing one's health, identity, and privacy.
- Revisiting or understanding medical decisions made in childhood, sometimes for the first time.
- Forming adult partnerships and considering family planning.

Identification: Some intersex individuals may only receive information about or fully understand their intersex variation in young adulthood. For healthcare professionals, it is important to probe if medical information was incomplete or withheld earlier in childhood. Healthcare professionals should sensitively probe relevant history, re-explain past interventions, and help rebuild trust.

Testing: Young adults now have the legal and ethical right to consent to or refuse medical tests or treatments. It is vital to explain all evaluations clearly, ensure they are necessary, and respect the individual's autonomy, especially regarding any non-essential or cosmetic procedures.

Care Focus:

- **Autonomy & Empowerment:** Ensure access to past medical records and support young adults in making their own informed decisions.
- **Multidisciplinary Support:** Provide coordinated and collective care from medical and mental health professionals, including peer counselors.
- **Medical Options:** Where appropriate and desired, provide clear, supportive pathways for gender-affirming or body-affirming interventions, always prioritizing the individual's informed choices and overall well-being. Young people should be counselled about relevant medical facts, including potential infertility due to under-functioning gonads resulting from histological disarray, the risk of malignancy, the importance of ongoing renal health care, and the possibility of intersex traits in future offspring.
- **Psychological Support:** Address trauma, body image, identity, and future planning with trauma-informed, rights-affirming care.
- **Community Connection:** Promote intersex-led peer groups to reduce isolation and affirm diverse experiences.

Support for Parents and Families:

- Offer counseling to help parents process past medical choices, let go of guilt, and shift from a protective role to a supportive ally-ship that respects the young adult's autonomy.
- Provide resources to help families understand intersex variations more deeply and communicate openly and respectfully.

Support for Partners:

- Provide counseling and/or educational sessions to encourage open, informed conversations.
- Normalize intersex variations in intimacy and relationships.
- Encourage active listening, respect for autonomy, and emotional support.
- Refer to intersex-affirming resources to build awareness and mutual growth.

This stage of life is pivotal in that young adults are building identities and futures in more open social contexts. Affirmative, rights-based care at this point helps protect self-esteem, fosters trust in healthcare systems, and equips young intersex people to thrive, both personally and in relationships.

2.2. Evidence-Based Approaches: Alternatives to Surgical and Hormonal Interventions

For decades, surgical and hormonal interventions have been the default response to intersex variations, often performed in infancy or early childhood without the individual's understanding or consent. Today, evidence-based care urges a shift toward child-centered, non-invasive approaches that prioritize dignity, bodily autonomy, and long-term well-being.

Why Avoid Early Interventions?

Non-essential procedures intended to “normalize” appearance—such as clitoral reduction, vaginal construction, or gonad removal—should generally be avoided. Irreversible and often unnecessary, these interventions can result in:

- Physical pain
- Loss of sexual function
- Potential infertility
- Psychological trauma

Surgery may be warranted only when medically necessary (e.g., obstructed hernia, urogenital sinus causing infections, or risk of malignancy). Even in such cases, minimally invasive methods (e.g., laparoscopy) should be prioritized.

Hormonal treatments also carry long-term consequences if initiated without informed consent, potentially disrupting natural development and gender identity formation.

Recognizing the Realities Intersex Children Face:

While deferring non-essential procedures (“watchful waiting”) protects bodily autonomy, it must be paired with active psychosocial support. Children often face stigma and exclusion in schools, public spaces, and clinical settings. These environments can intensify distress if families are left unsupported.

What Healthcare Providers Can Do:

- Recognize that non-intervention still requires proactive care, including access to mental health professionals who are intersex-affirming.
- Support families in advocating for inclusion in education and public life.
- Engage in shared decision-making, involving the child or adolescent wherever possible.
- Offer ongoing medical check-ups to monitor development and emerging needs—not to delay indefinitely, but to allow for reflection and readiness.
- Connect families to peer networks to reduce isolation, build community, and offer role models of pride and resilience.
- Delay irreversible interventions until the individual can meaningfully participate in decisions, ensuring respect for autonomy and future agency.

Clinical Best Practices:

- Use a multidisciplinary team (medical, psychological, social work) to provide holistic care.
- Follow protocols grounded in human rights, bodily integrity, and long-term well-being, not cosmetic appearance.

2.3. Ethical Considerations in Decision-Making: Global Examples and Best Practices

Ethical care for intersex individuals is grounded in principles of autonomy, non-maleficence, informed consent, and human rights. Around the world, a growing number of governments, medical bodies, and human rights institutions are reevaluating past approaches and developing practices that uphold intersex people's dignity and decision-making power.

International Best Practices of Holistic Healthcare for Intersex Children

Dimension	Best Practice	Established Models
Healthcare Provider Training	Ensure healthcare providers are trained on identity development and the intersectional nature of a person's sex characteristics, gender identity, gender expression, sexual orientation, and related lived experiences.	Malta, Argentina, Germany, Australia
Surgical Interventions	Delay non-essential, irreversible surgeries until the individual can give informed assent.	Malta, Colombia, Uruguay, Portugal
Informed Consent	Involve parents and children (when possible) in transparent, informed decision-making.	Chile, Germany, Switzerland
Multi-discipinary Care	Use integrated medical, psychological, and social support tailored to the child's needs.	Netherlands, Germany
Psychological Support	Offer ongoing, trauma-informed counseling to children and families.	Austria, Germany, Brazil
Peer and Community Support	Enable peer support to reduce isolation and strengthen identity.	Kenya, Colombia, Uruguay
Medical Records Access	Ensure individuals can access their records and past medical history.	Austria, Switzerland, Germany
Education and Inclusion	Integrate intersex awareness in schools; prevent bullying/discrimination.	Uruguay, Australia, Brazil

2.4. Mental Health Support and Counseling Best Practices

Intersex children and adolescents often face unique emotional and psychological challenges stemming from stigma, secrecy, medical trauma, and a lack of social understanding. Effective approaches prioritize affirming, trauma-informed, and culturally competent care that centers the fundamental human rights, bodily autonomy, and lived experiences of the child.

Key Principles of Effective Mental Health Support:

Confidentiality: Respecting the intersex child's and their parents' privacy is foundational to building trust in mental health care. Information shared during sessions should not be disclosed without informed consent, except in situations where there is a risk of harm to the individual or others.

Trauma-Informed, Non-Pathologizing Care: Mental health services must avoid framing intersex variations as disorders. Instead, emphasis should be given on supporting the child and family in coping with societal stigma and medical experiences, not "fixing" the body.

Early and Ongoing Counseling: Support should begin at the time of identification and continue across developmental stages. Children benefit from age-appropriate discussions that help them understand and affirm their bodies.

Family Counseling and Support: Parents and caregivers may feel overwhelmed, isolated, or uncertain. Mental health providers should create safe spaces for families to process emotions, resolve internalized biases, and build skills for open communication with their child.

Respect for Autonomy and Identity: As children grow, counseling should support self-exploration of gender identity, without assumptions or pressure. Affirming care recognizes that intersex individuals may have diverse gender identities and body relationships.

Culturally Competent, Affirmative Mental Health Approaches: Mental health professionals must be trained in intersex-affirming, culturally sensitive care. They should understand family dynamics, social environment, beliefs about gender and the body, and how to work with communities to reduce shame and promote acceptance.

Peer and Community Integration: Linking intersex children and youth with peer support groups, intersex-led networks, and community role models fosters belonging and emotional well-being. These connections help reduce isolation and build resilience.

3. Roles and Responsibilities of Healthcare Professionals

3.1. Creating Inclusive and Affirming Healthcare Environments

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Healthcare professionals play a pivotal role in shaping how intersex individuals and their families experience the healthcare system. From the first point of contact, they can either reinforce stigma and trauma or foster trust, dignity, and long-term well-being. Creating inclusive and affirming environments is essential to ensure ethical, respectful, and rights-based care, especially for our marginalized and misunderstood intersex children and adolescents.

