DISORDERS OF SEX DEVELOPMENT (DSD) OR INTERSEX SURGICAL REMEDIATION

Brief Coverage Statement
Disorders of Sex Development (DSD) refers to a group of genetic, endocrine and physical anomalies characterized by ambiguous external genitalia at birth or by discordance between the external genitalia and chromosomal gender. (Often, the antecedent assessment of chromosomal gender may have been made at the time of prenatal diagnosis.)

Colorado Medicaid covers surgery for treatment of DSD when medically necessary as described in this policy.

PHILOSOPHICAL OVERVIEW OF DSD

Optimal care for children with DSD requires an experienced multidisciplinary team that is generally found in tertiary care centers. Ideally, the team includes appropriate pediatric subspecialists in such areas as endocrinology, surgery, urology, psychology or psychiatry, gynecology, genetics, neonatology, and, if available, social work, nursing, and medical ethics. Core composition will vary according to DSD type. Ongoing communication with the family’s primary care physician is essential.

Because the gender effectuated through these surgeries plays such a critical role in a person’s life and because surgeries carry the risk of profound effects physically, psychologically and sexually, there has been considerable debate about whether surgical treatment in the first few weeks of life is necessary, when doing so is not critical to the physical well-being of the baby. Colorado Medicaid encourages each family to take the time it needs to make this complex decision.

Since there may need to be further surgery, particularly at the time of puberty, the surgeon has a responsibility to outline for the family the surgical sequence and subsequent consequences from infancy to adulthood.

Services Addressed in Other Benefit Coverage Standards

- None
Eligible Providers
All providers must be enrolled with Colorado Medicaid.
• Only surgeons with expertise in the care of children and specific training and credentialing in the surgery of DSD should perform these procedures.

Eligible Place of Service
1. Office – Testing
2. Clinic – Testing
3. Federally Qualified Health Center – Testing
4. Rural Health Center – Testing
5. Hospital – Surgical Procedures

Eligible Clients
1. All currently enrolled Medicaid clients, aged 20 and younger, are eligible to receive this service.
2. Clients enrolled in the Primary Care Physician Program (PCPP) or Accountable Care Collaborative (ACC) must obtain a referral to a specialist for services to be reimbursed.

Covered Services and Limitations
Intersex surgical remediation is covered as reconstructive surgery if the diagnostic criteria for DSD are met. Procedures can be performed as necessary throughout development, including at the time of development of pronounced secondary sex characteristics during puberty.

Note: Colorado Medicaid supports and encourages that discussions with the family be conducted by a professional with appropriate communication skills and knowledge of DSD. Open communication with clients and families is essential: their participation in decision-making is encouraged and their concerns should be respected. Counseling services related to DSD for the client and family are covered.

Prior Authorization Requirements
All DSD or intersex surgical remediation procedures require prior authorization.

Non-Covered Services
1. DSD or Intersex surgical remediation is not covered when the diagnostic criteria for DSD are not met.
   1.1. Specifically, transsexual surgery (sexual reassignment surgery or SRS) for gender identity disorder alone is not a covered benefit.
2. DSD or intersex surgical remediation procedure is **not covered for adults** aged 21 and older.

**References**


Lee, PA, et. al., in collaboration with the participants in the International Consensus
Conference on Intersex organized by the Lawson Wilkins Pediatric Endocrine Society and the European Society for Paediatric Endocrinology. *Pediatrics* 2006;118/2:e487-e500


