

Information Sharing in Differences of Sex Development: The Creation of a Caregiver-Support Tool

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Abstract

Introduction: Social support can be a protective factor against the negative mental health outcomes experienced by some parents and caregivers of children with differences of sex development (DSD). However, established social support networks can be difficult to access due to caregiver hesitancy to share information with others about their child's diagnosis. Healthcare providers in the field of DSD, and particularly behavioral health providers, are well positioned to help caregivers share information with the important people in their lives in order to access needed social support. This article summarizes the development of a clinical tool to help clinicians facilitate discussions regarding information sharing with caregivers of children with DSD. **Method:** Members of the psychosocial workgroup for the DSD - Translational Research Network completed a survey about their experiences facilitating information sharing discussions with caregivers of children with DSD and other health populations. The results of this survey were used to develop a clinical tool using ongoing iterative feedback from workgroup members, based on principles of user-centered design and quality improvement. **Results:** Workgroup members consider information sharing an important aspect of working with caregivers of children with DSD. Additional resources and tools were identified as potentially helpful to these discussions. **Discussion:** The DSD Sharing Health Information Powerfully – Team Version (SHIP-T) is a resource tool for DSD healthcare team members to utilize in hospital and ambulatory settings to help caregivers of children with DSD share information with their social support networks. The final SHIP-T is included in this article.

Keywords: Differences of sex development, intersex, parents, social support, clinical resource

Public Significance Statement: Medical professionals, especially behavioral health providers, working on teams providing care for children with differences of sex development can help parents to engage their social networks by sharing relevant health information with others. The SHIP-T was created as a clinician tool to facilitate these discussions with parents.

Information Sharing in Differences of Sex Development: Creating a Caregiver-Support Tool

Differences of sex development (DSD)¹ represent a heterogeneous group of congenital conditions in which development of sex chromosomes, external genitalia, or internal sex organs is atypical (Lee et al., 2006). Some parents and caregivers of children with DSD experience negative mental health outcomes, including increased parenting stress, decreased coping, perceived stigma, isolation, and posttraumatic stress symptoms (Delozier et al., 2019; Duguid et al., 2007; Pasterski et al., 2014; Rolston et al., 2015; Wisniewski & Sandberg, 2015). Although social support is one of the most robust protective factors against perceived stigma and negative mental health outcomes generally (Kondrat et al., 2018), caregiver hesitancy or perceived inability to share information about their child's DSD diagnosis with others can change the way caregivers typically access their support networks (Chivers et al., 2017; Duguid et al., 2007).

Information sharing comes in two forms: (1) sharing of information between providers, caregivers, and the patient, and (2) patients and caregivers sharing information with other important people in their lives (Sandberg et al., 2012). This paper focuses on the latter, with an emphasis on information sharing by parents and caregivers. Although there is considerable variability, most caregivers share information about their child's diagnosis with their partner and their own parents, while fewer share this information with their other children, close friends, and other relatives (Sandberg et al., 2017).

Broadly, whether someone chooses to share information regarding a concealable identity depends on a variety of factors, such as the content of the information, how well the individual understands the information, confidence in their ability to effectively communicate the information,

¹ The term disorder of sex development was suggested by the Consensus Statement on Management of Intersex Disorders (Lee et al., 2006). However, the word "disorder" is viewed by many as stigmatizing and other terms are preferred by some (e.g., Intersex). We chose to refer to these conditions as differences of sex development to recognize the controversy over labels and to promote person first language.

relationship quality, and anticipated response from the other person (Greene et al., 2012). In DSD specifically, caregivers choose to conceal information for similar reasons, including a desire to maintain a child's future privacy, perceived stigma, and discomfort around or perceived lack of ability to accurately describe the condition and associated features (Chivers et al., 2017; Crissmnan et al., 2011). Efficacy in describing the information is complicated by DSD terminology, which is neither consistently used nor universally accepted (Lundberg et al., 2018; Miller et al., 2018). Unfortunately, in addition to preventing caregivers from fully accessing their support networks, the very act of maintaining this privacy can increase stress (Crissmnan et al., 2011).