Key Responsibilities of Healthcare Professionals:

Confidentiality: Healthcare professionals must safeguard all personal and medical information shared by the intersex children and their parents, including details related to gender identity, sexual orientation, or intersex traits. Disclosure should occur only with informed consent, or when legally required to prevent harm. Maintaining confidentiality is essential to uphold trust, dignity, and ethical care.

Use Respectful and Accurate Language: Avoid pathologizing terms such as “disorders of sex development.” Instead, use terms like “intersex” or “differences/variations in sex characteristics” (DSD/VSC), unless the child or family prefers a specific medical term. Always ask how the child wish to describe themselves.

Offer Transparent, Informed Communication: Families deserve clear, honest information that is free from shame or urgency. Avoid language that implies something is “wrong” or must be “corrected.” Discuss all options, including the option of waiting, with their full risks, benefits, and long-term implications.

Practice Shared, Ethical Decision-Making: Involve parents and, where age-appropriate, the child in decisions. Avoid making assumptions about future gender identity or societal acceptance. Respect the child’s evolving ability to take part in choices about their body and care.

Provide Trauma-Informed, Non-Coercive Care: Recognize that many intersex individuals have experienced non-consensual or distressing interventions. Create environments that reduce fear, protect dignity, and prioritize emotional safety during examinations, discussions, and procedures.

Coordinate Multidisciplinary and Person-Centered Teams: Ensure collaboration between medical, psychological, social work, and advocacy professionals. Care should be holistic, individualized, and oriented around the child’s best interests.

Respect Privacy and Confidentiality: Medical records and histories must be handled ethically. Young people should have access to their records and a say in how their information is shared. Avoid unnecessary exposure or public discussion of their variation.

Create Inclusive Physical Spaces and Practices: From intake forms to patient rooms, ensure systems do not force binary categories or alienate intersex individuals.

Commit to Lifelong Learning and Accountability: Healthcare professionals must unlearn outdated practices and stay informed on rights-based, evidence-driven intersex care. Institutions should support ongoing education, ethical reflection, and feedback from intersex-led groups.

3.2. Sensitive Communication with Children and Families

Effective, respectful communication is central to providing ethical and affirming care for intersex individuals and their families. Sensitive communication helps build trust, reduce distress, and ensure informed, participatory decision-making. It also addresses the emotional needs of families while affirming the dignity and autonomy of intersex children and adolescents.

Core Principles for Sensitive Communication:

Listen Without Judgment: Begin by listening to the concerns, fears, and questions of the child and their family without making assumptions or rushing to solutions. Create a non-judgmental space where parents and children feel heard and respected.

Use Accurate, Affirming Language: Avoid stigmatizing or pathologizing terms such as “abnormal,” “defective,” or “disorder.” Use neutral and inclusive language like “intersex variation” or “differences in sex development” or “variation in sex characteristics.” Always ask the family and individuals the language they are comfortable with.

Be Transparent and Honest: Communicate clearly about what is known, what remains uncertain, and what options exist. Avoid over-simplifying or giving false reassurance. Explain medical information in accessible terms, avoiding technical jargon.

Avoid Rushing Decisions: Do not present irreversible medical interventions as urgent unless there is an immediate health risk. Emphasize that families have time to understand their child’s needs and make thoughtful, informed decisions.

Center the Child’s Best Interests: Ensure that all communication reflects respect for the child’s bodily autonomy and future ability to participate in decisions. Speak about the child in ways that affirm their value, wholeness, and potential.

Validate Emotions and Provide Reassurance: Acknowledge the emotional impact of an identification or added information. Reassure families that many intersex people live healthy, fulfilling lives and that their child is much more than their bodies. Offer support, not pity.

Involve Mental Health and Peer Support Early: Refer families to trauma-informed counselors and intersex-led peer support networks. Encourage them to connect with others who have walked similar paths.

Respect Privacy and Confidentiality: Discuss the importance of discretion and empower families to decide who they wish to inform and how much of information they want to share. Protect the child from unnecessary exposure or labeling.

Support Ongoing Dialogue: Offer follow-up conversations as understanding evolves. Communication and support should be a continuous, trust-based process, not a one-time event.

3.3. Multidisciplinary and Referral-Based Care Models

Multidisciplinary care models bring together diverse specialists to ensure comprehensive, ethical, and child-centered management throughout the child’s development.

Key Components of Multidisciplinary Care:

Integrated Care Teams: A multidisciplinary team typically includes pediatricians with specializations in endocrinology, surgery, gynecology, urology, genetics, and psychology as well as social workers, and child rights advocates. Collaboration among these professionals enable balanced decision-making and holistic support, apart from ensuring that all communication is consistent and accurate.

Central Role of Psychological Support: Mental health professionals are essential for supporting the individual and family emotionally from identification onward. They help in coping with uncertainty, body image, identity development, and social challenges.

Family-Centered Approach: Teams work closely with families to provide education, counseling, and guidance, empowering them as partners in care. This fosters trust and respects the family’s cultural and social context.

Respect for Autonomy and Informed Consent: Multidisciplinary teams prioritize the child’s evolving capacity for decision-making. They ensure that interventions are consensual, medically necessary, and ethically justified.

Referral Networks and Specialist Access: When specialized care is needed beyond the core team, seamless referral systems help access to experts such as fertility specialists, urologists, gynecologists, or legal advisors.

Coordinated Care Planning: Regular team meetings and shared decision-making on care protocols ensure ongoing communication, avoiding fragmented or siloed treatment. Care plans are individualized, flexible, and responsive to changing needs.

Peer and Community Resources: Teams connect individuals and families with peer support groups and community organizations led by intersex advocates. This reinforces social inclusion and lived experience.

Benefits of Multidisciplinary Care Models:

- Ensures comprehensive assessment and management of physical, psychological, and social aspects.
- Reduces unnecessary or harmful medical interventions.
- Supports the family unit through education and counseling.
- Enhances the child’s autonomy and respects their bodily integrity.
- Facilitates continuity of care over time and across developmental stages.

3.4. Ethical Responsibilities and Professional Code of Conduct

Healthcare professionals working with intersex individuals hold profound ethical responsibilities to ensure care that respects dignity, autonomy, and human rights. Ethical practice must guide every interaction, decision, and intervention.

Core Ethical Principles:

Confidentiality: Protecting the privacy of individuals, especially children, is a fundamental ethical obligation. Upholding confidentiality ensures that sensitive information—particularly related to intersex traits, gender identity, and mental health—is not disclosed without consent, fostering safety, autonomy, and trust in care relationships.

Respect for Autonomy: Professionals must prioritize informed consent from parents and and informed assent from children above 7 and below 18 years of age, honoring the child's and family's right to make voluntary decisions about identification, treatment, and disclosure. This includes respecting evolving capacities in children and adolescents.

Non-Maleficence and Beneficence: Providers must avoid harm by refraining from unnecessary, irreversible, or cosmetic surgeries without consent. Interventions should aim to maximize health and well-being, considering physical, psychological, and social impacts.

Justice and Equity: Equal access to quality healthcare, information, and support must be ensured regardless of background. Providers should actively work against discrimination, stigma, and bias affecting intersex children and families.

Professional Conduct Standards:

Transparency and Honesty: Communicate openly about identification of variation, available options, risks, benefits, and uncertainties. Avoid secrecy by involving children and families as partners in care.

Cultural Competence and Sensitivity: Recognize and respect diverse cultural, religious, and personal values. Provide care tailored to individual contexts without imposing normative assumptions about gender or sex.

Confidentiality and Privacy: Protect patient, especially children's, information rigorously. Disclose sensitive information only with informed consent and in ways that safeguard the child's dignity.

Commitment to Continuing Education: Healthcare providers must seek ongoing training on intersex variations, evolving ethical standards, and affirming care practices to support competence and empathy.

Advocacy and Support: Healthcare Professionals have a role in advocating for the rights and well-being of intersex children, adolescents and youth within healthcare systems and society. This includes opposing harmful practices and promoting policies that uphold bodily autonomy.

