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Defining Successful Outcomes and Preferences for Clinical Management in Differences/Disorders of Sex Development: Protocol Overview and a Qualitative Phenomenological Study of Stakeholders' Perspectives

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Summary

Introduction.—Utilizing a qualitative phenomenological design, the *Defining Successful Outcomes and Trade-offs* study examined stakeholder perspectives regarding optimal healthcare delivery and outcomes for individuals with a difference/disorder of sex development (DSD).

Objective.—We describe study methods and provide an overview of themes and subthemes.

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Ethical Approval: This project was approved by all relevant Institutional Review Boards. We confirm all patient/personal identifiers have been removed or disguised so the patient/person(s) described are not identifiable and cannot be identified through the details of the story.

Study design.—Interviews were conducted with individuals with a DSD (n=24), parents of those with a DSD (n=19), healthcare providers (n=37), and others (n=30). Primary questions regarding clinical management of patients with DSD were: “What is a successful outcome?” and “How do you achieve it?”

Results.—Themes included: understanding of DSD diagnosis and self-efficacy in management is necessary but complex; patient and family psychological well-being; support from others versus being stigmatized; affected person experiences physical health and accepts the implications of their condition; complexities in DSD decision making, roles and expectations; and knowledgeable providers and multidisciplinary teams are essential, notwithstanding persisting barriers (See Summary Figure). Participants recognized competing values potentially forcing trade-offs in decision making.

Discussion.—Recognition of diverse and sometimes conflicting perspectives regarding optimal pathways of care and outcomes – both within and among those with DSD and their providers – promises to enhance shared decision making.

Conclusion.—Diverse perspectives and perceptions of trade-offs associated with DSD healthcare emphasize the need to tailor care for patients and families.

Keywords

disorders of sex development; differences of sex development; intersex; healthcare; outcomes; shared decision making

Introduction

A central feature of patient/family-centered care involves engagement in decision making [1]. Shared decision making (SDM) in pediatrics is a collaborative process encouraging patients, parents/caregivers, and providers to make healthcare decisions by taking patient and family values and preferences into account alongside available evidence. In differences/disorders of sex development (DSD)[1], competing values may complicate decisions; e.g., parents of infants may emphasize experienced or anticipated stigma associated with atypical genital appearance, while affected adults may prioritize genital sensitivity and sexual function [2–6]. Further, decisions are frequently associated with trade-offs where projected positive outcomes in one domain are associated with potential negative outcomes in another; e.g., decisions to perform genital surgery in infancy may address worries about outsiders recognizing the child’s physical differences, while potentially threatening adulthood genital sensitivity [7, 8].

Adding to complexities of decision making in DSD, clinical opinion regarding what constitutes optimal care is in a state of flux. Differing perspectives exist within and between healthcare providers, advocacy groups, and patient communities. Controversies are documented in medical literature [9–11], by activist groups [12, 13], human rights

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[1] The Consensus Statement on Management of Intersex Disorders [20] coined the term disorders of sex development, which some perceive as stigmatizing. Others prefer differences of sex development, intersex, or their medical diagnosis. We utilize the acronym DSD to maintain person-first language.

organizations [14, 15], and courts of law [16, 17]. The medical literature on DSD generally reflects single-specialty foci (e.g., urology, gynecology, endocrinology, psychology, bioethics) or patient lived-experience perspectives, each outlining different pathways to better outcomes. Systematic evaluation of differing valuations regarding processes and outcomes in DSD care is lacking.

The *Defining Successful Outcomes and Trade-offs* (DSOT) study seeks to identify unique and overlapping perspectives of key stakeholder groups regarding the differential valuation of clinical practices and outcomes in DSD. The study comprises three phases: (1) identifying what constitutes successful clinical management practices and outcomes through in-depth, semi-structured interviews with members of diverse stakeholder groups; (2) ascertaining trade-offs that stakeholders make (e.g., between genital appearance and sexual function) using quantitative best-worst scaling methods [18]; and (3) designing provider educational content, informed by Phases 1 and 2, that clarify and integrate medical evidence with values and preferences to facilitate SDM. This initial report aims to describe Phase 1 methods and provide an overview of how stakeholders draw from their experiences to describe optimal DSD healthcare delivery and desired short- and long-term outcomes.

