

Giving pediatric patients a voice in treatment of DSD

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“This girl doesn’t have a uterus!” exclaimed the resident. Soon, a small group of residents was huddled around the ultrasound of a 15-year-old who had come into the small-town clinic for evaluation of primary amenorrhea. “Could she have androgen insensitivity?” mused one. “If she does, we’re not supposed to tell her.”

This was the story I heard from one of those residents. He was pretty sure the advice his colleague recalled from medical school — that a patient with androgen insensitivity syndrome should never be told the truth about her condition — was out of date, and he contacted me for more information about the ethical and legal implications of hiding this diagnosis from an adolescent patient. (By then the patient had appropriately been referred to a specialist. However, the residents wanted to learn from their experience.)

Along with other resources, I referred him to the American Academy of Pediatrics policy statement Informed Consent, Parental Permission, and Assent in Pediatric Practice. This four-page document is both straightforward and revolutionary in explaining key concepts of consent in pediatrics, and I find myself referring to it repeatedly in my consultations with medical providers caring for children with differences of sex development (DSD).

Unfortunately, although the policy has been around for almost 15 years, it does not seem to have received the exposure it deserves. Many of the doctors I meet are unfamiliar with it. Since it has application in many of the difficult situations that arise in treating children with DSD, I would like to review some key concepts from the policy along with examples of how they apply in cases of DSD.



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Consent in pediatric context

The AAP recognizes that the concept of consent operates differently in the pediatric context. Indeed, it suggests that the term “parental consent” is a misnomer, suggesting “parental permission” instead. Consent is an exercise of autonomy — true consent cannot be given by proxy. In pediatric cases in which true consent may not be possible, it is usually appropriate for parents to be the decision-makers. However, parents do not have an absolute right to make these decisions for their children in the same way that competent patients have a right to make medical decisions for themselves. The legal and ethical legitimacy of parental decision-making grows out of the presumption that parents will make decisions based on the child’s best interest. The provider’s obligation is to render care “based on what the patient needs, not what someone else expresses,” the authors wrote.

One situation in which this principle might come into play in caring for children with DSD is when decision-making about genital surgery is heavily influenced by parental discomfort with the child’s atypical genitals. For example, many providers have reported that parents who initially decide to refuse clitoral reduction often

change their minds when their child begins to masturbate. Anthropologist Katrina Karkazis quotes one doctor who said, “I had a little 2-year-old girl who had a very, very enlarged phallus and [the parents] didn’t have surgery. The little girl was masturbating, and the parents just fell apart and were back in the office the next week for surgery!” Although this doctor may have felt the parents were making the right decision, it is important to recognize that relieving parental discomfort is not an ethically sound basis for subjecting a child to the risks of elective surgery.

Children’s role in decision-making

In addition to clarifying the basis for parental decision-making, the AAP policy asserts that respect for the child’s dignity as a person requires allowing pediatric patients to “participate in decision-making commensurate with their development; they should provide assent to care whenever possible.”

Assent is explained as an informed, developmentally appropriate and uncoerced expression of willingness to accept the proposed care. The policy acknowledges that children are not always rational decision-makers capable of exercising autonomy and that therefore gaining assent may not always be possible. However, the AAP also suggests that performing invasive procedures without the child’s assent carries a risk for harm. This potential harm must be weighed against the necessity and urgency of the procedure. Also, even when it is necessary to proceed without the patient’s assent, the policy holds that the patient should still be informed and involved in developmentally appropriate ways.

In the case of the 15-year-old with androgen insensitivity, there was no immediate consideration of invasive procedures. However, it is likely in such a case that there would soon be a decision to make about gonadectomy to prevent cancer. Most 15-year-olds are quite capable of understanding and participating in a decision like this. Therefore, respect for her dignity and autonomy requires that she be told the truth about her condition and allowed to participate in decisions to the extent of her capacity. (Of course, even if there are no immediate decisions to make, respect for the patient requires that she be told the truth about her diagnosis in an appropriate way.)

Pediatric patient has the last word

Finally, the AAP policy states that there are times when the pediatric patient’s decision about medical care is ethically and even legally binding. The most obvious example here is in the case of deciding whether to participate in research, especially where there is no prospect of direct benefit to the patient. As momentum builds for more research into the outcomes of DSD treatment, it is important to keep this rule in mind. If the research will not benefit the patient directly, then her assent is necessary. In some other nonurgent situations, such as surgical repair of a malformed ear in a 12-year-old, the AAP policy strongly urges physicians not to proceed without assent. Generally, the older the patient and the less urgent the procedure, the more strongly the policy advises obtaining assent. These guidelines should be kept in mind for patients with DSD in all treatment decisions.

The AAP also recognizes that in some cases, adolescents do have full decision-making capacity and sometimes legal authority. In such cases, providers should obtain informed consent from the patient herself. For example, the policy states that obtaining the patient's informed consent is encouraged for performance of a pelvic exam in a 16-year-old. It seems obvious that providers should similarly obtain informed consent for genital exams in older teens with DSD.

Navigating the informed consent process has been one of the biggest problem areas in the history of DSD treatment. As providers develop improved, patient-centered models of care, the AAP's model policy for consent in pediatric cases offers invaluable guidance. I urge all providers to read it.

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For more information:

- American Academy of Pediatrics, Committee on Bioethics. *Pediatrics*. 1995;95:2:314-317.
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