

Dreger Article - Intersex

Intersex

One out of every two thousand births presents parents with a sudden gender dilemma. A tradition of secrecy means most parents are totally unprepared.

by Alice Dreger

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There was a time not so long ago when parents couldn't answer the question "Boy or girl?" until a child was born. But nowadays, most people expect parents to be able to answer that question well before birth. That makes things even more awkward for parents whose children have an intersex condition.

When a child is born with an intersex condition, even though the doctors and parents may have thought they knew what sex the child was from prenatal sonograms, the sex of the child may be unclear. There may be several days of tests before doctors and parents decide what gender to assign such a child.

"Intersex" is a general term used for any form of congenital (inborn) mixed sex anatomy. This doesn't mean that a person with an intersex condition has all the parts of a female and all the parts of a male; that is physiologically impossible. What it does mean is that a person with an intersex condition has some parts usually associated with males and some parts usually associated with females, or that she or he has some parts that appear ambiguous (like a phallus that looks somewhere between a penis and a clitoris, or a divided scrotum that looks more like labia). It's important to understand that intersex doesn't always involve "ambiguous" or blended external sex anatomy. Sometimes a child or adult who is intersexed can look quite unambiguous sexually, although internally their sex anatomy is mixed. This happens, for example, with complete androgen insensitivity syndrome, where a person has some male parts (including a Y chromosome and testes) internally, but is quite clearly feminine on the outside. It's important to also be clear that intersex is different from transgender in that a person with intersex is born with mixed sex anatomy, where as a person who is transgendered is a person who feels himself or herself to be a gender different than the one he or she was assigned at birth. Some people who are transgendered were born intersexed, but most were born with "standard" male or female anatomy.

When a baby or child is recognized to have an intersex condition, it can be quite traumatic for the parents. Parents want their children to have happy, "normal" lives, and they worry that a child with intersex cannot do so. All parents imagine their children's futures, and parents of children with intersex conditions can have a very hard time doing that; they're not sure whether to imagine that child will marry, whether the child will give them grandchildren. As a consequence, the parents' identities also become confused and uncomfortable.

This is why people like me who advocate for the rights of people born with intersex conditions also actively advocate for the rights of their parents. Too often, because some well-intentioned medical professionals dealing with intersex hope to provide a "quick fix," parents' persistent confusion and distress is not adequately addressed. Yet parents in such situations obviously deserve the best care available, including professional psychological and social services. They also deserve help finding other parents who have been through the same thing. Parents I've talked with tell me that being able to talk with another parent immediately reduced the amount of stress and confusion they felt, and enabled them to focus on the joy of having a beautiful (and often perfectly healthy) baby.

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Unfortunately, until recently, the dominant medical system for treating intersex treated parents as a means to an end. Psychologist John Money at Johns Hopkins University developed that system which assumed gender is all a matter of nurture, not nature. Money claimed that any child could be turned into any gender as long as the parents believed in the assigned gender. As a consequence, doctors told parents of children with intersex what gender a child was and then doctors scheduled intensive "normalizing" surgeries to try to make the genitals look clearly female or male (usually female). Confusion and distress on the part of the parents and child were downplayed, because doctors believed the only real issue was the gender assignment, and that once gender was assigned and sex "assignment" surgeries were started, they had to stay the course no matter what. They assumed a clear gender identity would alleviate all parental distress and therefore all distress on the part of the child, and that "normalizing" procedures would provide a clear gender identity.

Money claimed to prove this system worked with a case known as "John/Joan." After a pediatrician accidentally destroyed the penis of an identical twin boy (who was not intersexed) during circumcision at eight months, Money recommended to the parents that the child be made into a girl. They decided to take his advice and for years Money claimed the sex reassignment had worked. We now know that that child, who grew up to take the name David Reimer, was never happy as a girl. John Colapinto tells his story--including his attempts to rebuild what he could of the male anatomy that was taken from him in "reassignment" surgeries in the book *As Nature Made Him*.