Material and methods

Participants

Purposeful sampling to maximize variation in respondent values, preferences, and priorities was employed to recruit stakeholders from multiple communities: adolescents and adults with a DSD, parents of individuals with a DSD, DSD healthcare specialists, and other stakeholders. Whenever possible, stratified random sampling was used within groups to maximize perspective representation. Patient and parent participants were categorized and selected by patient age, diagnosis, gender, race, ethnicity, and region of residence. Healthcare providers were stratified by specialty, gender, and region of practice. Other stakeholder representatives were stratified by group. Given cross-national differences in the organization of healthcare systems, recruitment was limited to North America. Each recruitment site obtained institutional review board approval. Participants were offered a $20 honorarium.

Adolescents and adults (15–40 years) with DSD and parents with a DSD-affected child (newborn to 25 years), were recruited through three U.S. pediatric medical centers or through patient support and advocacy organizations (SAO), assisted by Accord Alliance, a non-profit convener of stakeholders in DSD care [19]. Participants with a diagnosis categorized as sex chromosome DSD, 46,XY DSD or 46,XX DSD were eligible. Individuals with Klinefelter or Turner syndromes were eligible only in the case of accompanying urogenital atypicality.

Healthcare providers represented “pediatric specialties ideally involved in the care of those with DSD (endocrinology, genetics, gynecology, neonatology, psychology, surgery and urology) and others (nursing, primary care and adolescent medicine, child life)” [20]. Participants were identified by reviewing professional organization roster, identifying lead authors of DSD-related publications, reviewing webpages of leading medical centers offering DSD services, and through a peer nomination/snowball sampling technique [21].

Other stakeholder groups included non-physician DSD clinical researchers, healthcare administrators, lawyers, medical ethicists, SAO leaders, and social scientists. Eligibility was restricted to those with active involvement in scholarship, advocacy, or other professional DSD-related work. Other stakeholders were identified by reviewing DSD publication authors, by reaching out to SAO leadership, through membership or participation on DSD-related committees, groups, or boards, and through peer nomination/snowball sampling. Clergy involved in hospital-based chaplaincy/pastoral care were added following review of initial interviews.

Procedures

Adopting a qualitative phenomenological study design [22], an interviewer/moderator led individual or small-group interviews. Interviews were held by phone or conducted in-person, audio-recorded, and limited to roughly one-hour. Group interviews were limited to individuals from the same stakeholder group. Study investigators and consultants created a semi-structured interview guide. Participants were asked to draw upon their experiences to define successful outcomes for those with DSD through various life stages, and to outline steps needed to achieve those outcomes (see Appendix A for interview). In addition to soliciting opinion on the two main open-ended questions (i.e., “What is a successful outcome?” and “How do we achieve it?” [labelled “outcome” and “process,” respectively, in Results and Discussion]), interviewers introduced specific topics identified in the research literature or by earlier participants. Participants completed surveys regarding sociodemographic characteristics. Interviewer training involved selected readings and completing practice interviews. To ensure adequate capture of emergent themes, audio recordings were reviewed on an ongoing basis to refine existing questions, add new ones, and remove those not generating new information. Recruitment of stakeholder group representatives continued until reaching thematic saturation – provided two to three representatives per group had participated.

Data Management and Analysis—Interviews were transcribed, de-identified, and coded to: identify common and divergent themes among participants; ascertain instances in which mutually exclusive goals or strategies were sought or recommended by participants; and inform curricula development. The research team developed an inductive codebook [23] to identify emergent themes based on study aims, the interviewer/moderator guide, and preliminary transcript readings. A member of the research team not involved in codebook creation validated the initial codebook. The codebook was iteratively modified based on ongoing coding. Overarching codes (themes) were defined and differentiated into subthemes reflecting more discrete topics. Through these data-reduction steps, descriptions of experiences living with, managing, or supporting those with DSD were developed. Transcripts were coded by two co-authors (KSJ and AB) at the paragraph level using NVivo 12 [24]. Inter-rater reliability (92% agreement) was established by double-coding 25% of transcripts beginning at the start of coding and intermittently thereafter. Disagreements were resolved through discussion. Quotes were included if they: 1) provided a theme/subtheme summary; or 2) highlighted a barrier, trade-off, or inconsistency.

Results

Participants

Participants (N=110) included individuals with DSD (n=24, mean age 22 years), parents of individuals with DSD (n=19; mean age 38 years), DSD healthcare specialty providers (n=37; mean age 46 years), and others (n=30; mean age 50 years; Tables 1 and 2). Most identified as women (71%), Caucasian (83%), non-Hispanic (92%), and heterosexual/straight (86%). A range of DSD conditions was represented (Table 2).

