Sudan Journal of Medical Sciences
Volume 21, Issue no. 2, https://doi.org/10.18502/sjms.v21i2.21305
Production and Hosting by KnE Publishing

Editorial

Socially Accountable Care for Disorders of Sex Development in Fragile Settings: Lessons from Sudan

Imad Fadl-Elmula[1,2]*, Rayan Khalid[2,3], and Nazik Elmalaika Husain[4]

[1]Department of Clinical Genetics, Al Neelain Stem Cell Center, Al Neelain University, Khartoum, Sudan
[2]Sudanese Intersex Working Group, Khartoum, Sudan
[3]Department of Clinical Genetics and Immunology, Assafa College, Khartoum, Sudan
[4]Department of Pathology, Faculty of Medicine, University of Tabuk, Tabuk, Saudi Arabia

Disorders of sex development (DSD) comprise a heterogeneous group of congenital conditions characterized by atypical chromosomal, gonadal, or anatomical sex development and affect approximately one in 4500–5500 live births worldwide [1]. Although advances in molecular diagnostics and multidisciplinary care have improved outcomes in high-income countries, individuals with DSD living in low-resource settings continue to face substantial barriers to timely diagnosis and appropriate management [2]. The aim of this editorial is to highlight the importance of socially accountable, culturally sensitive, and multidisciplinary care for DSD in resource-limited and conflict-affected settings, using the 20-year experience of the Sudanese Intersex Working Group (SIWG) as an example of how sustainable and patient-centered DSD services can be developed despite significant challenges.

Across many African countries, DSD care is influenced not only by limitations in diagnostic infrastructure but also by social stigma, cultural interpretations of sex variation, and rigid gender norms. These factors often delay presentation until adolescence or adulthood, when patients may present with primary amenorrhea, absent puberty, or unexpected virilization [2, 3]. In Sudan, where consanguinity rates are high and family decisions are strongly shaped by cultural and religious considerations, delayed diagnosis can have profound psychosocial and medical consequences. Previous studies have documented that some individuals with 46,XY DSD raised as girls underwent female genital mutilation because of sex misassignment, highlighting the serious consequences of inadequate early recognition and counseling [4].

These realities emphasize the need for approaches to DSD care that extend beyond biomedical management alone. The concept of social accountability, defined as the obligation of health institutions to direct education, research, and service activities toward the priority health concerns of the communities they serve, provides an important framework for addressing complex and culturally sensitive conditions such as DSD [5]. Similarly, people-centered health systems advocate care models that recognize patients within their social, cultural, and family contexts rather than focusing solely on disease [6].

Corresponding Author: Imad Fadl-Elmula; email: imad.assafa@gmail.com; p.imad@neelain.edu.sd

Received: 13 June 2026
Accepted: 16 June 2026
Published: 30 June 2026

Production and Hosting by KnE Publishing

Editor-in-Chief:
Prof. Nazik Elmalaika Obaid Seid Ahmed Husain, MD, M.Sc, MHPE, PhD.

The experience of the SIWG, which marks its 20th anniversary this year, illustrates how these principles can be translated into practice in a fragile and resource-constrained environment. Established as an independent multidisciplinary initiative, SIWG brought together expertise from clinical genetics, pediatrics, endocrinology, surgery, psychiatry, psychology, gynecology, law, and religious scholarship. This broad collaboration acknowledged that DSD affects not only biological development but also identity, family dynamics, legal status, and social belonging.

Over two decades, this model has contributed to the development of context-specific clinical practices that balance international standards with local cultural realities. The group has promoted multidisciplinary assessment, strengthened professional awareness through training activities, and facilitated dialogue between medical professionals, legal authorities, and community stakeholders. Importantly, the experience demonstrated that culturally sensitive care and ethical decision-making are possible even where access to advanced diagnostic technologies remains limited.

Research emerging from Sudan has also highlighted distinctive patterns of DSD presentation that differ from those reported in high-income countries. Adult presentation of DSD, particularly cases associated with 5α-reductase type 2 deficiency, appears relatively common, and novel SRY gene mutations have been identified [4, 7]. Such observations reinforce the importance of generating locally relevant evidence rather than relying exclusively on data derived from other populations.

Equally important has been the gradual evolution toward more patient-centered and ethically informed care. Contemporary international recommendations increasingly emphasize transparency, multidisciplinary counseling, and shared decision-making, including deferral of nonurgent irreversible interventions whenever possible until affected individuals can meaningfully participate in decisions regarding their bodies and identities [1, 8]. These principles are particularly relevant in societies where cultural pressures may favor early assignment and intervention.

The Sudanese experience also demonstrates the resilience of collaborative health initiatives during periods of conflict and instability. Despite displacement, service interruptions, and severe resource limitations, continuity of care has been maintained through professional networks, decentralization, and strong relationships with patients and families. Such experiences suggest that trust, community engagement, and interdisciplinary cooperation are as important as technological resources in sustaining specialized services.

As African healthcare systems continue to strengthen, DSD should be recognized as an important but frequently neglected component of reproductive and genetic health. Greater investment in professional training, early referral pathways, multidisciplinary clinics, and locally driven research is needed. Policymakers should also consider integrating DSD care into national health strategies to ensure equitable access and protection of patient rights.

Twenty years of experience in Sudan suggest that socially accountable and culturally responsive DSD care is achievable even in conflict-affected and resource-limited settings. Although models will necessarily differ across countries, the principles of multidisciplinary collaboration, community engagement, ethical practice, and respect for patient dignity are universally applicable. These lessons may provide valuable guidance to other countries

in Africa and the Middle East seeking to establish sustainable, people-centered DSD services.

References

[1] Lee PA, Nordenström A, Houk CP, Ahmed SF, Auchus R, Baratz A, et al.; Global DSD Update Consortium. Global disorders of sex development update since 2006: Perceptions, approach and care. Horm Res Paediatr. 2016;85(3):158–180.

[2] Asafo-Agyei SB, Ameyaw E, Nimako B, Amoah M. Challenges in management of ovotesticular differences in sex development in resource-limited settings. Case Rep Endocrinol. 2024;2024(1):9987144.

[3] Khalid R, Elkareem MM, Fadl-Elmula I. Genetic causes of primary amenorrhea using chromosomal analysis and PCR for SRY gene. Ethiop J Reprod Health. 2024;16(3).

[4] Ahmed SM, Fadl-Elmula I. Clinical, cytogenetic, and molecular characterization of disorders of sexual development (DSD) in Sudan. Genomics Appl Biol. 2016;6.

[5] Boelen C, Dharamsi S, Gibbs T. The social accountability of medical schools and its indicators. Educ Health (Abingdon). 2012;25(3):180–194.

[6] De Man J, Roy WM, Sarkar N, Waweru E, Leys M, Van Olmen J, et al. Patient-centered care and people-centered health systems in sub-Saharan Africa: why so little of something so badly needed? Int J Pers Cent Med. 2016;6(3):162–173.

[7] Elkareem MM, Ahmed SM, Khalid R, Fadl-Elmula I. Spectrum and determinants of disorders of sex development in Sudan. Afr J Reprod Health. 2026;30(10):85–94.

[8] Khalid R, Siddig AM, Elzien AE, Abudoam AA, Fadl-Elmula I. Unusual case of ovotesticular DSD presented at adulthood with mosaic karyotype, full functioning mullerian structure, two ovaries, and one ovotestis. Ethiop J Reprod Health. 2024;16(4).