What, then, should parents of a child with an intersex condition know? The first thing they should know is that "ambiguous genitalia" are not diseased. They just look different. Unusual genitalia may signal an underlying metabolic concern, like Congenital Adrenal Hyperplasia (CAH), but doctors can usually treat metabolic concerns without doing surgery on the child's genitalia. Many babies born with intersex conditions are perfectly healthy and do not require any medical intervention other than diagnostic tests. Parents therefore need to press doctors to make clear to them which parts of their child's anatomy involve threats to their child's physical well-being, and which are psycho-social concerns. They should also press doctors to explain which interventions must be done on an emergency basis (for example, when a child is born without any urinary opening) and which can be put off until parents have had the time to calm down, to get to know their own baby and other parents in similar situations, and to explore all of their options. They also should actively request referrals to professional and peer counselors, so that they can express, in a supportive and unhurried environment, their own feelings of confusion, grief, shame, and fear.

Parents should also know that doctors are likely to seek from them consent for "normalizing" genital surgeries when the child is still very young, because many doctors believe that this will make the parents' distress end and will prevent the child from feeling any distress. In fact, these surgeries carry great risks, including risks to genital sensation (which the child will need later for a healthy sex life), continence, fertility, and life. The risks should not be downplayed, particularly in consideration of the fact that "normalizing" surgeries are not medically necessary for physical well being. A nurse told me recently of one baby girl who ended up in intensive care on a ventilator because of complications from an elective "normalizing" surgery. Many parents have expressed to me disappointment in the surgeries after having discovered that the surgeries can't really give their child "normal" looking genitals. Some surgeries require that parents do follow-up care that parents may find very troubling. For example, "vaginoplasties" which lengthen or build vaginas out of skin or pieces of colon often require that parents regularly dilate the new vagina with a lubricated dildo. Several mothers have told me that, if they had understood that that was what would be involved in home follow-up

care, they would have waited until their child was old enough to consent to and do the dilations herself. Parents also need to know that the few follow-up studies available show that "normalizing" genital surgeries done in infancy or early childhood seem to have a poor long-term success rate. That is why more and more doctors are recommending that parents put off these surgeries until puberty, when the surgeries tend to be more successful and when children can provide input on the decision-making process. It is also why parents should press doctors to explain to them exactly what scientific follow-up studies can or can't tell them about the success of these interventions.

Parents should also be aware that legal scholars have recently shown that parents of children with intersex conditions are often not fully informed before they consent to "normalizing" surgeries. In the recent past they have not been told, for example, that the claim that gender comes from nurture has fallen into serious question, and that doctors cannot actually know what gender a child will end up feeling. As a consequence some parents have consented to have their micropenis boys turned into girls, only to discover later that studies by Dr. William Reiner at Johns Hopkins University have shown that many children born with micropenis ultimately take on the male gender identity regardless of having been raised as girls with surgically "feminized" genitalia. Parents have also not been adequately informed about which procedures were essentially elective. Finally, parents have not been advised of what was and was not known about the long-term effects of this system of treatment.

It is important that parents of children with intersex conditions press doctors to tell them the exact diagnosis once the doctors know it. This will enable the parents to do their own research, and to find other parents with similar experiences, as well as understand their options. Parents of children with intersex conditions--indeed, parents of any child with a complex condition--should ask for copies of the child's medical records on a regular basis. According to an article in December 2001, in the *British Medical Journal*, "a paternalistic policy of withholding the diagnosis is still practiced by some clinicians" in intersex cases. These physicians mistakenly believe that shielding parents from exact diagnoses in intersex cases protects parents and children from unnecessary harm. A few also mistakenly believe this practice is ethical and legal; it is neither.

A recent article in the British Journal of Urology notes that photographs taken of them as children and later published in medical journals and textbooks have unintentionally harmed some people with intersex conditions. Parents should guard against unnecessary photographing of their children as well as unnecessary display to medical students and residents, particularly as the child becomes old enough to understand and remember these incidents. While teaching hospitals will be inclined to use the opportunity of caring for a child with intersex for educational purposes, parents should resist any encounter that does not directly benefit their child, given the risks. The trauma to parents and child that can arise from repeated display of a child's genitalia to strangers should not be underestimated.

