

## **Parents of Youth with Disorders of Sex Development: Perception of Counseling Needs**

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Parents who have children with disorders of sex development (DSDs) – defined as congenital conditions of atypical chromosomal, gonadal, or anatomical sex (Hughes et al., 2006)- encounter numerous challenges, ranging from medical decision-making to psychosocial well-being. Appropriate guidance from a DSD medical multidisciplinary team should benefit children and families and facilitate better quality of life and positive adjustment in youth with DSD (Hughes et al., 2006). Providing not only information about medical management during the child’s life, but also counseling and support, resulted in fewer instances of gender identity concerns and/or depressive disorders within this population compared to those who do not receive psychological care (Slijper et al., 1998). The current study aims to 1) identify parental reported counseling needs over the course of the child’s early development so that healthcare providers will be better able to address their concerns, 2) identify parental reported counseling needs based on the child’s age/developmental stage (infant, toddler, preschooler), and 3) identify parental counseling reported needs according to DSD diagnosis. This is a descriptive, quantitative pilot study that will survey parents who have children ages 0-6 with DSDs. These caregivers were asked to complete a Health Related–Quality of Life (HR-QoL) online survey and demographic questionnaire. Results of this study show that overall, within a multi-disciplinary DSD clinic, caregivers feel they are informed enough to make decisions about their child’s care and feel confident in their decision regarding their child’s gender identity assignment. Parents are also comfortable with their child’s gender-related behaviors during early child development; this statement held true for parents when the data were analyzed according to their child’s DSD diagnosis. Parents reported confidence in the medical information provided by their health care team. Most parents identified future concerns regarding fertility issues. Unlike parents of children with severe 3 hypospadias, parents of children with Klinefelter syndrome and ambiguous genitalia reported future concern regarding their children’s social relationships. Our study intends to contribute to existing research on youth with DSD conditions by using a quantitative survey of parental need for guidance to better understand the specific areas perceived to be high priority for psychosocial counseling across a range of DSD conditions. This method of informing future interactions between providers and parents will potentially benefit the quality of life for parents and children with DSDs.