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Recommendations for the Establishment of Disorders/Differences of Sex Development Interdisciplinary Care Clinics for Youth¹

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ABSTRACT

Purpose: Provide recommendations for the development of an interdisciplinary care (IDC) clinic for the treatment of youth with disorders/differences of sex development (DSD). DSD consist of a group of complex congenital medical disorders in which the development of chromosomal, gonadal, or anatomical sex is atypical. Youth with DSD require care from multiple specialized healthcare disciplines, including several medical specialties, surgery, nursing, and mental health.

Method: Recommendations are based on an interdisciplinary care clinic model that allows for a team of relevant professionals who share knowledge, ideas, and responsibility of care. The framework established in this article is based largely on experiences at an established DSD clinic, as well as observations of multiple clinics across the United States.

Results: Preliminary outcome data on clinic adherence to treatment protocol under an IDC model are provided.

Conclusions: To meet the diverse healthcare needs of youth with DSD, comprehensive care clinics are recommended; however, few such clinics exist in the United States. Establishing new comprehensive DSD clinics can be challenging due to the highly unique treatment of DSD, but the current paper expands the literature available to guide clinic development in the United States.

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A growing number of specialized comprehensive care clinics have been developed to meet the complex needs of children with chronic health conditions, such as cancer, kidney disease, and spina bifida, among others (Brei, 2007; Menon, Valentini, Kapur, Layfield, & Mattoo, 2009; Ruhstaller et al., 2006). However, not all chronic health conditions have witnessed large scale development and implementation of such clinics. Among underserved populations are youth affected by disorders/differences of sex development (DSD), a group of complex congenital disorders in which the development of chromosomal, gonadal, or anatomical sex is atypical. DSD affect a variety of both medical and psychosocial domains requiring the consideration of hormonal and

surgical issues, as well as discussions about the appearance of atypical genitalia, gender, and sexuality (Lee et al., 2016). Although it is unclear how many children are born with DSD, it is likely that the prevalence is approximately 1 in 4500–5500 (Sax, 2002). As the treatment of this group of disorders is both complex and delicate, individuals with DSD may require comprehensive care from multiple specialties, including: endocrinology, surgery, genetics, nursing, and mental health (Hurwitz, 2010; Lee et al., 2016; Palmer et al., 2012). However, to the best of our knowledge, as of 2012, only 12 specialized DSD clinics existed in the United States (Davis, 2015).

According to the Consensus Statement on the Management of Intersex Disorders (2006) multidisciplinary care is considered 'optimal' for children with DSD (Hughes, Houk, Ahmed, & Lee, 2006). An update to the consensus in 2016 underscored the need for comprehensive care in the treatment of these children and further clarified the distinctions between the different models of comprehensive care (Lee et al., 2016). These models include multidisciplinary, interdisciplinary, and transdisciplinary models. As defined by the Institute of Medicine and outlined in the consensus update, these models vary by degree of collaboration and autonomy within the team (Cuff, 2014). *Multidisciplinary care* is described as simultaneous, but independent contributions from team members across multiple disciplines. The *interdisciplinary care* model is defined as

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a team that works jointly to achieve a common goal, with the recognition that each team member has their own, discipline-specific perspectives. Finally, the *transdisciplinary approach* integrates concepts from each team member's unique discipline to create a new, combined, model of care. Although the term "multidisciplinary" has been frequently used as an umbrella term for care teams with varying degrees of collaboration and autonomy, there is a need to be more explicit and concise when discussing comprehensive care (Lemieux-Charles & McGuire, 2006; Ples, 1995). The present article will utilize the term *interdisciplinary care (IDC)*, as defined above, as it is the most accurate term to describe what is considered to be the optimal standard of care for DSD.

Although it is possible to treat DSD without a formally developed interdisciplinary care clinic, specialized IDC DSD clinics are recommended due to the complexities of DSD, including the diversity of conditions, the unique treatments and varying duration of these treatments, and the need for an intricate understanding of the many medical and psychosocial nuances associated with each type of DSD (Lee et al., 2016). Additionally, having consistent DSD-specialized providers of care is believed to improve patient-provider communication and rapport. This is especially relevant for the treatment of DSD, because many medical decisions involve the discussion of personal, and often "taboo" topics such as genital appearance, sex, and gender (Telles-Silveira, Knobloch, & Kater, 2016). With this in mind, it is certainly acknowledged that financial and political obstacles may arise, and consequently it can be challenging for new clinics to be established. However, given the multifaceted needs of this population, we would argue that it is important to address these barriers, because current standards of care suggest that patients with DSD may be optimally served by an interdisciplinary model which enables providers to efficiently share knowledge, ideas, and responsibility of care (Lee et al., 2016).