3.5. Ethical Challenges and Considerations

Challenge	**Recommendations**
Navigating decisions involving infants and young children when assent is not possible	Defer non-essential, irreversible interventions until the child can participate in decision-making. Use a “harm reduction” approach: Select the least invasive choice while preserving bodily integrity and future autonomy. Engage ethics committees.
Balancing medical uncertainty with the child’s best interests	Prioritize open, honest communication with parents about uncertainties and options. Follow a “wait and watch” model when outcomes are unpredictable. Implement shared decision-making protocols guided by rights-based principles.
Addressing potential conflicts between family wishes and the child’s bodily integrity and future autonomy	Offer neutral, trauma-informed counseling to help families process emotions. Clearly explain that decisions must prioritize the child’s long-term well-being and autonomy. Include psychosocial professionals in care discussions. Involve peer support groups or parents of intersex children for supporting the children and their families.
Managing personal biases and societal stigma	Ensure training on intersex rights, gender diversity, and medical ethics for all healthcare providers. Foster self-reflection and peer accountability in clinical practice. Promote intersex-affirming guidelines and mentorship.

4. Healthcare Management and Emergency Considerations

4.1. Current Healthcare Landscape and Way Forward: Intersex Rights in India

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Absence of Human Rights-Aligned Guidelines: There is no international consensus on healthcare protocols for somatic intersex variations. While some countries have outright banned genital modification surgeries on children, and some have incorporated regulatory guidelines, most countries are still undecided on a standard approach. Some judicial orders, across the world, have ruled against early genital reconstruction surgeries and laid down guidelines to form multi-disciplinary teams for surgical decision-making. India does not have any national protocol for the management of healthcare for somatic intersex variations yet.

Recommendation: Enact law specifically for intersex persons, acknowledging their separate identity, and providing for protocols on medical and psychological care of somatic intersex variations amongst infants, children, adolescents, and youth. This should be a collaborative exercise between healthcare practitioners, psychological professionals, intersex adults, parents of intersex adults, educationists, and human rights experts.

Pathologizing Medical Framework: Till date, somatic intersex variations are termed as “disorders of sex development,” which intersex persons around the world strongly feel is pathologizing and stigmatizing. Unlike many other congenital medical differences, the care and management of somatic intersex variations are deeply shaped by cultural beliefs and societal norms. These influences often outweigh medical necessity and contribute to stigma, secrecy, and pressure to conform. While scientific understanding and ethical approaches to intersex care have evolved significantly in recent years, societal attitudes are slower to change. Shifting public perception and achieving widespread acceptance of bodily diversity will require sustained effort, dialogue, and education.
The use of the new nomenclature, the specific somatic intersex variation, which is based on the individual’s observed karyotype, can help ensure clear and standardized communication among healthcare providers and families. However, it should be applied sensitively, with care to respect the individual’s identity and to avoid unnecessary medicalization or stigma.

Recommendation: Reform curricula to include rights-based, trauma-informed, and gender-sensitive care and integrate intersex perspectives.

Lack of Multidisciplinary Care: Most hospitals lack coordinated care in the form of Multidisciplinary Teams (MDT), and psychological support is rare. Families often receive conflicting biomedical advice.

Recommendation: Institutionalize integrated, child-centered care teams with counseling and decision-making support.

Early, Irreversible Surgeries and hormonal treatments: Non-essential surgeries and hormonal therapies are still being performed on infants and children, driven by binary norms.

Recommendation: Prohibit surgeries and/or hormonal treatments on infants and children for non-emergency cases and promote alternative, non-invasive treatment options. Create a consensus statement on list of procedures that can be considered as valid reasons for surgical interventions.

Poor Consent and Record Practices: Consent processes are opaque and exclude children’s voices, while medical records are often inaccessible or withheld later.

Recommendation: Establish ethical, transparent consent/assent frameworks and guarantee access to medical history.

Stigma in Healthcare Settings: Intersex children face shame, secrecy, and bias within medical institutions, and there is no formal system for reporting the mistreatment.

Recommendation: Foster inclusive, affirming healthcare environments. Train staff in respectful communication; create grievance redressal mechanisms and make them easily accessible for children.

4.2. Ethical Guidelines on Consent and Non-Essential Surgeries

Bodily Autonomy and Integrity:

- All individuals have the right to bodily autonomy.
- Non-urgent, cosmetic, or gender-confirming surgeries should only be performed with the informed consent of the individual.

Evolving Capacities and Assent:

- Children capable of forming views must be involved in healthcare decisions that affect them.
- When full consent is not possible, age-appropriate assent must be sought and respected.

Informed Parental Consent:

- Parents must be fully informed of the medical, ethical, and psychosocial dimensions.
- Consent should be free of coercion, include alternatives (e.g., psychosocial support), and acknowledge the child's right to delay irreversible decisions.

When Is Surgery Justifiable?

Surgeries are ethically permissible **only** if:
- There is an immediate risk to life or health.
- The procedure cannot be delayed until the child can participate in decision-making.
- Full medical and psychological consultation has occurred, including multidisciplinary review.
- The child's rights and long-term well-being are prioritized over societal or parental discomfort.

Recommendations for Indian Healthcare Providers: In the Indian context, societal norms around sex, gender, and gender roles remain a dominant force in decision-making concerning intersex children. These norms influence how families perceive their child, how communities respond, and how healthcare professionals are pressured to act.

From naming and gender assignment to decisions about school enrollment, clothing, and especially medical interventions, cultural expectations often override medical necessity or ethical reflection. These social pressures contribute to irreversible decisions being made in haste that can have lifelong physical and psychological consequences.

Any meaningful reform in intersex healthcare must begin by recognizing and addressing these societal forces, rather than treating intersex variations purely as medical anomalies. Respecting bodily autonomy, delaying non-essential interventions, and prioritizing mental health support are not just medical imperatives; they are urgent social justice issues.

To align intersex care in India with international human rights standards and emerging best practices:

- Establish Multi-Disciplinary Institutional Review Panels: Any proposed surgical or hormonal intervention (unless needed due to immediate threat to life or health risks) must undergo review by multi-disciplinary committees, ensuring decisions are not driven by social anxiety or cosmetic expectations but in alignment with the best interests of the child.
- Adopt Standard Clinical Guidelines: Comprehensive, rights-based care protocols emphasizing transparency, multidisciplinary decision-making, and child and family involvement should be adopted by healthcare professionals and institutions. It should be ensured that the guidelines are sensitive to Indian cultural contexts, while being firmly rooted in fundamental human rights of every child.
- Prioritize Psychosocial Support: Mandate access to ongoing, intersex-affirming counseling and psychosocial support for families and children. These supports should not be contingent on surgical decisions but integrated as part of standard care.

4.3. Emergency Medical and Mental Health Crisis Management for Intersex Children and Adolescents

Criteria for Medical Emergencies:

- Acute, life-threatening situations such as urinary/vaginal obstruction or gonadal hernia.
- Severe infections or complications from earlier surgical interventions.
- Circumstances require immediate stabilization (e.g., electrolyte imbalance, salt-wasting).

Best Practice Protocols:

- Stabilize the child's health before any invasive procedures.
- Consult the multi-disciplinary team of specialists for a course of action.
- Ensure transparency with the family; explain options and risks clearly.
- Avoid irreversible surgeries unless necessary for saving life.

Criteria for Mental Health Emergencies:

- Trauma from prior medical interventions.
- Discovery of concealed medical history.
- Bullying, stigma, or familial rejection.
- Gender identity distress or body dysphoria.

Crisis Support Protocols:

- Immediate access to trauma-informed mental health professionals.
- Create a safe, affirming space for the child or adolescent to express distress.
- Avoid pathologizing or dismissing emotional responses.
- If suicide risk or self-harm is present, follow psychiatric crisis protocols while ensuring non-coercive, rights-respecting care.
- Engage family members sensitively; Offer immediate psychosocial support to families experiencing fear, guilt, or confusion.
- Provide factual, compassionate information to parents about the child's needs.
- Address stigma and reassure that delay in non-essential decisions is protective and ethical.

Institutional Recommendations:

- Train ER and pediatric staff in intersex-inclusive crisis protocols.
- Maintain a referral system to connect families with multidisciplinary care teams.
- Establish non-judgmental triage practices—no cosmetic surgery decisions in emergency settings.
- Include intersex-sensitive mental health care in hospital crisis plans.

