

## Shifting the Paradigm of Intersex Treatment

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KEY POINTS OF COMPARISON	CONCEALMENT-CENTERED MODEL	PATIENT-CENTERED MODEL
<b>What is intersex?</b>	Intersex is a rare anatomical <b>abnormality</b> which is highly likely to lead to great distress in the family and great distress for the person with an intersex condition. Intersex is pathological and requires immediate medical attention.	Intersex is a relatively common anatomical <b>variation</b> from the “standard” male and female types; just as skin and hair color vary along a wide spectrum, so does sexual and reproductive anatomy. Intersex is neither a medical nor a social pathology.
<b>Is gender determined by nature or nurture?</b>	Nurture. Virtually any child can be made into a “boy” or a “girl” if you just make the genitals look convincing. It doesn’t matter what the genes, brain, hormones, and/or prenatal life are/were like.	Both, surely, but that isn’t the point. The point is that people with intersex conditions ought to be treated with the same basic ethical principles as everyone else—respect for their autonomy and self-determination, truth about their bodies and their lives, and freedom from discrimination. Physicians, researchers, and gender theorists should stop using people with intersex conditions in “nature/nurture” experiments or debates.
<b>Are intersexed genitals a medical problem?</b>	Yes. Untreated intersex is highly likely to result in depression, suicide, and possibly “homosexual” orientation. Intersexed genitals must be “normalized” to whatever extent possible if these problems are to be avoided.	No. Intersexed genitals are <b>not</b> a medical problem. They may signal an underlying metabolic concern, but they themselves are not diseased; they just look different. Metabolic concerns should be treated medically, but intersexed genitals are not in need of medical treatment. There is no evidence for the concealment paradigm, and there is evidence to the contrary.
<b>What should be the medical response?</b>	The correct treatment for intersex is to “normalize” the abnormal genitals using surgical, hormonal, and other technologies. Doing so will eliminate the potential for parents’ psychological distress.	The whole family should receive psychosocial support (including referrals to peer support) and as much information as they can handle. True medical problems (like urinary infections and metabolic disorders) should be treated medically, but all non-essential treatments should wait until the person with an intersex condition can consent to them.
<b>When should treatments designed to make a child’s genitals look “normal” be done?</b>	As soon as possible because intersex is a psychosocial emergency. The longer you wait, the greater the trauma.	<b>ONLY</b> if and when the intersexed person requests them, and then only after she or he has been fully informed of the risks and likely outcomes. These surgeries carry substantial risks to life, fertility, continence, and sensation. People with intersex conditions should be able to talk to others who have had the treatments to get their views.
<b>What is motivating this treatment protocol?</b>	The belief that our society can’t handle genital ambiguity or non-standard sexual variation. If we don’t fix the genitals, the child with an intersex condition will be ostracized, ridiculed, and rejected, even by his or her own parents.	The belief that the person with an intersex condition has the right to self determination where her or his body is concerned. Doing “normalizing” surgeries early without the individual’s consent interferes with that right; many surgeries and hormone treatments are <b>not</b> reversible. The risks are substantial and should only be taken if the patient has consented.
<b>Should the parents’ distress at their child’s condition be treated with surgery on the child?</b>	Yes, absolutely. Parents can and should consent to “normalizing” surgery so that they can fully accept and bond with their child.	Psychological distress is a legitimate concern and should be addressed by properly trained professionals. However, parental distress is <b>not</b> a sufficient reason to risk a child’s life, fertility, continence, and sensation.

