

**Pediatric Decision Making and Differences of Sex Development:
A Societies for Pediatric Urology and American Urological Association
Joint Position Statement**

Medical decision-making for children should remain the responsibility of parents after consulting with medical professionals and obtaining information from other reliable sources and should not be legislated. While this is important for any medical situation, it is particularly important in complex medical problems. We recognize that intersex, differences of sex development (DSD), and other similar medical terms are broad in scope. They are reflective of many diagnoses and as such, the use of such terms in many situations is an over-simplification and possibly inaccurate because an exact diagnosis cannot be determined in many cases. In the absence of a better term, we will use DSD in this statement to represent this group of diagnoses. For example, the most common condition in the old paradigm, congenital adrenal hyperplasia (CAH), is a broad category that encompasses a large number of genetically-determined enzymatic abnormalities leading to a variety of phenotypic variations and abnormalities in the development of the genitals as well as other endocrinologic and metabolic imbalances. Decisions regarding how to approach patients with this condition, and indeed any complex medical problem, should remain within the shared decision-making process that involves the family and expert medical team and thus should not be legislated.

“One size fits all” legislation that dictates – or negates – a particular course of treatment will not serve the diverse interests of patients or families struggling to cope with the implications of DSD. Instead, the complexity of these cases requires that the evaluation and management of each child be individualized and undertaken using a multi-specialty and family-centered approach. Such a philosophy fosters a comprehensive and well-balanced methodology addressing the various and unique medical, psychological, developmental, and genetic issues of each individual. Many dedicated individuals and organizations, including medical professionals, educational foundations and patient advocacy groups, offer insights that may be helpful to parents searching for information about their child’s condition. Every child deserves unique attention and alternatives, and ultimately, we affirm the rights of parents to make medical decisions for their children, based on their review of all available management options, including observation, pharmacotherapy, or surgery, with full disclosure of the potential risks and benefits of these options. We also believe that children, to the extent possible and in consultation with their parents, should be involved in these decisions.

Surgical techniques continue to improve and the scientific literature reports current outcomes to be significantly better than in prior generations. Surgical repair, even at a young age, remains an important option in many cases, but it is not for everyone. Patients and their families will benefit from a holistic approach that presents the pros and cons of various options, including surgery, and empowers families to make decisions in their child’s best interest.

While significant strides in the care of these individuals have been made with growing scientific knowledge, more research is needed and we support efforts to fund and conduct such research. Gender recognition and therapeutic alignment is part of the multidisciplinary and family-centered approach and we support the right of every individual to self-assign or re-assign their gender. Moreover, we value and respect diversity among our patients, and we honor and welcome the perspectives offered by patients, families and all advocacy groups. Decisions regarding how to approach these, and indeed any, complex medical problem should remain in the purview of the family and expert medical team and thus should not be legislated.

Additional Resource

At the 2018 Interim Meeting, the American Medical Association House of Delegates adopted the recommendations of Council on Ethical and Judicial Affairs Report 3-I-18, "Amendment to E-2.2.1, 'Pediatric Decision Making.'" The Council issues this Opinion, which appears in the next version of AMA PolicyFinder and the next print edition of the Code of Medical Ethics.

E-2.2.1– [Pediatric Decision Making is available here.](#)