4.4. Managing Medical Records with Privacy and Dignity for Intersex Children and Adolescents

Key Principles for Dignified Record-Keeping:

Transparency & Access:

- Individuals have a right to access their full medical records, including surgical notes, identification, and treatment rationale.
- Disclosure should be age-appropriate and trauma-informed.
- Withholding records due to fear of emotional reaction is unethical.

Informed Disclosure:

- Young people must be supported with sensitive counseling when records are disclosed.
- Avoid sudden or uncontextualized revelation of medical history.

Privacy Protections:

- Safeguard intersex-related information in medical files using secure systems.
- Limit access to only those directly involved in care.
- Use respectful, non-stigmatizing language in records.

Family and Caregiver Involvement:

- Parents/guardians should receive full documentation at the time of identification or intervention, and also must be informed about the importance of preserving records for the child’s future understanding.
- Promote openness while respecting the child’s evolving right to confidentiality.

Institutional Responsibilities:

- Develop intersex-sensitive medical documentation protocols, ensuring clarity and dignity.
- Train healthcare staff on ethical recordkeeping and patient (especially children’s) rights.
- Include procedures for when, how, and by whom records should be shared with the individual.

Long-Term Goals:

- Create digital, secure, lifelong health records that move with the individual across healthcare settings.

5. Advocacy, Policy, and Practical Tools

5.1. Policy Engagement and Institutional Recommendations

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To ensure ethical, inclusive, and rights-based healthcare for intersex children and adolescents in India, systemic change must be driven through policy and institutional reform. This section outlines key strategic recommendations:

National Medical Protocol & Legal Reform:

- Recognize “sex characteristics” as a protected category in anti-discrimination and child protection laws.
- Develop a national protocol on intersex care aligned with human rights standards and lived experiences, explicitly banning non-consensual, medically unnecessary surgeries and hormone treatments on intersex minors unless posing a threat to the child’s life.

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Integration into Medical Education

- Revise medical curricula to include accurate, stigma-free information on sex variations, with emphasis on ethics, autonomy, and psychosocial care.
- Include intersex-specific modules in Continuing Medical Education (CME) and accreditation requirements.

Institutional Collaboration and Task Forces:

- Establish central and state-level interdisciplinary task forces involving key ministries: Health and Family Welfare, Women and Child Development, Social Justice and Empowerment, and Law & Justice.
- Set up multidisciplinary regulatory committees with medical experts, intersex advocates, and parents to oversee and restrict unnecessary and non-consensual interventions on intersex children.

Data Collection and Research:

- Mandate the Ministry of Health and Family Welfare to create a National Registry of Intersex Persons, ensuring standardized medical and demographic data reporting from all healthcare providers and institutions across the country.
- Involve the Department of Health Research to commission ethical, community-informed studies on intersex health and healthcare practices, ensuring that future policy is grounded on empirical evidence and human rights standards.

Community and Family-Centered Approaches:

- Develop policies that strengthen peer support networks, counseling services, and parental guidance, offering families accurate, compassionate, and non-directive support in raising intersex children.
- Facilitate training for frontline workers—including Accredited Social Health Activists [ASHA],, Anganwadi Workers [AWW], and school counselors—to recognize and sensitively support intersex children and their families within community settings.

5.2. Case Studies and Stories of Best Practices

Case Study 1: Christiane Völling (Germany)

Background: Christiane Völling, born in 1959, was assigned male at birth despite having XX chromosomes and internal female reproductive organs. At age 18, without her informed consent, surgeons removed her female reproductive organs.

Outcome: In 2008, the Regional Court of Cologne ruled in her favor, awarding €100,000 in damages for the unauthorized surgery. This marked the first known successful legal case for non-consensual intersex medical intervention. The case set a legal precedent in Germany, emphasizing the importance of informed consent and bodily autonomy in medical practices involving intersex individuals.

Case Study 2: M.C. v. Aaronson (United States)

Background: In 2006, a medically unnecessary sex assignment surgery was performed on M.C., an intersex child in South Carolina, while under state custody.

Outcome: In 2013, a lawsuit was filed against the doctors and the South Carolina Department of Social Services, alleging violation of constitutional rights. The case was among the first to challenge such surgeries legally. Although the federal court dismissed the constitutional claims, the case brought significant attention to the rights of intersex children and the ethics of non-consensual surgeries.

Case Study 3: Madras High Court – Arunkumar & Sreeja v. Inspector General of Registration (2019)

Background: In this case, a cisgender man and his partner, a trans woman, sought legal recognition of their marriage under the Hindu Marriage Act. The registrar had denied their application, questioning the validity of the marriage.

Judgment Highlights:

- Justice G.R. Swaminathan addressed the broader issue of non-consensual sex reassignment surgeries on intersex infants, emphasizing that such procedures violate the individual's rights to bodily autonomy and integrity.
- The court directed the Tamil Nadu government to issue a Government Order (GO) banning sex reassignment surgeries on intersex infants and children, except in life-threatening situations.

Impact: Tamil Nadu became the first Indian state to prohibit sex reassignment surgeries on intersex infants and children, with exceptions only for life-threatening conditions vide GO (Ms.) No. 355 on August 13, 2019.

Case Study 4: Kerala High Court – XXXX & Anr. v. The Health Secretary & Ors. (2023)

Background: Parents of a seven-year-old intersex child filed a petition seeking permission to perform genital reconstructive surgery to raise the child as female.

Judgment Highlights:

- The court directed the Kerala government to constitute a State-Level Multidisciplinary Committee to assess such cases, mandating that sex-selective surgeries on intersex children should only be allowed if considered essential to save the child's life, based on the committee's recommendation.

Impact: The judgment reinforced the principle that non-consensual, non-essential surgeries on intersex children violate their fundamental rights. It prompted the Kerala government to set up a regulatory framework for medical interventions involving intersex minors, ensuring decisions are made with utmost care and respect for the individual's rights.

5.2. Case Studies and Stories of Best Practices Contd.

These cases underscore the judiciary's role in safeguarding the rights of intersex children, emphasizing the importance of informed consent and bodily autonomy. Real-world examples play a vital role in illustrating how affirming, ethical, and rights-based care for intersex children and adolescents can be effectively implemented. The case studies from India and other global contexts highlight promising reforms in healthcare and legal frameworks.

These case studies demonstrate the tangible impact of:

Informed Consent and the Evolving Capacity of the Child: Irreversible medical or surgical interventions should never be performed unless the child and their parents are fully informed, emotionally prepared, and capable of making a voluntary, autonomous decision. In the case of intersex children, this means waiting until they can meaningfully understand the implications of the medical interventions. Consent/Assent should be viewed as an ongoing process—not a one-time signature—involving the child, family, healthcare providers, and, where necessary, independent advocates or counselors. This approach respects the right of every individual to make decisions about their own body, in their own time.

Delayed, Non-Invasive Diagnostics with Psychosocial Support: Rather than rushing to “normalize” a child’s body through surgery, a more compassionate, evidence-based approach involves delaying irreversible procedures and opting for non-invasive diagnostics—such as hormonal evaluations, imaging, and genetic testing—to monitor health and development. This watchful waiting strategy should be accompanied by regular psychosocial follow-up, offering families access to trained mental health professionals, peer support networks, and affirming, culturally right information. Such an approach allows children to develop their own identities and participate in healthcare decisions when ready, in alignment with international pediatric ethics and human rights principles.

Holistic, Multidisciplinary Care Models: Effective intersex care requires collaboration across disciplines. Holistic models bring together pediatricians, endocrinologists, psychologists, geneticists, surgeons, counselors, and ethicists to provide coordinated, individualized care that centers the child’s long-term well-being, not just physical appearance. These models emphasize bodily autonomy, support families with clear and compassionate guidance, and help reduce shame, stigma, and misinformation. They reflect international best practices and uphold commitments under frameworks like the UN Convention on the Rights of the Child and the Yogyakarta Principles plus 10.