Processes and Outcomes

Despite efforts to have participants distinguish “processes” and “outcomes” through interview prompts, coding revealed consistent overlap between these aspects. Accordingly, themes should be viewed as elements of successful outcomes. Seven major themes were identified (Table 3). Subthemes are italicized and bolded.

Themes

Understanding diagnosis and self-efficacy in management are necessary but complex—Although all stakeholder groups stressed the necessity of having ***knowledge and understanding of one’s condition***, it was not always clear when, how, or what information to share. Although some individuals with a DSD reported a good understanding of their condition, others experienced knowledge gaps. Understanding one’s condition resulted in ***self-efficacy for living with a DSD***. With intentions of promoting openness with their child, some parents emphasized candidness: *“With our girls, we never lied to them. We have always been upfront and honest.”* Withholding information, typically with the intention of shielding children from “harm,” was noted by others.

For some, ***receiving a definitive genetic diagnosis*** contributed to feeling more informed about the condition; knowing the underlying genetic cause was necessary for peace of mind and informing future decision making: *“I just wanted to know what [was] going on with me instead of people just telling me what they think. I like to actually know instead of just assume”* (adult with DSD). Others who had received a genetic diagnosis believed the implications of the condition were more relevant, obviating the need to identify a specific etiology.

Patient and family psychological well-being—Stakeholders agreed that quality of life or ***general well-being of individuals with DSD*** was a feature of successful outcomes. Additionally, it was repeatedly emphasized that ***those with a DSD felt “normal,”*** despite having a medical condition. Similarly, ***parental satisfaction and well-being*** were frequently mentioned. Stakeholders consistently indicated parents should be supported, especially early in the young child’s diagnostic process: *“Early on, the most important outcome to me is that the family is aware of and comfortable with the diagnosis”* (geneticist). Some parents noted they would have appreciated more emotional support from healthcare providers. Despite acknowledging family well-being as one aspect of successful outcomes, stakeholders did not prioritize this outcome at the possible expense of jeopardizing long-term outcomes for the person with the DSD (e.g., child undergoing early genital/gonadal surgery to relieve parental anxiety).

Overall ***mental health*** was similarly noted as a central element of successful outcomes. Stakeholders valued having a therapist/counselor in comprehensive patient care. This perspective was balanced with perceptions that barriers exist to receiving these services, most often citing lack of access or parent/patient disinterest.

Parental comfort with the child's gendered behavior and, as they grow older, ***patient comfort with their gender identity*** were noted as important. The risk of the child developing gender dysphoria was considered a threat to successful outcomes. Since parents of infants with DSD sometimes decide on their child's gender of rearing in infancy (i.e., before children can express preferred gender identity), stakeholders worried about the possibility *"someone might [be] assigned the wrong gender"* (adult with DSD) – at the same time recognizing societal trends toward greater acceptance of gender fluidity. One parent reported this perspective helped them cope with uncertainties about their child's future gender identity. Healthcare providers and chaplains emphasized complexities and misunderstandings surrounding the concepts of gender, resulting in challenges in effective communication and barriers to family acceptance.

Furthermore, stakeholders generally reported a preference for the ***individual with a DSD to feel comfortable with their sexual orientation***. The individual's sexual orientation, whether heterosexual, homosexual, or other, was less important.

Support from others versus being stigmatized—Many stakeholders believed successful outcomes are reflected in the person being ***comfortable and confident in their interactions with others***, especially peers. This meant that the individual did not experience shame or stigma related to their condition. Parents, in particular, worried about social implications of a DSD diagnosis for their child, with specific concern about teasing: *"Definitely my biggest fear is adolescence, because kids are so harsh."*

Mixed opinions existed regarding whether a ***person with a DSD should share information about their medical condition with others***. Some with a DSD expressed uncertainty about whether communicating their diagnosis to others would be beneficial, predicting outcomes could include increased intimacy or rejection. Parents also expressed concerns regarding their child sharing information with peers: *"Kids, at her age, can be very mean if it got out. So trying to get her to understand that, 'I understand you want to tell your best friend, but […] what if they are not your best friend next week?'"*

Family support was voiced as critical: *"Just support. Love and support"* (parent). However, some patient stakeholders reported not having received support from their family.

Peer support, either individually or as part of a group, was identified by a number of stakeholders as a central element to achieving successful outcomes. Notwithstanding strong endorsement, many did not personally choose to seek peer support.