Healthcare providers are well positioned to help caregivers share information with important people in their social networks. In particular, behavioral health providers (e.g., psychologists, social workers, psychiatric nurse practitioners) can support caregivers by improving caregiver understanding of diagnosis and confidence in their ability to communicate the information, exploring and helping regulate difficult emotions that arise in the context of important conversations, and identifying key people within social networks most likely to provide needed support (Ernst et al., 2016; Greene et al., 2012; Sandberg et al., 2012). The Disorders/Differences of Sex Development – Translational Research Network (DSD-TRN) is a United States-based collaborative network of clinicians and researchers invested in improving healthcare outcomes for persons with DSD. The DSD-TRN Psychosocial Workgroup (PSW) is a subgroup of the larger DSD-TRN that includes psychologists, social workers, researchers, and patient advocates interested in the psychosocial aspects of DSD. The PSW set as a priority the evaluation and facilitation of shared practices for helping parents and caregivers of children with DSD access their support networks through information sharing.

Purpose

The objectives of this article are to (1) describe the results of a clinician needs assessment regarding information sharing among PSW members, and (2) summarize the subsequent development

of a tool to help clinicians facilitate discussions regarding information sharing with caregivers of children with DSD. Using elements of User-Centered Design (Johnson et al., 2005) and Quality Improvement (Taylor et al., 2014), we implemented an iterative process of assessing clinician needs and subsequent feedback regarding this clinical resource tool.

Method and Results

PSW members were asked to complete a needs assessment survey examining clinical experiences with patients and families discussing the topic of sharing information about a DSD condition with family and close others. Results were reviewed with PSW members to clarify the needs of behavioral health providers to facilitate the creation of a clinician tool. The clinician tool was created and iteratively reviewed with the PSW for feedback and refinement.

Needs Assessment Survey and Results

The authors (De-identified) created a needs assessment to inform the development of a tool for PSW providers to use when discussing the importance of sharing information with caregivers. When completing the needs assessment survey, providers were asked to think of their clinical practice with patients with a DSD and their caregivers. See Table 1 for quantitative survey questions and response rates and Table 2 for qualitative survey questions and response themes. Nineteen members of the PSW completed the survey (70% completion rate). Quantitative questions asked members how important they think information sharing conversations are (5-point scale from “Not at all important” to “Extremely important”) and how comfortable they are facilitating these conversations (6-point scale from “extremely uncomfortable” to “extremely comfortable”). Members thought it was extremely to very important to have conversations with caregivers regarding sharing information about their child’s condition with family/close others (average of 4.4 out of 5), and they were moderately to slightly comfortable facilitating these discussions (average of 4.4 out of 6).

One open-ended question asked members how often information sharing is a specific topic discussed with new patients, and most members indicated that it is often or always the case. An inductive, data-driven approach was taken to analyze the answers to remaining open-ended questions. A total of 13, 18, and 17 people responded to questions about what might increase provider comfort with information sharing, patient-related barriers, and provider-related barriers, respectively. Item responses were categorized into themes by one author (de-identified) and verified by a second author (de-identified). Themes were later reviewed by all authors for clarity and consistency.

The most common themes for increasing provider comfort level in discussing information sharing included more experience/education and having a written resource, followed by more research, peer support for caregivers, and more time in clinic. Regarding caregivers sharing information, the most commonly identified barrier was perceived stigma, followed by a limited understanding about how to share with others and concerns about the child's privacy. The most commonly identified provider barriers to facilitating these discussions were a lack of education/training, caregivers not wanting to share, and other family factors.

Creation of the SHIP-T

The results of the needs assessment survey suggested that providers who are working on DSD teams may benefit from resource tools to help facilitate discussions about social support and information sharing. Two of the authors (De-identified) presented the results of the survey and a proposal to create specific resource tools to the PSW and received positive feedback. A team (De-identified) was formed to create information sharing tools. There are several aspects of information sharing, and we elected to first focus on caregivers sharing information with their own support networks. This first clinical tool was subsequently named the Sharing Health Information Powerfully – Team Version (SHIP-T). Based on principles of user-centered design and quality improvement, we

implemented an iterative process of drafting, soliciting feedback, and revising the SHIP-T to best serve the expressed needs of the group.