To date, little has been written to help guide the development of IDC clinics for DSD in the United States. A number of important articles exist to guide DSD management within IDC clinics; however, recommendations specific to clinics within the United States are still limited, as many such articles are written to reflect clinics in European, single-payer health care systems (Ahmed et al., 2011; Brain et al., 2010). Importantly, Brain et al. (2010) have provided an overview of a successful clinic's experience in implementing holistic care for youth with DSD in the UK. Additionally, Moran and Karkazis (2012) provided a preliminary protocol for the establishment of a DSD clinic; however, a comprehensive and practical guide to the broader structure and organization, as well as the day-to-day operations, of an IDC DSD clinic in the United States is still needed. The current article aims to provide both broad and specific recommendations for the development of IDC clinics for children with DSD and their families. The framework established in this article is based largely on the experiences at an established DSD clinic, as well as observations of multiple clinics across the United States. Preliminary data on clinic outcomes are provided, specifically as they concern adherence to treatment protocol.

Establishing the Interdisciplinary Team

The initiation of an IDC DSD clinic begins with a broad assessment of interest in, and need for, the clinic's development. It is helpful to garner early support from appropriate administrative parties, as access to facilities and support staff is essential. In our experience, garnering this support is most successful when a senior physician is a strong advocate for the establishment of the clinic. Beyond recruiting the support of a senior physician, recruiting specialists who have interest and expertise in treating this unique population is critical. An ongoing commitment from these specialists must be obtained prior to the founding of the clinic, as the clinic's success will be predicated on the team's ability to collaborate and function within the limitations of the larger medical institution (e.g., being housed in different departments). The primary goals in the initial phase of establishing a clinic should thus be to identify a small, but dedicated, group of individuals who are highly

motivated to prioritize their responsibilities for clinic development. Given the rarity of the condition and the complex nature of maintaining a functioning team whose members are not housed in the same department, specific requirements for being a team member should be explicitly conveyed to ensure each individual's commitment for ongoing support of the clinic. For instance, team members should be required to attend *all meetings* and clinics where their expertise is needed. It is particularly important that these team members maintain flexible schedules and are willing to accommodate other affiliates, such as meeting early in the morning to adapt to surgery schedules. Team members should agree to adhere to the outlined stipulations in order to establish a clinic that is functional, efficient, and collaborative.

The predominant needs of children with DSD and their families are specialized medical care, emotional support tailored to DSD, and coordination between providers and the family. Such needs clearly cannot be met without the involvement of multiple disciplines. A primary goal when developing an IDC DSD clinic is to include specialists who are able to work collaboratively to treat the diverse needs of DSD patients and their families. It is crucial that the team's personnel collectively fulfill six key roles necessary for the deliverance of integrated care. The following section outlines the vital roles that team members should fulfill in order to build and maintain a successful IDC DSD clinic. Although some of these roles would be seen in any IDC clinic for youth with a chronic health condition, there are many medical and behavioral/psychosocial issues that are unique to working with youth with DSD and their families, and such relevant issues will be noted throughout.

Registered Nurse (RN) Coordinator

The clinic coordinator is oftentimes the family's first contact with the clinic, thus it is essential that a team member with experience working with DSD patients fill this role. RNs are often in a favorable position to fill this role, as they have diverse training in both medical and behavioral/psychosocial disciplines. It is paramount to the efficient functioning of the IDC DSD clinic that the coordinator be not only knowledgeable about DSD, but also the medical institution and the providers on the team. The IDC DSD clinic coordinator schedules patients' clinic visits and manages clinic schedules for the multiple health care providers working within the IDC team. This role should be filled by an individual who evidences strong communication and organizational skills, as well as specialized knowledge related to meeting the medical and behavioral/psychosocial needs of families of children with DSD.

Surgical Specialist(s)

DSD surgeries that include both functional and cosmetic outcomes can be an important component of comprehensive DSD care. A recent survey of DSD care teams in the United States found that urologists or surgeons were involved in every team surveyed (Rolston et al., 2017). Importantly, concerns and controversy continue to surround the role of surgery in the context of DSD. A full discussion of these issues is beyond the scope of this paper; the reader is referred to Johnston (2012) for additional information on these debates. Despite these unresolved issues, it is recommended that a qualified surgeon be included as part of the IDC DSD clinic team. It is imperative that surgeons have previous specialized training and experience in pediatric urogenital surgeries, and for this reason, this role is often filled by a pediatric urologist (Lee et al., 2016). It is our opinion that by including a specialized surgeon as part of the IDC DSD clinic team, the needs of patients are better met, avoiding the undesirable outcomes that may occur when patients with DSD undergo surgery by surgeons without extensive experience in the treatment of DSD.

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