

CONCLUSION, OR A PERSONAL APPEAL

Over the past decade, genital normalizing surgeries on intersex children have become a site of increasingly heated debate within the medical community and beyond. Paper after paper call for “more follow-up studies” to find out whether we should continue to perform these procedures or to abolish them, but we have real live intersex babies born every day across the country who cannot wait until we have all the data. Activists and medical professionals need to put aside our differences and find areas in which we can come together to think about what we can do to improve the lives of five or so intersex children born every day.

This article is an attempt to open such dialogue from the activist side. Personally, I am highly critical of normalizing genital surgeries on intersex children and wish to put an end to them if I could; however as an activist I know that real changes often happen not through heated screaming matches, but through finding a common ground with those I disagree.

Whether you happen to endorse surgeries or oppose them (or occupy a space in between), I trust that you want to take away the pain in the world as much as I and other intersex activists. It is in this trust that I also trust that we can work together to make small changes in the lives of our children as we push for more and better follow-up studies.

Ultimately, the goal in my activism is to make intersex normalizing surgeries obsolete. By that, I do not mean some top-down decision from the AAP or the Congress or the Supreme Court to step in and solve our problem; what I mean is that I would like to help build a society in which intersex bodies are not considered shameful, so that parents would not even think about cutting into the child’s skin unless it is medically necessary.

In that society, the cloud of shame and secrecy no longer surrounds intersex; instead, it is approached with openness, honesty and support. I believe that the medical community—along with activists, families, scholars, and other allies—will have a pivotal role in moving our society closer to that vision. I invite you to join us.

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Intersex Initiative is a Portland, Oregon based national activist and advocacy group for people born with intersex conditions. We would love to hear from you! Please send email to info@intersexinitiative.org or visit www.intersexinitiative.org.

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Intersex:

From Controversy to Consensus

An Activist Perspective

This year marks the eleventh year since the first intersex patient activist organization was founded, and the eighth since the first-ever public demonstration was held by activists and allies at the annual meeting of American Academy of Pediatrics in order to challenge the AAP’s official position at the time, which called for normalizing genital surgeries to be performed between 6 weeks to 15 months of the birth of a child with an intersex condition, particularly those born with atypical or “ambiguous” genitalia.

Today, patient advocates and medical professionals have a lot more knowledge about how people born with intersex conditions have been impacted by various medical procedures. And yet, there is a lot more we wish we knew. Many of us have strong views about how intersex children should be treated, and sometimes we fiercely disagree because none of us have all the data to fully convince “the other side.” But **it is time that we move beyond these areas of contention, and find areas we can work together for the betterment of the medical and social treatment of children born with intersex conditions.**

MAKING INFORMED CONSENT GENUINE

In the past, some in the medical community called for withholding information from the parents of intersex children under the premise that too much information could lead them to reject or question the gender assignment. Today, many people consider it unjustifiable to withhold information or mislead parents about the risks and benefits associated with these surgeries (and the lack of complete knowledge about both). While recent medical journal articles call for a more honest approach to communicating with the parents of an intersex child, many parents continue to report that they had to go out of their way to find the kind of information they wanted to know because their child’s physician did not discuss them.

Today, most of us consider it unjustifiable to withhold information or mislead parents about the risks and benefits associated with these surgeries (and the scarcity of our general knowledge about both). While recent medical journal articles call for a more honest approach to communicating with the parents of an intersex child, many parents continue to report that they had to go out of their way to find the kind of information they wanted to know because their child’s physician did not discuss them.