Our goals for the tool were to (1) increase frequency of health care provider information-sharing conversations with caregivers of children with a DSD and (2) improve the quality of those conversations by incorporating best practice components of disclosure interventions. Therefore, we designed the tool keeping in mind the literatures on both health care provider behavior change (Gupta et al., 2021) and models for health information disclosure (Greene et al., 2012; Rochat et al., 2013; Schulte et al., 2021). Both areas of literature highlight the importance of providing tailored, contextually relevant information as well as behavioral rehearsal to increase self-efficacy. In addition, research shows that closeness of the recipient of the disclosure impacts willingness to share information (Greene et al., 2012).

Thus, the first version of the tool included the following elements: (1) an evidence-based rationale for facilitating information sharing conversations with caregivers along with references (to increase health care providers' confidence in the merits of information sharing as well as having resources to share with caregivers), (2) common clinical considerations and potential behavioral communication interventions, and (3) a series of prompts to help caregivers explore their social support networks for the purpose of identifying potential recipients of shared information. Motivational Interviewing (MI) was highlighted on the tool as a framework for discussions with caregivers because MI has a strong evidence-base for promoting behavior change and dovetails with a tailored, person-centered intervention approach (Miller & Rollnick, 1991). PSW members reviewed this draft of the SHIP-T and provided feedback on the format and content.

We revised the tool, then asked PSW clinicians to use the tool in their DSD clinics and subsequently surveyed them on the utility and effectiveness of the tool in practice. Three workgroup members provided written feedback on the survey, one individual with a DSD provided additional written feedback, and one additional clinician provided oral feedback. The final version of the SHIP-T can

be found in the accompanying online supplemental materials. The feedback and survey results regarding the SHIP-T will also be used to inform a companion handout that can be given to caregivers when having these discussions. See Figure 1 for a diagram of this process of tool design and iterative feedback.

Discussion

The results of a needs assessment among members of the DSD-TRN PSW suggest that providers find it very important to help caregivers share information with others, but barriers exist to optimizing those discussions. The aims of this paper were to present the findings of the needs assessment, along with the subsequent development of the SHIP-T: a clinician tool designed to facilitate information sharing. Needs assessments have been used by multi-disciplinary, pediatric teams to improve communication between providers, patients, and families (e.g., Schneider et al., 2016) and inform clinician resource development (e.g., Painter et al., 2018). The results of the current needs assessment similarly suggested that additional education and resources might help clinicians facilitate discussions about information sharing with caregivers.

The SHIP-T clinician tool was developed in response to the identified needs of behavioral health providers working on DSD teams. The tool highlights what is known from the literature on information-sharing more broadly, while also highlighting important distinctions specific to DSD, such as concerns related to stigma (Greene et al., 2012; Kondrat et al., 2018). The importance of cultural norms related to self-disclosure is referenced, as well as the fact that cultural norms regarding gender, sex and other DSD concerns such as infertility are important to consider (Ediati et al., 2016; Weidler & Peterson, 2019; Yuki & Schug, 2012). The tool capitalizes on evidence-based approaches such as Motivational Interviewing (Miller & Rollnick, 1991) to promote caregiver accessing social support, and behavioral rehearsal strategies to increase caregiver confidence in information-sharing (Rochat et al., 2013; Schulte et al., 2021). The tool also promotes use of the standardized assessment protocol used within the DSD-TRN (Sandberg et al., 2017) to facilitate the discussion of information-sharing with caregivers. An example of

a potential intervention step includes questions for exploring a caregiver's uncomfortable feelings about their child's diagnosis. To explore social support networks, prompts ask "can you think of a person who..." with several potential options such as "confides in you" and "is very involved with your family." Once a person is identified, follow-up questions include "What are the potential benefits/costs of telling this person?" and "What do you predict their reaction to be?"

We believe this tool addresses several identified barriers from the needs assessment, such as caregivers lacking understanding of how to share with others and providers needing more education and training on how to facilitate discussions. When used clinically, this tool may further address barriers such as caregiver perceived stigma and concerns about child privacy.

Limitations and Future Directions

Some barriers identified during the initial needs assessment may not be addressed by the SHIP-T. For example, having a limited amount of time in clinic to have these discussions with families and the ongoing diagnostic uncertainty that often accompanies some DSD diagnoses.

