

## BACKGROUND

- The COVID-19 pandemic caused an international shift towards telemedicine and virtual interactions for support groups.
- The absence of in-person interactions highlighted shortcomings of pre-existing support resources and infrastructure for medical support groups.
- LGBTQIA+ adolescents faced significant stress from the COVID-19-related social distancing compounded with personal and structural difficulties regarding their identities.<sup>1</sup>
- Differences of Sex Development (DSD) are a group of conditions in which the individual's sexual characteristics do not fall within the typical binary of male or female.<sup>2</sup>
- Individuals with DSDs may also identify as intersex, which is represented by the "I" in LGBTQIA+

## OBJECTIVE

This quality improvement project aimed to identify strengths and areas for improvement in the support resources offered by the Children's Hospital Colorado SOAR Clinic, a pediatric DSD multidisciplinary clinic (MDC).

## METHODS

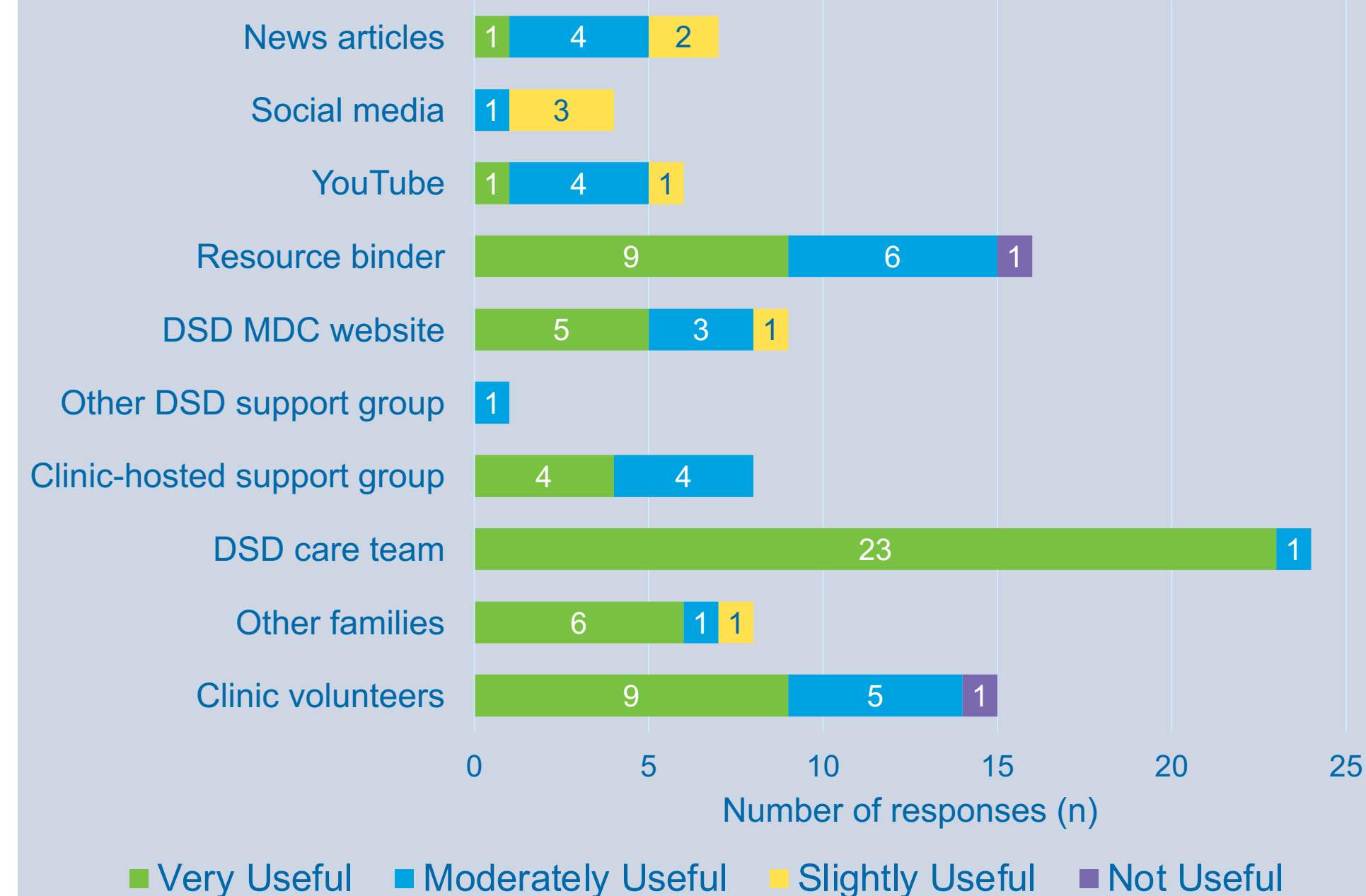
- 99 patients and families in the Children's Hospital Colorado SOAR Clinic were invited to complete an online survey between October 2021 and March 2022
- Participants received surveys via an electronic medical record message or during an in-person clinic visit
- Survey included
  - 9 demographics questions
  - Questions about 12 available support resources
  - Experiences with and perceived usefulness of resources
  - Free-text option
- Of 30 total responses received (30% response rate), 21 were complete and 9 were incomplete