<p><b>How do you decide what gender to assign a newborn with an intersex condition?</b></p>	<p>The doctors decide based on medical tests. If the child has a Y chromosome and an adequate or “reconstructable” penis, the child will be assigned a male gender. (Newborns must have penises of 1 inch or larger if they are to be assigned the male gender.) If the child has a Y chromosome and an inadequate or “unreconstructable” penis according to doctors, the child will be assigned a female gender and surgically “reconstructed” as such. If the child has no Y chromosome, it will be assigned the female gender. The genitals will be surgically altered to look more like what doctors think female genitals should look like. This may include clitoral reduction surgeries and construction of a “vagina” (a hole).</p>	<p>The parents and extended family decide in consultation with the doctors. This approach does <b>not</b> advocate selecting a third or ambiguous gender. The child is assigned a female or male gender but only <b>after</b> tests (hormonal, genetic, diagnostic) have been done, parents have had a chance to talk with other parents and family members of children with intersex conditions, and the entire family has been offered peer support. We advocate assigning a male or female gender because intersex is not, and will never be, a discreet biological category any more than male or female is, and because assigning an “intersexed” gender would unnecessarily traumatize the child.</p> <p>The doctors and parents recognize, however, that gender assignment of infants with intersex conditions as male or female, as with assignment of <b>any</b> infant, is preliminary. Any child may decide later in life to change their gender assignment; but children with intersex conditions have significantly higher rates of gender transition than the general population, with or without treatment. That is a crucial reason why medically unnecessary surgeries should not be done without the patient’s consent; the child with an intersex condition may later want genitals (either the ones they were born with or surgically constructed anatomy) different than what the doctors would have chosen.</p> <p>Surgically constructed genitals are extremely difficult if not impossible to “undo,” and children altered at birth or in infancy are largely stuck with what doctors give them.</p>
<p><b>Who should counsel the parents when a child with an intersex condition is born?</b></p>	<p>Intersex is a psychosocial emergency that can be alleviated by quick sex assignment and surgery to reinforce the assignment. Professional counseling is suggested but typically not provided. Peer counseling is typically not suggested or provided.</p>	<p>Intersex is a community and social concern requiring understanding and support. Counseling should begin as soon as the possibility of intersex arises and/or as soon as the family needs it. Professional counselors trained in sex and gender issues, family dynamics, and unexpected birth outcomes should be present. Families should also be actively connected with peer support.</p>
<p><b>What should the person with an intersex condition be told when she or he is old enough to understand?</b></p>	<p>Very little, because telling all we know will just lead to gender confusion that all these surgeries were meant to avoid. Withhold information and records if necessary. Use vague language, like “we removed your twisted ovaries” instead of “we removed your testes” when speaking to a woman with AIS.</p>	<p>Everything known. The person with an intersex condition and parents have the right and responsibility to know as much about intersex conditions as their doctors do. Secrecy and lack of information lead to shame, trauma, and medical procedures that may be dangerous to the patient’s health. Conversely, some people harmed by secrecy and shame may avoid future health care. For example, women with AIS may avoid medical care including needed hormone replacement therapy.</p>
<p><b>What’s wrong with the opposing paradigm?</b></p>	<p>Parents and peers might be uncomfortable with a child with ambiguous genitalia. Social institutions and settings like locker rooms, public restrooms, daycare centers, and schools will be brutal environments for an “abnormal” child. The person with an intersex condition might later wish that her or his parents had chosen to have her or his genitals “normalized”.</p>	<p>The autonomy and right to self determination of the person with an intersex condition is violated by the surgery-centered model. In the concealment model, surgeries are done without truly obtaining consent; parents are often not told the failure rate of, lack of evidentiary support for, and alternatives to surgery. Social distress is a reason to change society, not the bodies of children.</p>
<p><b>What is the ideal future of intersex?</b></p>	<p>Elimination via improved scientific and medical technologies.</p>	<p>Social acceptance of human diversity and an end to the idea that difference equals disease.</p>
<p><b>Who are the proponents of each paradigm?</b></p>	<p>John Money and his followers, most pediatric urologists and pediatric endocrinologists, and many gynecologists and other health care practitioners.</p>	<p>Intersex activists and their supporters, ethicists, some legal scholars, medical historians, and a growing number of clinicians.</p>

For additional reading or to download a copy of this protocol, please visit the website of the Intersex Society of North America: <http://www.isna.org>