

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



Anschutz



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## Introduction

- Differences of sex development (DSD) are conditions where chromosomal, gonadal, and anatomic sex differ from the male-female binary, and management involves specialized care tailored to one's hormonal, surgical, and psychological needs<sup>1,2</sup>
- Individuals with DSD have historically faced stigmatization and prejudice, including lack of disclosure of diagnosis, genital normalization, and gonadectomy<sup>3,4</sup>
- Pediatric patients with DSD often benefit from education and psychosocial support related to their DSD<sup>5,6</sup>
- The Children's Hospital Colorado (CHCO) SOAR Clinic is a pediatric DSD multidisciplinary clinic
  - Includes endocrinology, urology, gynecology, psychology, genetics, social work, nursing, and volunteers
- Conducted QI project of patients and families from Oct 2021 to Mar 2022 evaluating SOAR Clinic support resources<sup>7</sup>
  - n=30/99 (30% response rate)
  - 62% of respondents used clinic volunteers and 32% used clinic-hosted support groups, with a majority rating these resources as moderately or very useful
  - Participants reported increased desire for connection amongst patients and families

## Aims

- Offer individualized psychosocial support for individuals and families seen in the SOAR Clinic through clinic-hosted informal support groups
- Collaborate with SOAR Psychologists and Patient Advocate Volunteers to restart in-person clinic-hosted informal support groups
- Celebrate individuality and community in the SOAR Clinic through a patient-centered art project

## Methodology

- SOAR QI project approved by CHCO ORRQIRP – QI #2007-12
- Medium: collaborative puzzle project based on mentor experiences, available time, resources, and support.
- Target populations:
  - Primary – pediatric patients in SOAR Clinic
  - Secondary – families and caregivers of SOAR Clinic patients
- Support groups:
  - Held in CHCO Family Meeting rooms (see **Figure 2**) from April 2025 to October 2025 during monthly SOAR Clinic days
  - Led by SOAR Clinic psychologists and volunteers
- Resources created and utilized:
  - Six worksheets (see **Figure 1**) covering the topics of Brave, Strong, Unique, Friend, Kind, and Curious
  - Flyer provided to patients during rooming
  - Patient and parental consents to participate
  - Blank puzzle pieces, markers, pens, and pencils
- Destination of final piece to be determined by CHCO art review committee, but plan to include in SOAR Clinic resource binder

## Outcomes

- Between **April 2025 and October 2025**,
  - A total of seven informal clinic-hosted support group sessions were held
  - Participation of over 30 SOAR Clinic patients and families, with total of 28 decorated puzzle pieces contributed to final piece (see **Figure 3**)
- Informal feedback shared by participants included:
  - Parents and caregivers enjoying connecting with volunteers and other families informally
  - Participants enjoying seeing their artwork included in the final piece and getting to have snacks during clinic
  - Time constraints and individual interest in art were often barriers to participation