## RESULTS

Table 1. Demographics	n	(%)
Complete Responses	21	70
<b>Patient Age</b>		
0-6 months	3	14.3
6-12 months	4	19.1
1-5 years	1	4.8
6-10 years	5	23.8
11-15 years	4	19.1
16-20 years	2	9.5
Over 20 years	2	9.5
<b>Who answered survey</b>		
Patient	3	10.0
Parent/Guardian	17	85.0
Filled out together	1	5.0
<b>Race*</b>		
White	14	63.6
Non-white	8	36.4
<b>Ethnicity</b>		
Hispanic	3	14.4
<b>Patient Gender Identity</b>		
Female	12	57.1
Male	8	38.1
Something else not listed here	1	4.8
<b>Patient DSD Diagnosis*</b>		
46,XX DSD**	8	32.0
46,XY DSD***	8	32.0
Atypical development of the external genitalia	4	16.0
Do not have specific diagnosis yet	1	4.0
Something else not listed here	4	16.0
<b>Patient Age of Diagnosis</b>		
Prenatal diagnosis	2	9.5
0-6 months	9	42.9
6-12 months	3	14.3
1-5 years	3	14.3
6-10 years	1	4.8
11-15 years	1	4.8
16-20 years	2	9.5
<b>Primary Language</b>		
English	18	85.7
Spanish	1	4.8
Amharic	2	9.5
<b>Parent/Guardian Highest Level of Education</b>		
Less than high school diploma	1	4.76
High school diploma or GED	3	14.3
Some college, but no degree	3	14.3
Associate Degree	1	4.8
Bachelor's Degree	2	9.5
Master's Degree	5	23.8
Professional Degree	3	14.3
Doctorate	3	14.3
<b># of Lifetime SOAR Visits</b>		
1-3 visits	13	61.9
4-6 visits	7	33.3
7+ visits	1	4.5

\*multiple select allowed  
\*\*46,XX DSD includes Congenital Adrenal Hyperplasia, Mayer-Rokitansky-Kuster-Hauser Syndrome  
\*\*\*46,XY DSD includes androgen insensitivity syndrome, disorders of testosterone synthesis

**Figure 1. Utilization and usefulness of support resources**



**Figure 2. Themes from free-text responses regarding DSD MDC support resources**

### What aspects of the resources could be improved?

- Information on supporting siblings of patients
- Organizing resources by ages or interests
- Intentional engagement with adult volunteers

### What resources would you like that are not currently offered?

- Opportunities for kids with DSDs to talk to each other
- Access to diagnosis-specific counseling resources
- Videos of adult volunteers with DSDs sharing their experiences
- Private social media communities

## CONCLUSIONS

- Comprehensive and thoughtful support resources for patients with DSDs and their families are important parts of multidisciplinary care.
- Valued and utilized resources include: volunteer communication, family-to-family communication, communication between clinic team members, clinic website, clinic resource binder.
- Areas of improvement include: clinic-specific support groups, YouTube or other videos, social media resources.

## IMPLICATIONS AND FUTURE DIRECTIONS

- These data will inform the creation of new resources and augmentation of existing resources.
- We need more information about how to support families from varied cultural and religious backgrounds, as well as those whose primary language is not English.
- Follow-up survey to SOAR will be performed to assess the impact of updated resources.

## REFERENCES

- <sup>1</sup>Fish, J. N., McInroy, L. B., Pacey, M. S., Williams, N. D., Henderson, S., Levine, D. S., & Edsall, R. N. (2020, 2020/09/01/). "I'm Kinda Stuck at Home With Unsupportive Parents Right Now": LGBTQ Youths' Experiences With COVID-19 and the Importance of Online Support. *Journal of Adolescent Health, 67*(3), 450-452. <https://doi.org/10.1016/j.jadohealth.2020.06.002>
- <sup>2</sup>Cools, M., Nordenström, A., Robeva, R., Hall, J., Westerveld, P., Flück, C., Köhler, B., Berra, M., Springer, A., Schweizer, K., & Pasterski, V. (2018, Jul). Caring for individuals with a difference of sex development (DSD): a Consensus Statement. *Nat Rev Endocrinol, 14*(7), 415-429. <https://doi.org/10.1038/s41574-018-0010-8>