This article presents the creation of the SHIP-T based on principles of user-centered design and quality improvement, including clinician self-reported practices, clinical needs, and perceptions of the tool. However, there is no empirical data to date on the utility of the SHIP-T, as measured by objective outcomes such as caregiver-reported effectiveness, social support, and mental health. One future direction is to empirically study the utility of the SHIP-T as a clinical tool. Caregivers were not involved in this initial development of the SHIP-T. Caregiver perspectives and feedback may be useful in the future to further refine this tool, especially in our next steps of converting the tool into a supplemental caregiver worksheet.

We believe the SHIP-T can help behavioral health providers and other clinicians facilitate discussions with caregivers regarding sharing information about their child's diagnosis with their own support network. This is only one aspect of information sharing that is relevant to the care of children

with DSD and their families. Another future direction for the DSD-TRN information sharing sub-workgroup include (1) creating a companion handout to the SHIP-T that can be given to caregivers, and (2) creating parallel tools related to (a) caregivers sharing information with their children, and (b) children sharing information with their own support networks. Regarding caregivers sharing information with their child, one study found that 90% of the caregivers surveyed reported never receiving guidance in this area, and 43% reported that they desired this type of support, highlighting the need for ongoing resource development (Blankstein et al., 2022).

Conclusion

The SHIP-T is a clinical tool for DSD healthcare team members to utilize in hospital and ambulatory settings to help caregivers of children with DSD share information with their social support networks. By making the SHIP-T freely available, we hope behavioral health providers and other clinicians working with DSD will feel empowered to facilitate these important discussions. A user-centered design approach can be used to create clinical tools that best serve the needs of the clinicians who use them.

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Table 1. Quantitative Results of Needs Assessment Survey (N = 19)			
Quantitative Questions	Response Options	Count	Percent
How comfortable are you in facilitating discussions about "information sharing" with parents of a newborn/young child with a new DSD diagnosis?	Extremely comfortable	4	21.1
	Moderately comfortable	8	42.1
	Slightly comfortable	1	5.3
	Neither comfortable nor uncomfortable	3	15.8
	Slightly uncomfortable	1	5.3
	Extremely uncomfortable	1	5.3
	No answer	1	5.3
How important do you think it is for providers to facilitate discussions about "information sharing" with parents of a newborn/young child with a new DSD diagnosis?	Extremely important	10	52.6
	Very important	4	21.1
	Moderately important	3	15.8
	Slightly important	0	0
	Not at all important	0	0
	No answer	2	10.5

Table 2. Qualitative Results of Needs Assessment Survey (N = 19)

Qualitative Questions	Response Themes	Quote Examples	Count
When working with parents of a newborn/young child with a new DSD diagnosis, how often is "information sharing" (i.e., sharing information with close others to allow for social support) a specific target of therapy?	Always	Every time; Universally; Always	5
	Often	Very common; Often	8
	Sometimes	Sometimes; Moderate amount	3
What would help you feel even more comfortable in facilitating discussions?	More experience/education	More experience (I'm fairly new to DSD population); More education	6
	Having a written resource	Written material to provide family; Scripted language	6
	More Research	List of citations/research on social support in DSD	2
	Peer support for parents	Peer parent groups or mentors that can share personal experiences related to information sharing	2
	More time	More time with [the] family	1
What are barriers parents experience related to sharing information with close others (family/friends)?	Perceived stigma	Shame around sex/gender issues	14
	Lacking information/understanding	Unclear diagnosis; Lack of knowledge	7
	Privacy concerns	Protecting their child's privacy	7
	Culture	Cultural and ethnic issues	2
	Denial/avoidance	Denial of diagnosis; Avoidance	2
	Interpersonal history	Strained past relationships	1
What are barrier providers experience related to facilitating parents sharing information with close others (family/friends)?	Education/training	Lack of confidence on what to say; lack of uniform understanding about the harm that can derive from secrecy	5
	Family factors	Hard to make specific recommendations without understanding more about family and community	5
	Parents do not want to share	Parents being adamant that no one will know	4
	Limited time	Inadequate time; Timing	3
	Ongoing diagnostic process	Fact that in many cases team is still gathering information, may be talking with parents about sharing incomplete information or information that may change over time	3
	Privacy/legal concerns	Fear of legal violations; Protecting the child's privacy	2

