

Fertility preservation for children with differences of sex development

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Children with differences of sex development (DSD) are born with reproductive organs that are not typically male or female. They may face infertility from abnormal development of testes or ovaries, and in some patients these organs are surgically removed to prevent an increased risk of germ cell cancer. With advancing techniques, however, children with DSD may be able to preserve their fertility for the future. This potential also presents important ethical issues, which are examined in an article published in the *Journal of the Endocrine Society*.

"Our earlier research suggests that in children with DSD, we might be more successful in preserving fertility at younger ages," says senior author Courtney Finlayson, MD, from Stanley Manne Children's Research Institute at Ann & Robert H. Lurie Children's Hospital of Chicago. "This poses a dilemma in terms of the ideal timing for surgical removal of testes or ovaries for patients who need it. If we wait until the age of majority, when the patient can give consent, we might miss the opportunity for fertility preservation. And yet we might want to delay the surgery since we must also take into account a person's sense of self as a man or a woman and autonomous decision making. It is a delicate balance."

Fertility preservation techniques involve preserving at very low temperatures the mature or immature tissue from the testes or ovaries. The procedure is still experimental for pre-pubertal patients, since it relies on the development of technologies to mature germ cells in the lab. Given the uncertainty of success, there is concern that these

techniques can lead to false hope for patients and parents. Cost and [insurance coverage](#) are additional concerns. Fertility preservation is expensive, ranging from thousands to tens of thousands of dollars. It is rarely covered by insurance and is mostly considered an elective procedure.

"We can make an argument that fertility preservation in children with DSD should be covered by insurance since DSD treatment can cause infertility, which can result in serious psychological distress," says Finlayson, an endocrinologist with the Gender and Sex Development Program at Lurie Children's and an Assistant Professor of Pediatrics at Northwestern University Feinberg School of Medicine. "Lack of insurance coverage significantly limits access to preserving future fertility in these children."

Because many DSD are genetic conditions that can be inherited, there is also concern about transmission to offspring. Some ethicists argue that it is irresponsible to knowingly have children with a medical condition or disability. On the other hand, advocates assert that people with disabilities can lead happy, productive lives. Furthermore, many with DSD object to their condition being referred to as a disorder or disease. In either case, adults concerned about having children with the same condition could benefit from pre-implantation genetic screening of embryos.

Another ethical consideration revolves around gender dysphoria, or the distress that some individuals with DSD experience when their early sex assignment does not match their eventual gender identity. For example, youth initially assigned male but identifying as female might feel emotional distress at providing sperm for fertility preservation. Also, high-dose estrogen or testosterone required for fertility preservation can cause irreversible physical changes that are inconsistent with gender identity.

"There are no easy answers to any of these ethical concerns," says Finlayson. "Fertility-related care for [children](#) with DSD is in its infancy. We must carefully consider the unique ethical issues that [fertility preservation](#) presents in this population."

Provided by Ann & Robert H. Lurie Children's Hospital of Chicago

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