Parental Support that Centers the Child’s Dignity: Families often face intense pressure to make immediate decisions. Structured support initiatives can transform these moments from crisis to empowerment by providing correct, stigma-free, non-directive guidance.

Key components of effective parental support include:
- Access to trained psychosocial counselors
- Peer support groups to reduce isolation and foster shared learning.
- Decision-making tools that respect both medical ethics and family values
- Educational materials in local languages to aid advocacy in schools, healthcare, and communities.

Medical Institutions Revising Protocols to Delay Irreversible Interventions: Progressive medical institutions around the world are beginning to revise their care protocols for intersex individuals, especially children, to align with human rights standards and ethical healthcare practices. A central element of these revisions is the deliberate postponement of irreversible medical or surgical interventions (such as genital surgeries or gonadectomies) until the individual can meaningfully take part in the decision-making process and give informed, voluntary consent. This shift is based on growing recognition that early, non-consensual interventions—often performed to conform to binary notions of sex—can cause long-term physical, psychological, and emotional harm.

5.2. Case Studies and Stories of Best Practices Contd.

Revised protocols typically include:

- Explicit deferral policies that delay cosmetic or non-life-saving procedures until the child is mature enough to be involved in decisions.
- Multidisciplinary review boards or ethics committees to assess each case with input from pediatricians, psychologists, surgeons, and independent child rights advocates.
- Standardized consent pathways that outline how and when decisions should be revisited as the child grows, ensuring evolving ability is respected.
- Enhanced documentation and audit systems to track decision-making, medical outcomes, and family support measures over time.
- Emphasis on psychosocial support as a first-line response—providing families with affirming counseling, mental health care, and connections to peer support networks.

By implementing these changes, medical institutions show a commitment to trauma-informed, child-centered care that upholds the principles of bodily integrity, autonomy, and dignity. This not only prevents avoidable harm but also builds trust between families and healthcare providers, ensuring that care is compassionate, respectful, and rights-based.

5.3. Guidelines for Initial Assessment of Infants with Non-Normative Genitalia

The first assessment of an infant born with variant or non-normative genitalia must be handled with sensitivity, caution, and adherence to ethical principles. The focus must be on understanding the underlying variation, avoiding unnecessary urgency, and supporting the family emotionally and informationally. These guidelines promote a non-pathologizing, rights-affirming approach grounded in international best practices.

Immediate Priorities (First 24–48 Hours):

Any newborn presenting with non-normative genitalia and signs of illness should be promptly evaluated for potential life-threatening presentations, particularly a salt-wasting crisis associated with Congenital Adrenal Hyperplasia (CAH), one of the more common intersex variations, or Urogenital Sinus, or irreducible or obstructed inguinal hernia with gonadal involvement.

A history of death under similar circumstances within the immediate family, especially with unexplained electrolyte disturbances, should raise strong clinical suspicion for CAH.

Stabilize and Assess General Health:

- Ensure the infant is medically stable (e.g., feeding well, maintaining body temperature, no metabolic distress).
- Rule out urgent presentation such as salt-wasting Congenital Adrenal Hyperplasia (CAH), urogenital sinus, or irreducible and/or obstructed inguinal hernia with gonadal involvement.

·**Avoid Immediate Sex Assignment:**

- Do not assign sex immediately or recommend surgical intervention without a thorough diagnostic process and multidisciplinary input.
- Communicate to the family that some cases require time and further testing to decide the best course of care and sex of rearing.

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Ensure Privacy and Dignity:

- Limit genital examinations to what is medically necessary.
- Minimize unnecessary documentation or photography; obtain consent if any imaging is needed for medical records.

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Initial Clinical Assessments:

- Appearance of genitalia – whether non-conforming.
- Location of the urethral meatus
- Phallic structure: Size (stretched flaccid phallic length, corporal body girth)
- Gonad Location: Bilateral nonpalpable/unilateral palpable or nonpalpable, consistency (firm/soft, homogeneous/heterogeneous)
- Genital folds: Labial/scrotal/labio-scrotal; fusion of labio-scrotal folds, anogenital ratio, and anogenital distance (posterior labial fusion)
- Presence of separate vaginal and urethral opening or single urogenital sinus
- Abdominal examination.

Recommended Diagnostic Workup (Non-Invasive First):

- Pelvic ultrasound to assess the presence/absence of uterus or gonads.
- Hormonal profile: 17-OHP, testosterone, DHEAS, LH, FSH, cortisol, ACTH.
- Karyotype and/or chromosomal microarray.
- Genetic testing, if available (e.g., for CAH, androgen insensitivity, 5-alpha reductase deficiency).
- Avoid Biopsies or Surgical Exploration at This Stage

In centers where these facilities are not available, the neonate should be appropriately referred after stabilization.

5.3. Guidelines for Initial Assessment of Infants with Non-Normative Genitalia Contd.

Multidisciplinary Team (MDT) Involvement:

MDT should consist of the following specializations.

- Neonatologist
- Pediatrician
- Endocrinologist (with specialization in pediatrics and adolescence)
- Surgeon and/or Urologist (with specialization in pediatrics and adolescence)
- Gynecologist
- Clinical Geneticist
- Radiologist
- Clinical Psychologist or Psychiatrist (with specialization in children and Family Counseling)
- Medical Ethicist / Clinical Ethicist
- Social Worker
- Intersex Adult or Parent of an Intersex Child

MDT must work collaboratively with the family, respecting their cultural context while upholding the child's rights.

Social workers must be adequately trained to assist parents with the necessary documentation and registration of identity certificates, ensuring access to entitlements and legal recognition.

Why Involvement of Intersex Adults and Parents of Intersex Children is Essential in MDT:

Lived Experience as Expertise: Intersex adults and parents of intersex children bring critical insight into the long-term impact of early medical interventions, social stigma, and lack of informed consent. Their experiences offer a lens that no textbook or clinician can provide, thereby helping shape policies, protocols, and services that are truly rights-based and person-centered.

Grounded, Ethical Decision-Making: Parents of intersex children, when informed and supported, can serve as strong advocates for their child's bodily autonomy and well-being. Including them ensures that care decisions are made with compassion, nuance, and long-term impact in mind and not just short-term cosmetic or social conformity.

Building Trust and Legitimacy: Policies and care frameworks gain legitimacy when they are co-created with the communities they impact. This is especially true for intersex people, who have been systemically excluded from decisions about their bodies and rights.

Family Engagement and Communication:

- Provide Clear, Non-Stigmatizing Information
- Use terms like "variations in sex characteristics" or "intersex traits" rather than "disorder" or "condition."
- Avoid suggesting urgency unless life-threatening presentations are found.
- Offer Immediate Psychosocial Support
- Refer families to a counselor trained in intersex issues.
- Offer written and verbal information in the family's preferred language.
- Introduce the Concept of Watchful Waiting
- Emphasize that it is often in the child's best interest to delay non-essential interventions until they are older and can take part in decisions.

Documentation and Follow-up:

- Record findings, respectfully, and confidentially.
- Schedule regular, non-invasive follow-ups for developmental monitoring.
- Establish referral pathways to trained mental health professionals and community-based support.

5.5. Framework for Deferring Non-Urgent Surgical Interventions

This framework provides healthcare teams with a structured, ethical, and rights-based approach to deferring non-urgent surgical interventions on intersex infants and children. It emphasizes respect for bodily autonomy, informed consent, and the evolving ability of the child.

Initial Assessment and Triage

☐ Determine whether the identified variation poses an immediate health risk (e.g., urinary obstruction, salt-wasting CAH).
☐ If no immediate risk is found, clearly document the presentation as non-urgent.

Multidisciplinary Review and Recommendation

☐ Convene a multidisciplinary team (MDT) to assess the case.
☐ Review all medical findings, psychosocial considerations, and ethical implications.
☐ Ensure that irreversible interventions are not recommended unless strictly medically necessary.

Family Engagement and Counseling

☐ Provide families with clear, compassionate, and non-directive counseling.
☐ Explain the rationale for deferral and the benefits of watchful waiting.
☐ Offer written materials and access to peer support groups.

