

NORTH AMERICAN SOCIETY FOR PEDIATRIC AND ADOLESCENT GYNECOLOGY

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NASPAG Position Statement on Surgical Management of DSD

"Differences of sex development include a heterogenous group of conditions where there is chromosomal, gonadal, or anatomic sex that falls somewhere in the middle of the typical understanding of male and female sex. These conditions may be identified during prenatal diagnosis, at birth, during infancy, during adolescence, or during an evaluation for infertility. The recent Human Rights Watch report details the interviews of several adults and parents of children with DSD conditions as well as health care providers. This report addresses the controversy surrounding surgery in children with DSD conditions prior to their ability to give assent or consent for irreversible treatments. We appreciate the time and effort that went into this report and the necessary conversation that must occur regarding parental support and medical care of patients with DSD conditions. Although DSD care is rapidly evolving with advances in genetic testing, hormonal therapies, and surgical technique, there still remains significant heterogeneity of care and lack of consensus among health care providers for optimal care for children, adolescents, and adults with these conditions. Additionally, there is a paucity of long term data, particularly regarding psychological and health outcomes. With this in mind, the North American Society for Pediatric and Adolescent Gynecology would like to affirm that DSD care should be provided to parents and patients through multidisciplinary or transdisciplinary care with teams of providers with expertise in DSD conditions. These teams should include pediatric and adolescent gynecology, pediatric urology, pediatric surgery, pediatric endocrinology, genetics, psychology/psychiatry, adolescent medicine, neonatology, social work, nursing, ethicists and legal experts. We believe in respecting the autonomy of the individual patient as well as providing ample support and guidance for the patient and family. All parents and affected patients should be actively encouraged to seek psychological counseling and peer support given the stress, confusion, and isolation that many experience. We believe that surgery alone does not address all the implications associated with DSD conditions. Some DSD conditions require early surgical intervention to optimize health and fertility. Ideally, if surgical interventions could be safely delayed, patients would have time to express their gender identity and to be actively involved in the decision making process. True informed consent or assent includes an accurate discussion of the options, benefits, known short and long term complications, expected pain and recovery, as well as need for reoperation. Finally, we believe that if there is a possibility for fertility, that this should be preserved and optimized."

