

Creating a Patient Support Resource for Pediatric Difference of Sex Development Multidisciplinary Clinic

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I. Abstract

Background: Differences of sex development (DSD) are conditions in which an individual's phenotype and karyotype do not fit within the typical male-female binary. Research on supporting individuals with DSD is limited in the literature. A quality improvement (QI) study at the Children's Hospital Colorado SOAR Clinic, a DSD multidisciplinary care clinic (MDC), revealed that patients and families desire increased peer connection and support.

Objective: This project aims to create a patient support resource through a collaborative art piece created in clinic-hosted patient support groups.

Methods: This project, entitled "Together We SOAR," is a collaborative art project with patients and families seen in the Children's Hospital Colorado SOAR Clinic from April to October 2025. Patients were invited to participate in informal support groups, and participants received art materials, a blank puzzle piece, and reflective worksheets designed to guide conversation about individualism and community. Topics of discussion included "Strong," "Brave," "Friend," "Kind," "Curious," and "Unique," and patients had the opportunity to decorate a puzzle piece based on each topic. The decorated puzzle pieces will be compiled into a completed puzzle to be displayed in a patient-facing psychology workspace and photographed for distribution to patients.

Discussion: Over 30 individuals and families participated in this creative project, and 28 individual puzzle pieces have been contributed to the final art piece. By restarting clinic-hosted support groups, patients and families have the opportunity to connect and share experiences, supporting the psychosocial wellbeing of individuals affected by DSD. This project is a celebration of individuality and creativity and symbolizes the value of community for individuals with DSD.

Conclusion: Support resources for patients and families with DSD are often limited, and patients and families report a desire for increased connection with peers with DSD. Through this creative project, we aimed to foster patient individualism and a sense of community amongst patients with DSD. This project serves as a continued resource for patients and families within the SOAR Clinic. Further research on patient support groups and support resources is needed to promote psychosocial well-being for patients and families with DSD.