Patient has good physical health and accepts the implications of their condition for their body—*Physical health* was repeatedly identified as an important index of successful outcomes for those with a DSD. Stakeholders recognized the role diagnosis-specific therapies (e.g., hormone replacement) played in maintaining physical health. Nevertheless, stakeholders recognized that other outcomes, such as fertility preservation, may require accepting some degree of health risk (e.g., germ cell tumor).

Fertility preservation was identified as a complex and emotionally-laden feature of successful outcomes; with risks and benefits of gonadal removal carefully weighed. Providers spoke about their approaches to coaching parents on discussing ***infertility*** with their child, including alternative ways of building a family.

When specifically asked about the importance of ***physical appearance, especially of the genitalia***, stakeholders generally minimized it. Some stakeholders were willing to trade-off cosmesis to secure genital tissue sensitivity or ***urogenital function***. However, as one child life specialist pointed out, physical appearance can impact self-confidence and well-being: *"I think that, as a mental component, because regardless of the physical appearance, if that person or patient is comfortable with how things look […] physically -- because everyone defines what is normal for them. So I guess just being comfortable in their own physical appearance or physical features involved with the DSD."* Some stakeholders viewed urogenital ***surgery*** as part of a successful outcome; others did not.

Complexities in DSD decision making—Stakeholders expressed the view that ***families, and especially patients, should be involved in medical decision making***. ***Informed consent/assent*** was noted as necessary for the decision making process. However, stakeholders reported that signing a document alone was not adequate to ensure informed consent. Stakeholders mentioned several factors that can influence decision making within DSD, including ***perceived or experienced stigma***, ***gathering narratives from peer support groups***, and ***agreement between provider and family/patient*** perspectives.

Decision making around genital and gonadal surgery were frequent topics, including whether surgery should be performed and whether the ***child should be the ultimate decision-maker***. Evidence of internal conflict was observed in cases where a parent or person with the DSD expressed satisfaction with care they received, but recommended something different for others; e.g., one patient maintained that children should not undergo surgery at a young age while believing her parents acted correctly by choosing early surgery.

Explicitly ***choosing to wait to pursue urogenital surgery*** constituted a success for some. However, this decision, too, was qualified: "*My biggest worry coming out of this is that she is going to be mad at us that we didn't do the surgery"* (parent). Others pointed to potential negative trade-offs in postponing surgery until the individual was older (e.g., no health insurance as an adult). ***Contextual circumstances impacting decision making*** were also discussed, for example, frequent mention of controversies related to genital surgeries, including proposed legislation in some states banning elective procedures.

Roles and Expectations—It was generally felt the primary ***role and responsibility*** for parents and providers was supporting DSD-affected children. For providers, an additional role was supporting children's families. ***Parental expectations*** were discussed as elements contributing to, or preventing, successful outcomes; e.g., a neonatologist noted parents' expectations about their child's sex before birth can make adjustment to the newborn's DSD more difficult.

Knowledgeable providers and multidisciplinary teams are essential, but barriers persist—Receiving care at a ***center of excellence from specialists working in multi/interdisciplinary teams*** was valued by most stakeholders. However, barriers to receiving this type of care were also noted, including distance to centers and some stakeholders noting that meeting with a team of providers could be "*overwhelming*." Regardless of the model of care, stakeholders noted it was essential for ***patients to have access to highly knowledgeable and experienced providers***. ***Candid and open communication***, among healthcare providers and between providers and families/patients, was consistently mentioned, although this was not always achieved in practice. Stakeholders consistently valued a ***positive, supportive relationship between patients, families, and providers***, emphasizing the importance of ***providers caring for families and patients over time***. A major gap in services involved ***continuity of DSD care into adulthood***.

Discussion

Stakeholder interviews yielded numerous strategies for achieving successful outcomes that included roles and expectations of families and providers, attributes promoting a supportive model of clinical care, and factors that can impact decision making. Stakeholder agreement was observed in several areas (e.g., physical health and well-being were universally valued); lack of consensus was expressed in others (e.g., importance of surgical intervention or patient involvement in decision making). Differing perspectives are echoed in the literature: consensus statements [20, 25] recommend early surgical intervention in some instances, but other sources claim these practices are harmful because they are elective and because patients are not involved in decision making [14]. Distinctions blurred between whether a theme was viewed as a successful outcome or as a process to achieve a successful outcome. Additionally, stakeholders did not necessarily maintain the same valuation of an element when talking about their own care versus a hypothetical other. For example, some proclaimed the importance of seeking social support through DSD-specific support groups, sharing medical information with close others, or working with mental health professionals, yet had not personally done so, nor wished to. The extant literature recommends support groups, sharing information with others, and mental health services [20, 26], but patients and parents are less likely to partake in these activities in practice [27–31]. Finally, consistent with complexities of DSD decision making [20], numerous potential trade-offs were identified that required compromising one desired outcome or process in favor of another (e.g., removing the risk of gonadal cancer balanced against the loss of fertility with gonadectomy).