When facing the possibility of intersex, parents should know that every child can and should be assigned a gender as boy or girl and that doing so does not require any surgery. Gender assignment is accomplished for every child (intersexed or not) through the social and legal labeling of a child as boy or girl. In intersex cases, doctors and parents can work together to try to figure out what gender a child is likely to feel given that particular child's anatomy and physiology, given what doctors know from scientific studies of outcomes in similar cases, and given how the parents see that child's gender. The parents will have to recognize that there is a small but real chance that gender assignment may not hold, that the child may express the other gender later, and that this is why it is best to leave the child's anatomy intact as much as possible. Removing parts doesn't

remove the possibility that the child may change gender later; it only makes it a lot harder for the child to do what she or he wants or needs later.

When parents are making decisions on behalf of a child with intersex, they should keep in mind what the sociologist Suzanne Kessler has shown: Kessler asked a group of men whether, if they had been born with "micropenis," they would have wanted to be turned into girls, and she asked a group of women whether, if they had been born with large clitorises, they would have wanted to have their clitorises surgically shortened. The vast majority of men said they would rather grow up with micropenis than as girls. The vast majority of women said they would have wanted to have their large clitorises left alone. But asked what they would choose for a child in the same situation, many said they would opt to turn micropenis boys into girls and would opt for cosmetic surgeries on girls' large clitorises. The reason behind the different answers is the compassion we all feel for children. We all want to protect children from hardship. But the key to keep in mind is what the child would likely want for himself or herself. Kessler's study as well as interviews with adults with intersex (both those who were subject to "normalizing" surgeries and those who were raised without "normalizing" surgeries) indicates that the vast majority of people want their parents to let them decide for themselves whether to risk health, appearance, genital sensation, continence, fertility, and life. Putting off the surgeries until at least puberty allows the child to have input on the decision, and it seems to provide for better outcomes as well as providing for the possibility that surgical techniques and outcome data will improve in the interim.

Finally, parents should know that intersex does not have to be treated with shame and secrecy. The social (and sometimes also the medical) system by which we treat parents of "different" children as pitiful or shameful is a system that harms those parents and children. Intersex is a natural variation--we see it in all animal species and throughout history. People with intersex can grow up as healthy boys and girls, men and women. Their best shot at doing so is when their parents are not made to feel ashamed of themselves or their children. Unfortunately, "normalizing" procedures like cosmetic genital surgeries sometimes inadvertently make parents and children feel unnecessary shame. Many adults I know with intersex conditions feel that their parents' decision to change their genitals for cosmetic reasons means that their parents saw them as freaks, even though that isn't what their parents intended. Dealing openly with intersex is the best defense against the shame-game. Parents should therefore have access to professional and peer support as they learn to talk with their child about intersex in an open, honest, and accurate manner. Parents will also find that connecting their child to peers with intersex will allow their child another opportunity to talk openly about the challenges of living with intersex. Talking this through undoes the shame and secrecy that pretty much everyone involved agrees has historically been the most harmful aspect of intersex.

No one is suggesting that in cases of intersex we "do nothing." But parents need to know that intersex is primarily a psychosocial concern, and that it is therefore best treated with substantial and continuous psychosocial support, professional and peer. The bottom line is that children with intersex conditions and their parents deserve honesty, respect, and support. But we are not yet at the point where that is automatically provided. We all need to do our part, as doctors, parents, neighbors, and teachers, to demystify intersex and see to it that parents of children with intersex conditions know the same pride and joy of parenting as others.

For more information see www.isna.org.

Alice D. Dreger, Ph.D.
Affiliations:

Associate Professor of Science and Technology Studies, Michigan State
University
Chair of the Board of Directors, Intersex Society of North America

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