

# Helping Caregivers of Children with Differences/Disorders of Sex Development Decide on Treatment

## Principal investigator

David E. Sandberg, PhD

## Organization

University of Michigan at Ann Arbor

## What was the research about?

Differences/disorders of sex development, or DSD, occur when a child's reproductive organs don't develop as expected. Parents of a child born with DSD may need to make difficult decisions for their child. These decisions are hard because there is no one right or wrong answer for everyone. Also, some decisions, like surgery, are permanent and can affect a child's mental and physical health later in life.

In this study, the research team wanted to help parents and healthcare providers, such as doctors, nurses, and social workers, make hard decisions for children with DSD. The team designed a decision support tool, or DST, for this purpose and then looked at how parents and providers used the DST.

## What were the results?

In the first part of the study, the research team talked with parents, providers, and patient advocates to learn more about what decisions they had to make for children with DSD and what was helpful to them. Based on the discussions, they created a web-based DST that included:

- Information about DSD and its treatments
- Questions to learn more about parents' values and preferences for specific decisions, like what gender to rear a child
- Questions to find out what support parents have for making decisions

- Personal stories from parents who have a child with DSD

When they looked at how the DST was used, researchers did not see a big difference in discussions during clinic visits between parents who had access to the DST and those who did not. Parents often didn't think there were decisions they needed to make about their children's care. Of the parents who reviewed the DST, 15 percent reviewed all the content, and 46 percent reviewed parts of the DST. Few providers talked about the DST at clinic visits. Many providers thought they were already doing well at helping parents participate in decisions about their children's care.

In the third part of the study, parents, providers, and patient advocates shared different ideas about how to improve the DST, including:

- Revise the DST until it works well for most parents
- Clarify for parents what decisions about care happen and when
- Clarify what else providers can do to help parents participate in decisions
- Find ways to fit the use of DST into regular clinic visits

---

## Who was in the study?

There were three parts to the study. The first part, developing the DST, included 15 parents of children with DSD, 23 primary care and DSD-specialist providers, and 11 patient advocates. The second part, testing the DST, included 63 parents and their children's providers. The third part, getting feedback on the DST, included 10 parents, 25 providers, and 4 patient advocates.

## What did the research team do?

First, the research team talked with parents, providers, and patient advocates to learn what decisions about care for children with DSD are hard to make. The team also wanted to learn what information was most helpful when making a decision. Using this input, the team created the web-based DST.

Next, the research team wanted to know how parents and providers used the DST. The team listened to recordings of discussions between parents and DSD providers during clinic visits. About half of the discussions were with parents who didn't have access to the DST.

Finally, the research team asked parents, providers, and patient advocates for feedback on the DST and how to improve it.

## What were the limits of the study?

Although providers helped create the DST, the research team didn't train providers on how to use it during visits with parents. This lack of training may have affected how much providers used the DST with parents.

Future research could look at how to ensure that the DST meets the needs of parents and providers. Researchers could also study how best to help parents and providers use the DST.

## How can people use the results?

Researchers can use the results to better understand how to help parents and providers use the DST.

*To learn more about this project, visit [www.pcori.org/Sandberg111](http://www.pcori.org/Sandberg111).*