Controversies surround the delivery of DSD care [14, 32–34]. Differences of opinion, both within and across stakeholder groups underscore the challenges of providing comprehensive care for individuals with DSD that considers the breadth of stakeholder values. An interdisciplinary care model, affirmed by most stakeholders in our study as a key ingredient to achieving successful outcomes, and supported by consensus statement guidelines [20, 26], can present challenges given that those involved may hold different assumptions and expectations about the goals of care. This strongly indicates the need for training DSD teams in the operations of SDM. Numerous SDM training programs exist within adult health [35, 36], but availability of similar pediatric trainings is limited [35, 37]. Parents may also benefit from decision coaching (see [38]) to help prepare for conversations with providers.

This project is the first to systematically explore processes and outcomes promoting success for those with DSD from a wide range of stakeholder perspectives. Iterative evaluation of responses and refinement of interview questions until achieving thematic saturation ensured the capture of a comprehensive range of perspectives. Established qualitative research methods delivered rigor in completing this study [23, 39] and reporting of results [40]. Recruiting participants from numerous stakeholder groups resulted in a large and diverse study sample. However, despite efforts at purposeful sampling [41], most participants were Caucasian women. As in other pediatric research, the majority of parents were mothers [42].

Furthermore, themes and quotes represent multiple viewpoints - some controversial. Single participant quotes may not represent the larger stakeholder group. Nevertheless, they are presented to document the range of opinions, even if important to a small number of participants. For readers, genital and gonadal surgical views are a notable area of caution. In Phase 2 of the DSOT study, utilizing best-worst scaling, different stakeholder group representatives will prioritize the various attributes of care delivery and outcomes from Phase 1. Therefore, Phase 2 will provide a better understanding of the importance of each attribute.

Conclusions

This study, the first within a three-phase project, systematically examined processes and outcomes of DSD care from multiple stakeholder perspectives. Although there was consensus in some areas, important differences were identified both across and within groups related to what outcomes were valued and what approaches should be taken to achieve a “successful outcome.”

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Appendix A.

Semi-Structured Interview: Examples of prompts

Overall Question #1: What are Successful Outcomes in Conditions Affecting Reproductive Development?

A. What is a "successful outcome" of care for those who have medical conditions that affect genital appearance or reproductive function?

- **a.** First, please imagine what a successful outcome for a person born with [*DSD / genital anomalies / (use the term the participant favors)*] would look like at different stages of the person's development (childhood, adolescence, young adulthood and beyond).
    - **i.** …take into account success in terms of well-being, quality of life, social relationships, physical function and any other aspect that you believe is part of a successful outcome.
- **b.** [wait a moment and then ask]: Are you having any difficulties in imagining what a successful outcome looks like?
    - **i.** [if the interviewee reports being clear on the task]: Now that you have the image of a successful outcome in your mind, can you think of what would be a "successful outcome"…
        - **1.** [or] What do you think of as a "successful outcome"…
        - **2.** [or] How would you define a "successful outcome" for a person born with a condition affecting reproductive development?
    - **ii.** [if unclear, add prompts like this before asking them to describe what they're envisioning]: When I use the word "outcome," I mean physical, emotional, and mental outcomes of the condition and its treatment…
- **c.** How about in the short-term -- what is a successful outcome in the short-term? How about in the long-term? What about mid-range? [define what short-term and long-term are: hours, days, weeks, months, years, etc…]
- **d.** What are successful outcomes in infancy? Early childhood? Mid? Late? Teenage years? Young Adulthood? Etc…
- **e.** As in the case of most things in life, decisions can have both positive and negative features; benefits and risks; pros and cons; upsides and downsides. Is it possible that success in one area might compete with success in another? Do you think it's possible that a good outcome in one area might mean not such a good outcome in another area?
    - **i.** If yes, can you think of some example of these decisions in conditions affecting reproductive development?
    - **ii.** How do you decide to weigh the risks and benefits?
    - **iii.** What is absolutely essential? What is most important to you?
    - **iv.** What is of secondary importance?

