



Rationale for promoting information-sharing (IS)

- Some caregivers of children with DSD experience negative mental health outcomes, including increased parenting stress, decreased coping, perceived stigma, isolation, and posttraumatic stress symptoms.^{1,2,3,4}
- Among caregivers, social support is an important protective factor against negative mental health outcomes.^{5,6}
- Having a child with a DSD can change the way caregivers typically access their support networks due to hesitancy or perceived inability to share information with others about their child's diagnosis.^{1,5}
- Reasons for concealing information from others include a desire to maintain a child's future privacy, perceived stigma, and discomfort with / perceived inability to accurately describe the condition and associated features.^{5,7}
- Unfortunately, in addition to preventing caregivers from accessing their support networks, maintaining this privacy can cause even more stress.⁷
- DSD teams are well positioned to help caregivers share information with important people in their social networks by improving caregiver understanding of and confidence to communicate health information.^{8,9,10}

Clinical Considerations

- Adopt a **Motivational Interviewing** approach: ask permission to discuss IS; help family self-identify IS benefits, provide support rather than argue a position; recognize there will be different stages in IS readiness)¹¹
- Although IS can provide significant benefit (see Rationale), there can also be perceived and actual costs to the family for sharing their child's medical condition; for example, stigma³ and loss of privacy¹²
- **Culture** can impact caregivers' willingness to share information related to factors including:
 - Cultural norms related to self-disclosure¹³
 - Cultural norms and religious beliefs about sex/gender, and negative implications of infertility in some cultures (particularly for women)^{14,15}
 - Differences from societal norms can cause distress and fear of rejection, impacting IS
- Helpful sources of information from the DSD-TRN Assessment Battery:
 - **Knowledge of Condition Form:** Having less understanding about the DSD may decrease IS
 - **Supports and Resources Assessment:** Explore information-sharing decisions already made
 - **Psychosocial Assessment Tool:** Knowing who provides resources can help identify supportive others
 - **Patient Health Questionnaire-4:** Depression and anxiety can impact willingness to share/seek support
- Common concerns and responses:
 - *"Everyone doesn't need to know"* – There can be a black and white perception of IS (no one knows vs everyone knows). Suggest identifying a few close people in their life with whom they feel comfortable.
 - *"This information is private"* – Caregivers may struggle with *what* to share (too much vs just enough). Reflect with caregivers on what is essential to share to optimize support from carefully selected people. Help them develop a story that allows them to comfortably share information with chosen individuals – modeling a matter-of-fact approach to IS may positively impact child's self-acceptance

Potential Intervention Steps

- **Assess caregiver's understanding of their child's condition:**
 - **Ask/say:** "What do you know so far about your child's diagnosis?"
 - "What questions do you still have about your child's diagnosis? What parts remain confusing to you?"
 - "Let's put all these points together, so that beyond having a thorough explanation for yourself, you might also have a way to describe the situation to others?"
 - **Offer:**
 - Normalize that it can be difficult to understand complicated medical information, and repeated reviewing of information is typical and important.
 - Provide psychoeducation about DSD diagnosis to educate and clarify. Involve other disciplines as needed. Use "Teach back" technique to determine understanding.
 - Provide written educational materials that use plain language.
 - Resources (e.g., DSD Families, Accord Alliance, How Sex Development Works websites)
- **Explore parent's uncomfortable feelings about their child's diagnosis & explain rationale for IS:**
 - **Ask:** "What are you finding difficult in thinking about your child and their diagnosis?" and/or
 - "What kinds of thoughts or feelings come up when we talk about your child's diagnosis?"
 - "Many caregivers experience conflicting thoughts and feelings, is this true for you?"
 - "Many caregivers would like to tell the people important to them about what is going on, but don't know how to say it, or worry about how others might react. Is this true for you?"



- **Offer:**
 - Provide support and management strategies around difficult emotional experiences.
 - Normalize challenges that occur within any parenting experience (i.e., not just parenting a child with a DSD), such as fear that child will be rejected/isolated/teased or feel bad about themselves.
 - “Having difficult or conflicting thoughts and feelings related to your child’s diagnosis is an experience many parents have when given a new diagnosis.”
 - “Some things known to be helpful include having a good understanding of what the diagnosis means, and having trusted people in your life whom you can rely on for social and emotional support.”
 - “Some parents find it helpful to talk with other families who have experienced similar situations – would you like to be connected with a support group or another family with a child with [diagnosis]?”
- **Help caregivers develop/refine a diagnosis/condition “story” for others:**
 - **Ask:** “Who have you told so far? “What did you share?” “How did that go?”
 - “What would you change about how you shared the information?”
 - “Can we work together to develop a “story” about the diagnosis that you feel comfortable with sharing?”
 - **Offer:**
 - Story should be truthful, but does not need to be “technically accurate” or include *all* information
 - Phrases/metaphors/talking points that have worked for other families (in specific context):
 - “The doctors wanted to do some follow-up tests from [child’s] surgery. We don’t have any clear updates yet, but have to go back to the hospital for another visit next week. What we do know is that [child] is healthy.”
 - “When [child] was in utero, his/her reproductive organs didn’t fully develop.”
 - Help caregivers practice their “story”. Model conversations. “Try language on for size”
- **Help caregivers ID important people in their lives to share information with for a particular purpose:**
 - **Ask:** “Who have you told so far, what did you say, and what was the response?” and/or
 - “If you knew there would be no negative consequences for you / your child
 - who would you want to tell & why?” What would you say?”
 - “What are you worried will happen if you share information (either broadly, or with a specific person)? How realistic is that outcome? Are there some ways to reduce the risk, either by changing what is shared, or how it is shared?”
 - “What do you think will be the most difficult part of sharing information?” (Conversation starter? How much to say? What to say? How to end?)
 - **Offer:**
 - Story might be different depending on who it is being shared with (e.g., babysitter vs grandparent)
 - Help caregivers practice sharing their story, or parts of their story
 - Strategies for changing the subject: [Share “story”] *then* “And how is your child doing?” Or “But the most important thing is that [child] is healthy. How is your work?”
 - Strategies for setting boundaries:
 - “That is a good question, I am actually not sure.”
 - “I appreciate that you have questions - that is what we are sharing with people right now.”
 - “I’m not comfortable sharing that information (right now).”
 - To open up IS possibilities, explore questions below.

Exploring Caregiver Social Support Networks	
Ask: Can you think of a person who...	Then ask: What is/are the.....
Confides in you	Name of this person?
You seek support from	Potential benefits of telling this person?
Has “your back” no matter what	Potential costs of telling this person?
Is very involved with your family	What information would be the best to share?
Would want to help	Tell “all at once” or “test the waters”?
Provides care to your child	What do you predict their reaction to be?
Is a close family member you trust	How confident are you in this prediction? 0 (not at all) to 10 (very)



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