

## A word on nomenclature

Terminology in this area of biology remains controversial.

One term that is commonly applied to people with variations in either genital appearance or sex organ development or function is "intersex", a term that arose in the early to mid-20<sup>th</sup> century. Many people prefer to use this term, but others contend that it is not a precise term that distinguishes one of the many conditions from another, and that it does not cater well for those whose biological sex is closely aligned to typical male or female.

In 2005, an international group of doctors, scientists and patient group representatives met in Chicago to discuss management and possible classifications for this range of conditions. This group suggested the term "**Disorders of Sex Development**" (**DSD**) to define <u>congenital</u> conditions in which anatomical, chromosomal or gonadal sex is atypical. This terminology has since been adopted by the international classification of diseases (ICD).

Some welcomed the term DSD for the following reasons. It is considered helpful for those seeking access to insurance and medical assistance, as with other medically defined conditions. Some find it helpful to describe their variation as a condition with a medical name and in some cases, a defined genetic cause. The DSD classification system allows the medical and scientific community to refer more specifically to individual conditions (47,XXY DSD, 46,XY DSD and so on). This degree of accuracy is important when trying to learn more about outcomes related to a given variation (for example malignancy risk in a certain DSD subtype). Finally, some variations of sex anatomy are adequately covered by "intersex", but others are DSDs without being intersex conditions.

On the other hand, some contend that variations in sex development are not disorders at all, but simply a reflection of a continuum that exists, similar to height or eye colour. They consider the term DSD unhelpful and express a concern that applying the term "disorder" can have negative psychological impacts. Some feel that the Chicago meeting did not include enough people with lived experience to support the development of an inclusive terminology and reject the term DSD for that reason. Other groups accept the term DSD but prefer for it to denote "Difference of Sex Development". This, or indeed use of DSD to denote both 'disorder/difference of sex development' is increasingly employed.

There is currently no single term that is considered acceptable to all groups, and adequately covers the breadth of variations that exists in the population.

On this website, readers will frequently encounter the term DSD, which we have found to be a precise and workable professional term from a scientific and medical perspective. However, we also choose to use other terminology (such as atypical sex development, variations of sex development, and so on) in many places. We acknowledge the different opinions in relation to this and mean no disrespect to those with alternative preferred terminology. For conversations at an individual level, it is helpful to ask about preferred terminology and to use terms that a person is comfortable with in relation to their own variation.