Documentation of Deferral Decision

☐ Document the MDT’s recommendation to defer surgery.
☐ Include notes on family counseling sessions and their understanding/agreement.
☐ Record a timeline for periodic reassessment and follow-up.

Follow-Up and Ongoing Support

☐ Establish a schedule for follow-up visits to check physical and psychosocial development.
☐ Offer access to intersex-affirming mental health professionals.
☐ Continue age-appropriate conversations with the child as they grow, respecting their evolving autonomy.

This framework aligns with international human rights standards, including the UN Convention on the Rights of the Child and the Yogyakarta Principles plus ten.

5.6. Standards for Psychosocial Support and Family Counseling

This document outlines core standards for delivering affirming, ethical, and culturally sensitive psychosocial support to intersex children and their parents. These standards aim to reduce stigma, promote informed decision-making, and protect the dignity and rights of the child.

Foundational Principles

☐ Support must be non-directive, rights-based, and trauma-informed.
☐ Care should affirm bodily diversity and avoid pathologizing language.
☐ Families must be treated with empathy, respect, and without judgment.

Access to Qualified Professionals

☐ Ensure referral to mental health professionals trained in intersex-affirming care.
☐ Provide access to peer support groups and intersex-led organizations.
☐ Counseling services should be free or low-cost and available in the family's preferred language.

Initial Counseling and Emotional Support

☐ Offer immediate, compassionate support to address emotional distress and confusion.
☐ Provide clear information about intersex variations in simple, accessible terms.
☐ Normalize uncertainty and reinforce that immediate decisions are not necessary.

Ongoing Psychosocial Engagement

☐ Schedule regular counseling check-ins for the family and child.
☐ Adapt counseling approaches as the child matures, ensuring age-appropriate communication.
☐ Support the development of a positive self-image and family acceptance.

Culturally Appropriate and Inclusive Practices

☐ Use inclusive language that aligns with the family's social and cultural context.
☐ Address myths and misconceptions with sensitivity and evidence-based information.
☐ Ensure that materials and services reflect the diversity of family backgrounds.

Ethical Considerations

☐ Always prioritize the best interest and autonomy of the child.
☐ Respect confidentiality and consent at every stage of support.
☐ Avoid recommending irreversible interventions in counseling sessions.

These standards are aligned with global good practices in pediatric psychosocial care, as well as human rights frameworks such as the UNCRC and Yogyakarta Principles plus ten.

5.7. Psychological Assessment of Gender Identity, Expression, and Sexual Orientation

This section guides mental health professionals conducting developmentally appropriate, affirming psychological assessments for children and adolescents with intersex variations. The aim is not to predict or assign identity, but to understand everyone has lived experience and provide supportive, non-pathologizing care.

Core Principles:

- Affirmation and Respect: Center the child's sense of self. Do not assume binary outcomes or conflate physical traits with identity.
- Developmental Sensitivity: Recognize that identity, expression, and orientation may evolve. Avoid pressuring children into early or fixed declarations.
- Non-Pathologizing Approach: Differences in gender identity, expression, or orientation are not disorders. Frame assessments to explore, not diagnose.

Areas to Explore (Age-Appropriate & Culturally Sensitive):

A. Gender Identity
- How does the child describe themselves? (Pronouns, name, gender label, if any)
- Are there changes or consistencies in how they express this over time?
- What language or terms does the child use for their body and experience?

B. Gender Expression
- Does the child's clothing, play, communication style, or behavior reflect a certain expression? How is this perceived by family or peers?
- How free does the child feel to express themselves across settings (home, school, community)?

C. Sexual Orientation (for adolescents)
- Does the individual have questions or thoughts about attraction or relationships?
- How do they feel about these experiences—confused, affirmed, distressed?
- Are they experiencing stigma or fear related to orientation or identity?

Psychological Well-being and Support Needs:

- Assess for signs of stress, anxiety, low self-esteem, or trauma related to body image, medical interventions, bullying, or family pressure.
- Explore the child's and family's coping strategies, support systems, and experiences with the healthcare system.
- Offer age-appropriate psychoeducation and connect with affirming peer networks or community groups.

Family and Social Context:

- What are the family's beliefs, concerns, and expectations around gender and sex characteristics?
- How do caregivers respond to the child's self-expression?
- Is the child exposed to supportive, neutral, or hostile environments (school, religious spaces, extended family)?

Ethical and Clinical Considerations:

- Ensure informed assent or consent depending on the child's age and maturity.
- Maintain confidentiality, particularly in matters of identity or orientation disclosure.
- Collaborate with a multidisciplinary care team when relevant (medical, educational, social work).

5.7. Psychological Assessment of Gender Identity, Expression, and Sexual Orientation Contd.

Tools and Approaches:

- Use open-ended interviews and narrative methods rather than standardized “gender identity tests,” which may not be appropriate for intersex populations.
- Apply trauma-informed and strength-based practices.
- Reflect cultural, linguistic, and regional realities in how identity and expression are discussed.

Some Scientifically Tested Assessment Tools:

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- The Gender Identity Questionnaire for Children (GIQC)
- Gender Identity Interview for Children (GIIC)
- Gender Identity/Gender Dysphoria Questionnaire for Adolescents and Adults (GIDYQ-AA)
- Gender Diversity Questionnaire (GDQ)

Key Message: The goal of psychological assessment is not to fit the child into a category, but to listen, affirm, and walk alongside them as they discover who they are, in their own time and on their terms.

Table: Signs of Psychological Distress in Intersex Children:

This table highlights common emotional, behavioral, and psychosomatic signs that may indicate psychological distress in intersex children. Early identification and supportive intervention can help prevent long-term mental health challenges.

Category	**Possible Signs of Distress**
Emotional	• Persistent sadness or withdrawal • Excessive fear, anxiety, or worry • Low self-esteem or shame related to the body • Mood swings or irritability
Behavioral	• Avoidance of social or school activities • Reluctance to attend medical appointments • Sudden academic decline • Anger or oppositional behavior
Psychosomatic	• Frequent stomachaches or headaches • Changes in sleep or appetite • Fatigue without a clear medical cause • Enuresis (bedwetting) or other regression
Relational	• Difficulty trusting adults, especially healthcare providers • Withdrawal from family or peers • Expressions of wanting to be “normal” or “fixed” • Verbalizing confusion or distress about their body or identity

5.8. Comprehensive Do's and Don'ts for Intersex-Affirming Healthcare

Avoid (Microaggressions)	**Use (Affirming Communication)**
'Disorder of Sex Development (DSD)' is the default term.	Terms like 'intersex variations' or 'variations in sex characteristics'.
Referring to intersex traits as 'abnormal' or 'defective' or “a condition”.	'biologically occurring diversity'.
Saying 'we need to fix this' or 'we need to normalize the genitals'.	'There’s no medical urgency—we’ll support you as your child grows. ‘
Asking 'Is it a boy or a girl?' as a first question.	'Your child is healthy—let’s take time to understand their unique traits. ‘
Using the male/female binary as the only reference points.	Acknowledge the full spectrum of sex characteristics and gender identities, as appropriate.
Insisting on early surgical interventions for social reasons.	Emphasize informed consent and the child's right to bodily autonomy.
Minimizing intersex identity as 'just a medical condition'	Recognize that intersex identity may be deeply personal and valid.
Saying that 'They won’t have a normal life without surgery'.	Affirm the child’s right to define a fulfilling life on their terms.
Ignore or dismiss the child’s emotional and psychological needs.	Offer psychosocial support and mental health resources proactively.
Exclude the family from care decisions or use jargon	Use plain language and engage the family with empathy and openness.

