

# Diagnosing and treating disorders of early sex development

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Differences of Sex Development: Consensus paper regulates medical treatment of affected infants and adolescents. Credit: Medical University of Vienna

Diagnosing, advising on and treating disorders of early sex development represent a huge medical challenge, both for those affected and for treating physicians. In contrast to the earlier view, DSD (Difference of Sex Development) are now regarded as rare and complex disorders with many different clinical manifestations. The aim is to provide interdisciplinary care, depending upon age and severity, rather than immediately performing sex reconciliation surgery in childhood. A new consensus paper produced by European doctors, psychologists, patients and self-help groups is now to serve as a basis for uniform medical management of DSD throughout Europe.

Paediatric urologist Alexander Springer from the Division of Pediatric Surgery and paediatrician Stefan Riedl from MedUni Vienna's Department of Pediatrics and Adolescent Medicine were among the participating Austrian representatives. The paper was recently published in renowned journal *Nature Reviews Endocrinology*.

People who suffer from the rare condition referred to as diverse sexual development (DSD) were previously designated as being "intersex." This means that, for genetic, anatomical or hormonal reasons, they cannot be unambiguously assigned to either the male or female gender. However, DSD is not a clear-cut diagnosis but rather an overarching designation for very different clinical phenomena with diverse biological causes. In contrast to this, from the medical perspective, people who are transsexual can be clearly defined biologically but subjectively feel that they belong to the other gender. It is assumed that one in 1,500 newborns suffers from DSD. This equates to approximately 50 children a year in Austria.

Over the past decades, children who could not be clearly assigned to a particular gender often underwent gender-matching surgery at a very early age, often without parents being properly informed about the measures and aims and without knowing the long-term consequences.

This situation has continuously improved, due to increasing engagement and self-awareness of the affected adults. In the "Chicago Consensus" of 2005, experts established for the first time that children should only be operated on once their sexual identity was clear and that they should be given intensive medical and psychological care over a long period of time. Nonetheless, there were repeated instances of incorrect diagnosis and treatment.

As the outcome of a three-year research project, leading medical experts, self-help groups and affected adults have now produced a new Consensus Paper on the subject of DSD. The aim was to establish a holistic perspective of the broad subject of DSD, taking account of all areas of life such as sexuality, working life and the desire to have children.

The basic agreements also include recognition that DSD is a package of tiresome and complex disease phenomena and has hitherto been dealt with in a less than optimal way. According to the MedUni Vienna experts, it was agreed that diagnosis and treatment should only take place in an interdisciplinary setting in specialist medical centres. A consensus was also reached on the fact that DSD is a life-long condition, which needs to be managed for the corresponding length of time. Finally, it was agreed to establish a prospective register, that is to say a multidisciplinary and international database. Says Alexander Springer, paediatric urologist at MedUni Vienna's Division of Pediatric Surgery: "We have now laid the foundations for establishing uniform management throughout Europe. However, this is just the beginning. We need long-term data and high-quality studies to enable us to determine the optimum treatment for each individual patient.

**More information:** Caring for individuals with a difference of sex development (DSD): a Consensus Statement, *Nature Reviews Endocrinology* (2018). [DOI: 10.1038/s41574-018-0010-8](https://doi.org/10.1038/s41574-018-0010-8)

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