Informed consent is more than just signing a paper. In order for parents to make a decision they and their child can live with, they need to know more than what they are being told today at hospitals across the country. Providing parents with more information would protect physicians from potential future

liability as well. Such information should include:

- diagnosis and its impact on the child's health beyond the irregular genital shape
- whether a suggested procedure addresses biomedical problems or psychosocial ones
- whether a procedure is necessary for biomedical reasons or for social ones
- whether a procedure is a response to a true medical emergency or it can be postponed until later
- likelihood that repeated surgeries might become necessary
- that surgical assignment of sex is not necessary for gender assignment
- that surgery does not guarantee that the child would grow up to identify with the assigned gender
- that some preliminary follow-up studies have shown potential adverse physical, emotional and sexual impacts resulting from normalizing genital surgeries on children
- that normalizing surgeries on intersex children is controversial, with experts arguing from both pro and con sides of the debate
- availability of less drastic alternatives to surgery, including counseling and support groups to deal with psychological difficulties
- referral to knowledgeable counselors, support groups, patient advocacy groups, and/or other families with similar experiences.

KEEPING THE CHILD'S BEST INTEREST AT THE CENTER

All of us involved in this "debate" are here because we all want what is best for the child. None of us want to hurt, damage, shame, isolate, or humiliate children, even though these words are exactly what some adult intersex individuals use to describe how they have been impacted by some of the medical procedures. While we may hold different views in terms of how surgeries might improve or diminish one's quality of life, there are other areas in which we can work together in order to reduce pain and suffering.

1. "Medical display" is a phrase used by some advocates to refer to the seemingly routine and widespread practice of using an intersex child as a live educational tool. Upon arriving at the hospital to see an endocrinologist or for a routine exam, the child is stripped to nude or semi-nude and displayed to a large number of doctors, medical students, interns, and others "for the advancement of science and medicine." Many intersex adults recall this experience as extremely humiliating and sexually traumatic, and that it contributed to their sense that they are freakish or shameful. Further, it may lead some adults to refuse to seek medical care altogether because they associate medical care with this type of traumatic experience.

This practice is clearly harmful to any child, let alone the ones who are taught strictly by their parents to hide their bodies from other people to keep

the "secret" safe. We urge the medical community to utilize photo and video educational materials that have already been produced instead of putting the live child on display.

2. In the past, physicians advised parents of an intersex child to keep the diagnosis hidden as much as possible because the child would be confused and ashamed if they found out. We now know that children feel confused and ashamed because their doctors and family members kept secret from them and nobody told them what was going on. As young adults, many intersex people research their own histories and are often severely shocked and upset when they learn about what was kept secret from them by people they trusted—their doctors and parents.

Many studies on the psychological adjustment of children with severe disabilities have shown that how well a child can adapt to living with that condition depends more on how open and supportive his or her family members are than the severity of the disability itself. We feel that this holds true for families with an intersex child also.

In order to end shame, secrecy and isolation, physicians should advise the parents to tell their child about their condition and what it means throughout their development in age-appropriate and non-shaming ways. Just few years ago, everyone thought that this was impossible—and yet, we know many parents who are doing just that today. There is a lot to be learned from these pioneer parents—which is why we need to establish more support groups and networks for parents.

3. Parents' authority to make medical decisions on behalf of their minor child is well founded in the U.S. legal tradition, but it is not meant to be absolute or unlimited: physicians have the obligation to refuse to participate in medical procedures if they believe that they are contrary to the interest of the child. In the case of intersex, however, parents' need for comfort is often cited as the primary justification for the surgical intervention at the earliest stage of the child's life, rather than giving a more careful consideration for the child's long-term quality of life, including her or his adult sexual functioning.

While we may have different opinions about normalizing surgeries on intersex children in general, we should all be in agreement that if any surgery is to take place, it has to be because careful examination of available evidences suggest that surgery is in the best interest of the child, and not because parents would have difficulty accepting and raising the child without it. Some might argue that surgery is indeed in the child's interest if it makes the parents accept him or her, but this is insufficient justification because there are far less invasive and risky alternatives to address parental anxiety and frustration (e.g. counseling and support group for the parents) that should be sought first.

We would further argue that it is not in the interest of the child to grow up in a family that suppresses anxiety and frustration with concealment and silence. Like all children born with disabilities and atypical bodies, intersex children deserve parents who are open and supportive of their unique conditions, whether they have surgery or not.