5.8. Comprehensive Do's and Don'ts for Intersex-Affirming Healthcare Contd.

Avoid (Microaggressions)	**Use (Affirming Communication)**
Exclude the family from care decisions or use jargon.	Use plain language and engage the family with empathy and openness.
Use photos for teaching without consent or anonymization.	Always seek consent and anonymize medical images when used for education.
Conduct repeated exams out of curiosity, not clinical need.	Limit exams to what is necessary and explain the purpose each time.
Talk about the child as a 'case' rather than a person.	Speak respectfully and person-first: 'This child has unique traits'.
Use humor or euphemisms when discussing sex characteristics.	Maintain professionalism and sensitivity in all communication.
Say 'Most parents choose surgery—don't you want to help your child?'	Say 'Many parents choose to wait and allow their child to decide later'.
Frame gender as a fixed outcome based on chromosomes or anatomy.	Frame gender as personal, evolving, and not determined at birth.
Avoid mentioning the possibility of identifying as intersex.	Include intersex as a valid identity and offer affirming resources.
Tell families to keep the variation a secret.	Encourage openness and help families manage stigma compassionately.
Claim that delaying surgery is 'denying care'.	Clarify that delaying unnecessary surgery protects the child's autonomy.
Use scare tactics to rush decision-making.	Provide balanced information and facts without pressure or fear.

5.9. Referral Pathways to Affirming Specialists and Peer Networks in Intersex Care

This guide provides a structured referral pathway for healthcare providers to connect intersex individuals and their families to trained, affirming specialists and peer support networks. The goal is to ensure prompt, respectful, and holistic support that centers bodily autonomy, emotional well-being, and social inclusion.

Initial Contact and Primary Care:

☐ Ensure the primary care provider is trained in intersex-inclusive and affirming communication.
☐ Provide correct, non-stigmatizing information at first disclosure or identification of somatic variation.
☐ Offer immediate psychosocial support and normalize the need for further consultation.

Referral to Medical Specialists:

☐ Pediatric Endocrinologist – for hormonal evaluation and longitudinal monitoring.
☐ Pediatric Urologist/Surgeon – only for medically indicated or deferred consults.
☐ Clinical Geneticist – to guide chromosomal and gene-based analysis.
☐ Pediatrician or Neonatologist – for ongoing developmental tracking.

Referral to Mental Health and Psychosocial Support:

☐ Child Psychologist or Psychiatrist – affirming, trauma-informed, and experienced in gender/sex diversity.
☐ Intersex-affirming Counselor – ideally linked to local intersex-led organizations.
☐ Family Therapist – to support the emotional needs of caregivers and siblings.

Referral to Peer Support and Community-Based Resources:

☐ Intersex-led support groups (e.g., regional or national intersex organizations).
☐ Parent peer networks for families of intersex children.
☐ Civil society and rights-based organizations offer legal aid, advocacy, or policy support.

Follow-Up and Feedback Loops:

☐ Maintain a centralized referral log with contact details, dates, and outcomes.
☐ Schedule follow-up appointments with both medical and psychosocial specialists.
☐ Encourage families to share feedback on the support they receive to improve future referrals.

These referral pathways should be regularly reviewed and updated to reflect the availability of trained professionals, community networks, and evolving standards of intersex-inclusive care.

6. Consent and Assent in Medical Procedures: Context and Considerations in India

Legal and Ethical Framework:

- In India, informed consent is a foundational, legal, and ethical requirement for any medical procedure. The consent must be:
- Voluntary (given without coercion),
- Informed (based on a clear, comprehensible explanation of risks and benefits), and
- Competent (provided by someone legally and mentally capable of decision-making).
- Adults (18 years and above) are presumed to have the legal capacity to consent to or refuse medical treatment.
- Minors (under 18 years) cannot legally provide binding consent, but their assent and evolving capacity must be ethically considered, especially in cases involving irreversible or invasive procedures.

Consent for Children and Adolescents:

Children (Typically Under Age 12):

- Consent must be obtained from parents or legal guardians.
- However, assent, that is, a child's affirmative agreement to procedures, should still be taken. Children should be given age-appropriate information about what will happen, and their willingness or discomfort must be taken seriously.
- In intersex care, irreversible interventions must not be performed solely on parental consent unless there is an urgent, life-saving reason.

Adolescents (Typically 12–17 years):

- While legal consent still lies with the parent or guardian, Indian courts and ethical guidelines increasingly recognize the mature minor doctrine in limited contexts, especially in sexual and reproductive health.
- Adolescents who show sufficient understanding of their condition, risks, and options should be actively involved in all medical decisions that affect them.
- Ethical standards, including those set by the Indian Council of Medical Research (ICMR), emphasize evolving ability and shared decision-making for adolescents.

Intersex-Specific Considerations: For intersex individuals, especially children and adolescents, consent and assent are critical in preventing harm and protecting rights:

- Non-essential, irreversible procedures (e.g., genital “normalization” surgeries, gonadectomies) must be deferred until the individual can provide informed, voluntary consent.
- The Madras High Court (2019) and Kerala High Court (2023) emphasized that such surgeries should only be allowed in life-threatening cases and must not go ahead without careful multidisciplinary and ethical review.
- Counseling and information should be provided in non-coercive and developmentally appropriate ways that empower the individual, rather than pressure them or their family into conformity.

Adults with Intersex Variations: For intersex adults (18+), the right to consent or refuse any medical procedure is legally protected under:

- The Indian Contract Act (1872), which underpins consent in healthcare.
- The Mental Healthcare Act (2017), which upholds autonomy in decision-making.
- Constitutional protections under Articles 21 and 14, ensuring the right to bodily autonomy, privacy, and equality.

No procedure (surgical, hormonal, or otherwise) may be performed without free, prior, and informed consent of the adult individual.

6. Consent and Assent in Medical Procedures: Context and Considerations in India Contd.

Best Practice Recommendations:

- Always explain medical options, risks, and alternatives in clear, culturally, and linguistically appropriate terms.
- Respect the voice of the child or adolescent—even if they cannot legally consent, they have the right to take part in decisions that affect their body and life.
- Document the assent process, including the child’s questions, understanding, and emotional response.
- Involve an independent advocate or counselor where possible, especially in sensitive or irreversible decisions.
- Recognize that refusal of a procedure, even by a minor, is ethically significant and cannot be overridden casually.

Intersection of the BNSS and the Mental Healthcare Act in Intersex Medical Decisions

In India, medical decision-making for intersex individuals—especially children—must be understood through the intersection of two key legal frameworks:

Bharatiya Nagarik Suraksha Sanhita (BNSS), 2023: The BNSS, which replaces the Indian Penal Code (IPC), introduces stronger safeguards around bodily harm and medical interventions without consent. Any non-consensual or non-therapeutic surgical intervention, particularly on minors, could be construed as causing grievous hurt or assault, especially if done in the absence of a life-threatening medical indication. This aligns with constitutional protections under Article 21 (Right to Life and Personal Liberty), reinforcing the child's right to bodily autonomy and protection from harm.

Mental Healthcare Act (MHCA), 2017: The MHCA affirms that every person—regardless of age—has the right to make decisions about their mental and physical health, provided they can do so. It also introduces the concept of supported decision-making, requiring that individuals (including children and adolescents) be provided information in an accessible manner and be involved in decisions about their treatment. Importantly, it recognizes the right to refuse treatment and mandates informed consent, which is especially relevant in cases involving psychosocial interventions and identity-related care.

Why This Intersection Matters in Intersex Care:

- BNSS offers a criminal deterrent against unauthorized, irreversible medical procedures on intersex infants and children.
- MHCA supports a rights-based, autonomy-centered model of care that requires consent, psychological support, and age-appropriate decision-making.

Together, these frameworks reinforce that non-emergency, cosmetic surgeries on intersex children—without informed consent and psychosocial evaluation—are not only unethical but may also be legally actionable.

Sample Informed Consent and Assent Form for Intersex-Related Medical Care

This sample form is intended for use in cases involving intersex variations and should be adapted in consultation with legal, ethical, and clinical guidelines.

Section A: Informed Consent (For Parent/Guardian)

Name of Child: ____________________________________
Date of Birth: ____________________________________
Name of Parent/Guardian: ____________________________
Relationship to Child: ______________________________
Proposed Procedure(s): _____________________________

I have been fully informed about my child's medical presentation involving variations in sex characteristics. The healthcare team has explained the recommended diagnostic tests and treatment options, including the risks, benefits, and alternatives. I understand that no unnecessary medical surgery will be performed without further discussion, and that my child has the right to bodily autonomy and future participation in medical decisions.