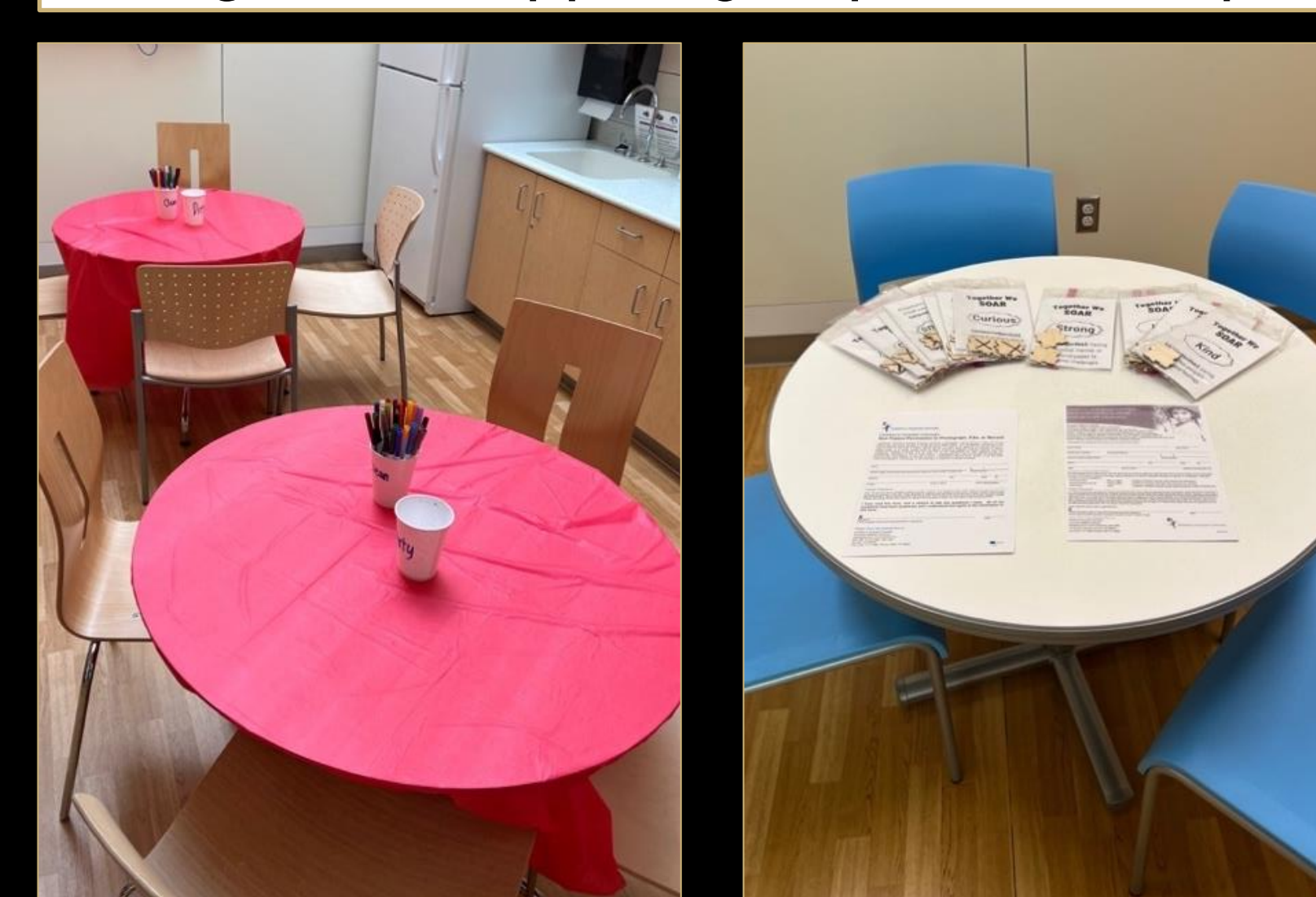
## Discussion

- Informal support group format supported patient autonomy and comfort
  - Participants could choose location and manner of participation
  - Contribution to community puzzle piece was encouraged but not required
  - SOAR psychologists and volunteers had opportunities to adapt activity to individual needs
- Individualism was highlighted through topic selection, conversations, and artistic approach
- Nature of puzzle symbolizes the importance of community for individuals with DSD
  - Unfinished edges of puzzle offers infinite opportunities for growth
  - Blank puzzle pieces offer patient opportunity to express themselves and lived experiences
- For new patients and those not yet ready to meet others with DSD, inclusion of final art piece in SOAR resource binder is a physical reminder of an ever-expanding community of support

## Figures

**Figure 1.** Support group worksheet example

**Figure 2.** Support group room setup



**Figure 3.** "Together We SOAR" puzzle



## Limitations and Barriers

- Limitations
  - Patients and families have heterogeneous psychosocial support needs, and not all needs were addressed by project
  - Worksheets in English limited participation and peer-to-peer engagement for non-English speaking patients
  - Project design did not include formal data collection and project evaluation → informal feedback cannot be generalized to understand impact of clinic support groups
- Barriers
  - Difficulty creating developmentally-appropriate support worksheets → simplification of worksheets
  - Availability of volunteers and SOAR psychologists during clinic visits to facilitate support groups
  - Staffing changes and required review by CHCO art committee → destination of final piece is still unknown

## Future Applications

- Evaluating impact of participating in creative projects and clinic-hosted support groups for individuals with DSD could guide future support projects
- Understanding how to individualize psychosocial support to meet heterogeneous needs of patients and families with DSD

## Conclusions

- Facilitation of creative activity during informal support groups facilitated community amongst participants and families, support the psychosocial wellbeing of individuals with DSD
- Restarting clinic-hosted support groups with a creative project offers new opportunity to support SOAR patients and families
- Collaborative art piece showcases patient individuality and represents a welcoming community of support for individuals with DSD that will always have space for growth
- This project showcases an opportunity for future projects involving non-clinical psychosocial support for patients and families with DSD and opportunities for future research

## Disclosures & Acknowledgements

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