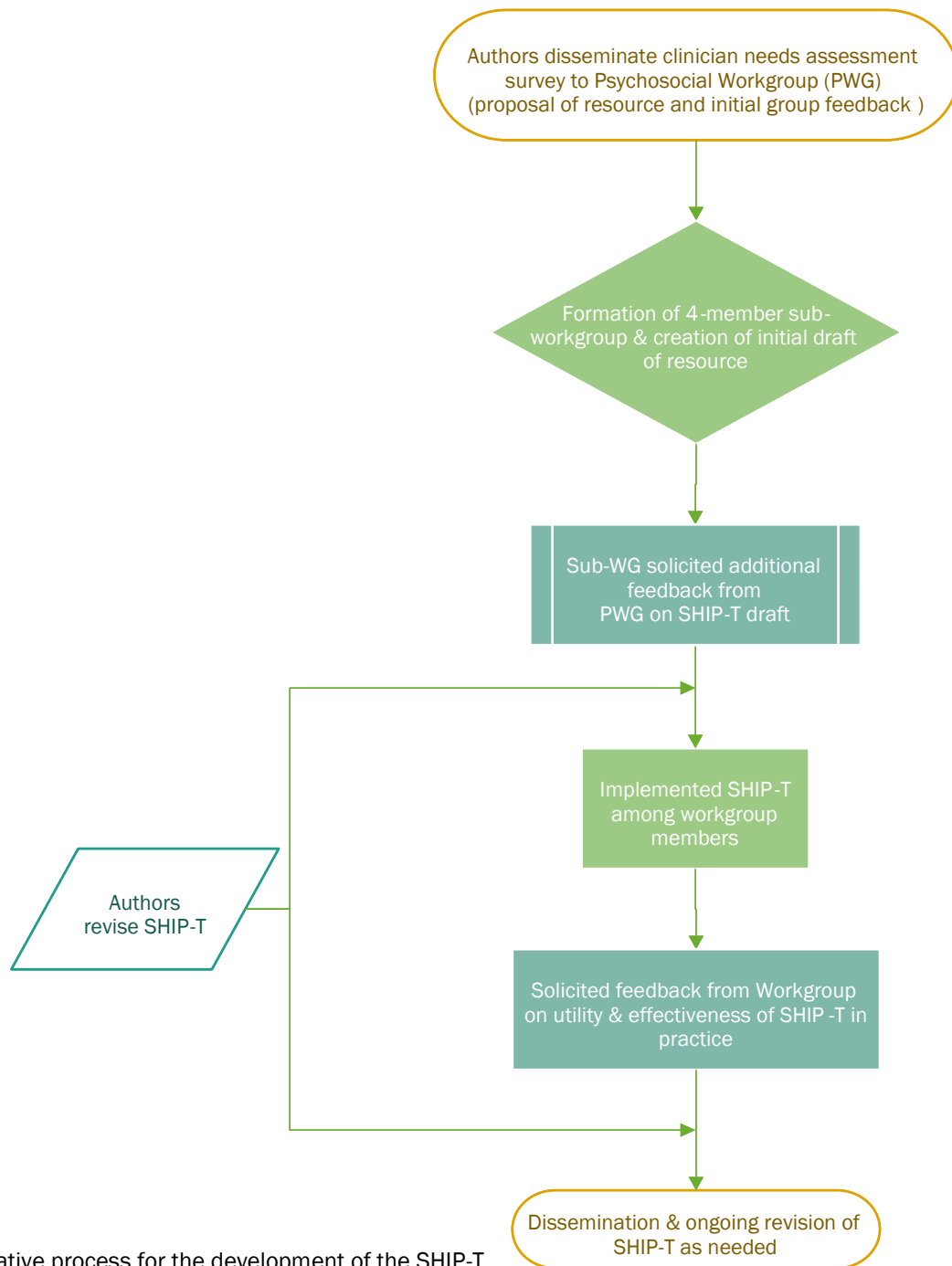


Figure 1. Iterative process for the development of the SHIP-T



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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