☐ **I give my informed consent for the recommended tests or procedures.**
☐ **I do not give consent currently and prefer to defer decisions.**

Signature of Parent/Guardian: ________________________ Date: _____________
Name of Doctor/Clinician: ___________________________ Signature: _____________

Section B: Informed Assent (For Child if age-appropriate)

My name is ____________________________________
My age is __________

The doctor and my family have talked to me about the medical care I may need. I understand that I can ask questions. I know I do not have to agree, and I can say yes or no. I also understand that some things may be done only if I agree, and that my voice matters.

☐ **I agree with the care or tests being done.**
☐ **I am not ready to agree right now.**

Signature of Child (if applicable): ____________________ Date: _____________

Witness Name and Signature: _________________________ Date: _____________

7. Annexures

7.1. Glossary and Reference Materials

This section provides clear, rights-affirming definitions of key terms used in intersex healthcare and advocacy, along with a list of recommended references and resources for further reading and training.

Intersex: A term used to describe individuals born with physical sex characteristics that do not fit typical definitions of male or female. Variations may involve chromosomes, gonads, hormones, or genitals.

Differences of Sex Development (DSD): While "DSD" is widely used in clinical settings, it is also controversial because the term originally stood for “Disorders of Sex Development,” which many intersex individuals and advocates find pathologizing. As a result, some now interpret DSD as “Differences” instead of “Disorders” to promote a more respectful and inclusive framing.

Variations in Sex Characteristics (VSC): A human right–affirming term that includes all forms of intersex traits. Often used interchangeably with 'intersex' in legal and policy frameworks.

Bodily Autonomy: The right of every individual to make decisions about their own body, including the timing and nature of any medical interventions.

Informed Consent: A process by which a person voluntarily agrees to a proposed medical procedure, based on a full understanding of risks, benefits, and alternatives.

Evolving Capacity: A principle recognizing that children gain the ability for decision-making over time and must be involved in decisions affecting them, per their maturity.

Non-Directive Counseling: A supportive counseling approach that provides correct information and emotional support without pushing specific decisions or outcomes.

Multidisciplinary Team (MDT): A group of medical, psychological, and social care professionals who collaborate to ensure comprehensive and ethical care.

Watchful Waiting: A careful approach that delays non-urgent interventions to allow the individual to grow and take part in decision-making.

Trauma-Informed Care: A model of care that recognizes and responds to the impact of trauma, aiming to avoid re-traumatization in medical settings.

Peer Support: Support provided by individuals or families with lived experience, offering emotional connection, validation, and shared learning.

A comprehensive glossary of terms of intersex variations is provided in Section 5.12.

7.2. Recommended Reference Materials and Resources

Sarin YK, Singh D, Babu R, Das K, Rao S; DSD Guidelines Committee of Indian Association of Pediatric Surgeons. Indian Association of Pediatric Surgeons Guidelines on the Management of Differences in Sex Development. J Indian Assoc Pediatr Surg. 2022 Jul-Aug;27(4):376-380. doi: 10.4103/0971-9261.352296. Epub 2022 Jul 26. PMID: 36238321; PMCID: PMC9552656.

Babu, Ramesh. Changing Paradigms in Intersex Management: Legal, Ethical, and Medical Implications. Journal of Indian Association of Pediatric Surgeons 27(4) p 372-375, Jul–Aug 2022. | DOI: 10.4103/jiaps.jiaps_41_22.

“Medical Protocol for the Assessment of Children with Atypical Genital Development” / “

UN Free & Equal Campaign – Fact Sheet: Intersex Awareness (OHCHR)

World Health Organization – Sexual Health and Human Rights Guidelines (2015)

Human Rights Watch – 'I Want to Be Like Nature Made Me' Report (2017)

Yogyakarta Principles plus 10 (2017) – Principles on the Application of International Human Rights Law about Sexual Orientation, Gender Identity, Gender Expression and Sex Characteristics

UN Convention on the Rights of the Child – Articles 3, 5, 12, 13, 16, and 24

InterACT: Advocates for Intersex Youth – Clinical and Legal Toolkits

OII Europe – Intersex Human Rights Guidelines and Position Papers

Global Action for Trans Equality (GATE) – Intersex Policy Briefs and Publications

Intersex Asia – Regional Intersex Advocacy and Language Guidelines

Intersex Children’s Foundation of India – Resources on Ethical Care, Parental Support, Policy Advocacy, and Referral Network for Intersex Children in the Indian Context

Beyond the Binary: Advancing Legal Recognition for Intersex Persons in India by Center for Law and Policy Research.

Country Report on Intersex Rights in India by Intersex Asia.

A Critical Review of DSD/Intersex Research in India & Recommendations for augmenting medical care protocols and practices by Koushumi Sujata Chakraborti (Intersex Children’s Foundation of India).

Epistemological Deviant, Epistemic Abjection and Lost Opportunities: A Case Study of a Muslim Trans Intersex Student’s Othering and Dehumanisation in an Indian Science Classroom by Sayantan Datta

Intersex/Differences of sex development: Human rights at the intersection of cure and care by Satendra Singh, Koushumi Chakraborti, Aqsa Shaikh; Published online first on August 25, 2022. DOI:10.20529/IJME.2022.064.

Family and Gendered Violence and Conflict by Ruchi Sinha and Pekham Basu.

Handbook on Sex, Gender and Health – Perspectives from South Asia by TK Sundari Ravindran, M. Sivakami, Anjana Bhushan, Sabina Faiz Rashid, Kausar S. Khan.

Jorge JC, Valerio-Pérez L, Esteban C, Rivera-Lassen AI. Intersex care in the United States and international standards of human rights. Glob Public Health. 2021 May;16(5):679-691. doi: 10.1080/17441692.2019.1706759. Epub 2019 Dec 24. PMID: 31874072; PMCID: PMC8659864.

Recommended Reference Materials and Resources Contd.

Affirming Primary Care for Intersex People 2020 [https://www.lgbtqiahealtheducation.org/wp-content/uploads/2020/08/Affirming-Primary-Care-for-Intersex-People-2020.pdf]

PROVIDING ETHICAL AND COMPASSIONATE HEALTH CARE TO INTERSEX PATIENTS, INTERSEX-AFFIRMING HOSPITAL POLICIES
https://legacy.lambdalegal.org/sites/default/files/publications/downloads/resource_20180731_hospital policies-intersex.pdf]

Intersex Variations Glossary.
https://interactadvocates.org/wp-content/uploads/2022/10/Intersex-Variations-Glossary.pdf

Affirming Primary Care for Intersex People 2020 [https://www.lgbtqiahealtheducation.org/wp-content/uploads/2020/08/Affirming-Primary-Care-for-Intersex-People-2020.pdf]

PROVIDING ETHICAL AND COMPASSIONATE HEALTH CARE TO INTERSEX PATIENTS, INTERSEX-AFFIRMING HOSPITAL POLICIES
[https://legacy.lambdalegal.org/sites/default/files/publications/downloads/resource_20180731_hospital-policies-intersex.pdf]

Thank You!

We extend our heartfelt gratitude to every healthcare professional, caregiver, researcher, and intersex advocate who has engaged with this guide. Your willingness to listen, learn, reflect, and share feedback is the first and most important step toward building a truly ethical, rights-affirming, and compassionate model of care for intersex children in India.

This guidebook not only sets a benchmark for ethical, informed, and inclusive intersex care in India but is also poised to influence both clinical practice and public policy meaningfully.

While we have made every endeavor to make this as comprehensive as possible, it is not the final word, but a living, evolving resource. As knowledge grows and the voices of intersex individuals and their families continue to shape the landscape of care, this guide will grow, adapt, and deepen.

We welcome your feedback, experiences, and questions to help us improve future versions. You may share your feedback at support@icfi.org.in.

Together, we can move toward a future where every child is treated with dignity, affirmed in their uniqueness, and supported to live a full and flourishing life, without shame, secrecy, or harm.

Thank you for being a part of this journey.

Intersex Children's Foundation of India (ICFI)