



Technical Assistance Partnership for Child and Family Mental Health Cultural and Linguistic Competence in Focus: LGBTQI2-S Learning Materials

DSD/Intersex Resource List

The following resources have been reviewed and recommended by a mental health practitioner based upon materials currently available at the time of this writing. As with all resource recommendations, these materials may become outdated or may no longer be available. In sharing these materials and links with families and individuals, it is important to review them first, not only to verify that they are still current, but also to provide a context and/or understanding of the emphasis, biases or limitations of each resource. Since, this is by no means an exhaustive list, practitioners may wish to supplement this with additional materials. It is similarly important to review new materials for accuracy and appropriateness before sharing with families and individuals.

Materials for Families

- **Handbook for Parents** (<http://www.accordalliance.org/dsdguidelines/htdocs/parents/index.html>)
The Accord Alliance's Handbook for Parents walks families through the process of learning of an initial diagnosis all the way through caring for teenagers with DSD. It uses affirmative and normalizing language while providing some basic medical background.
- **Downloadable Booklet Explaining Sex Differentiation** (<http://www.hopkinschildrens.org/intersex>)
A website and downloadable guide, written in layman's terms by a pediatric endocrinologist and a psychologist specifically for parents who are trying to learn more about the biology of DSD. Note that while its language describes sex development as "normal" or "abnormal" it is written with the belief that affected individuals can be "expected to grow up successfully and lead enriched lives."
- **ISNA's Tips for Adoptive Parents** (http://www.isna.org/articles/tips_for_adoptive_parents)
Though the Intersex Society of North America has shut its doors as an organization, its website still provides a wealth of information. Based upon its 'Tips for Parents' page, this page has tips for adoptive parents who may need special consideration given the limits of knowledge they may have around their child's medical history.

Materials for Practitioners

- **Handbook for Practitioners** (<http://accordalliance.org/dsdguidelines/htdocs/clinical/index.html>)
These guidelines were developed to assist health care professionals in the provision of diagnosis, treatment, education, and support to children born with disorders of sex development (DSDs) and to their families using a patient-centered model.
- **APA Brochure on Intersex** (<http://www.apa.org/topics/sexuality/intersex.pdf>)
Brochure from the American Psychological Association's Task Force on Gender Identity, Gender Variance, and Intersex Conditions answering common questions clinicians might have about intersexuality and DSD.
- **Endotext** (<http://www.endotext.org/pediatrics/pediatrics10/pediatricsframe10.htm>)
Endotext is a free online endocrinology textbook edited and written by experts in the field. It includes several chapters that may be of interest to those seeking a better understanding of the biological basis of DSD. This chapter in the 'Pediatric' section of the text describes sex differentiation and gives an overview of various disorders of sex development. Other chapters in the 'Pediatric' and 'Adrenal Disease Function' sections of the book go into greater depth.
- **Consensus Statement on Management of Intersex Disorders**
(<http://pediatrics.aappublications.org/content/118/2/e488.full.pdf+html>)
DSD treatment recommendations prepared by the International Consensus Conference on Intersex organized by the Lawson Wilkins Pediatric Endocrine Society and the European Society for Paediatric Endocrinology.





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Support and Advocacy Groups

- **Androgen Insensitivity Syndrome/ Disorders of Sex Development Support Group** (<http://www.aisdsd.org>)
Originally founded as a support group for Androgen Insensitivity Syndrome, the AIS/DSD Support Group is now inclusive of all families and individuals living with DSD regardless of diagnosis, gender assignment, or identity. There are separate confidential email circles for adults, teens and families. Given the group's history, the majority of its adult members identify as women but the parent group, which currently contains 150 families with biological and adopted children ranging in age from infancy to adulthood, includes families of both girls and boys.
- **Major Aspects of Growth In Children (MAGIC) Foundation**
(http://www.magicfoundation.org/www/docs/107.127/disorders-of-sexual-development_in_children)
MAGIC is made up of 25,000+ families whose children (and affected adults) have growth hormone deficiency or other medical conditions which affect their growth. While not a DSD-only group, they host a section on their site focusing on Genital and Reproductive Anomalies in Children (GRAC)
- **Congenital Adrenal Hyperplasia Research Education and Support (CARES) Foundation**
(<http://www.caresfoundation.org>)
CARES leads the effort to improve the lives of the CAH community and seeks to advance quality health care through support, advocacy, education and research. In addition to a wealth of resources, the site also has an event calendar of conferences and meetings, and an extensive network of support group leaders listed by state/country.
- **Congenital Adrenal Hyperplasia Education and Support Network** (<http://congenitaladrenalhyperplasia.org>)
The CAH Education and Support Network serves primarily as a message board for individuals and families with CAH. They offer boards for adults and kids as well as topic- or country-specific boards.
- **Turner Syndrome Society of the United States** (<http://turnersyndrome.org>)
TSSUS is a national non-profit organization that provides health-related resources to patients, families and physicians for the diagnosis and treatment of Turner syndrome. There are chapters and support groups located throughout the country, as well as an annual conference with speakers from a variety of professions including medical experts, social workers, educators and psychologists
- **The Hypospadias and Epispadias Association** (<http://www.heainfo.org>)
HEA is a non-profit organization founded for the support and education of people born with hypospadias or epispadias and their families, loved ones, and medical care givers. Although HEA is based in the USA, they invite participation from all people in all countries, and offer an annual conference, message boards and scheduled, moderated online chats.
- **Knowledge, Support and Action** (<http://www.genetic.org>)
KS&A's mission is to help individuals with one or more extra X and/or Y chromosomes and their families lead fuller and more productive lives. They work to increase support, education, research and treatment.

Legal Assistance

- **Advocates for Informed Choice** (www.aiclegal.org)
AIC is the first, and only, organization in the U.S. to focus on legal advocacy for DSD. AIC engages parents, doctors, attorneys and intersex activists in strategy discussions focusing on the rights of families and children affected by intersex conditions or DSD.