B. Inquire about specific issues and ask where they fit into participants' conceptualization of a successful outcomes (i.e., probe for thoughts about issues that haven't yet been brought up in the group)

a. Specific issues: Overall quality of life; appearance of external genitals; stigmatization; sharing information with others; reproductive function / fertility; sexual function; gender identity (feeling like a girl / woman or boy / man); gender role (behaving like a "typical" girl / woman or boy / man); sexual orientation; religious / spiritual values and beliefs; physical health; cancer risk

b. Prompts:

  i. Can you tell me about [Issue] …?

  ii. Is it a part of achieving a successful outcome?

  iii. How important do you consider [Issue] in relation to successful outcomes?

  iv. Where does [Issue] rank on your list of successful outcomes?

C. Tell me more about…

a. Goal: refine and confirm themes and attributes mentioned by participants.

b. Reflect participants' statements back to ensure accuracy & understanding; add these to the list of other follow-up questions in subsequent interviews.

c. Prompts:

  i. Tell me more about [*topic suggested by participant*] …

  ii. I heard you say [*reflect topic suggested by participant*] …

  iii. [*Summarize what participants have stated about successful outcomes*]; if you had to rank these in most to least important, what is at the top of the list? The bottom?

    1. Is [*one thing mentioned by participant*] more or less important than [*other thing mentioned by participant*]?

  iv. Based on our conversations so far (both with you and with other people), I'd like to ask your opinion about something that has come up – it's the relationship between the patient's overall well-being and the family's well-being.

  v. If you had to make a trade-off between them (like if a decision might make things a bit better for one and a bit worse for the other), how would you choose between them? Which would "win" over the other?

  vi. What haven't we talked about yet in terms of "successful outcomes?"

Overall Question #2: How do we Achieve Successful Outcomes in Conditions Affecting Reproductive Development?

A. What goes into creating a "successful outcome?"

a. Now that we've talked about what a successful outcome looks like, I'd like you to focus on the concrete things you believe need to occur in order to achieve successful outcomes in [*DSD / genital anomalies / (use the term the participant favors)*].

  i. What are some concrete things a person should do to have a successful outcome?

  ii. What are the steps a person should take to help ensure a successful outcome?

  iii. What would you do? …avoid doing?

  iv. Are there others who are involved -- or should be involved? And what should they do/not do?

b. What's important?

  i. Most? Least?

c. What about trade-offs? [*Ideally, use the elements they mentioned above. If they did not provide elements which might be in conflict, then use an example; e.g., early genital surgery may make the genitals appear more typical, but there is the risk that this is accomplished at the expense of later genital sensitivity. Another example might be the degree of openness one shares with family or friends about the details of your child's condition; in an effort to preserve your child's privacy might others suspect there is a secret you are keeping leading to rumors being created?]*

  i. What trade-offs are there in the ways we go about treating conditions affecting reproductive development?

  ii. How do you decide to make one more of a priority than another?

  iii. What is most important to you?

  iv. What's less important?

d. What's most important in decision making?

  i. What's most important in decision making on behalf of children?

B. Inquire about specific issues and ask where they fit into participants' conceptualization of how to create successful outcomes (i.e., probe for thoughts about issues that haven't yet been brought up in the group).

a. Specific Issues: Not telling others about it (patient privacy / stigma) vs talking to others; surgery; timing of surgery; appearance; urogenital function; fertility; wait for patient to be old enough to make their own decisions; having a precise genetic diagnosis; seeking care from a large academic medical center ("Center of Excellence"); involvement in patient support, resource, or advocacy organizations; providers presenting a single treatment plan vs telling families about all the options and the pros and cons of each; using words like "DSD" or "intersex" or "condition affecting reproductive development"; communication within the team.

- **b.** Prompts:
  - **i.** Can you tell me about [Issue] –
  - **ii.** Is it a part of how to achieve a successful outcome?
  - **iii.** How important do you consider [Issue] in relation to [other issue]?
  - **iv.** *If participants have not mentioned the specific issues noted above on their own, ask about them (note: some participants may say that a certain factor isn't important to a successful outcome and that's why they didn't mention it ← and that's fine!):*
  - **v.** In addition to what we've covered, other people have mentioned a few other ideas. I'd like to hear your thoughts on them.

C. Tell me more about…

- **a.** Goal: refine and confirm themes and attributes mentioned by participants.
- **b.** Reflect participants' statements back to ensure accuracy & understanding; add these to the list of other follow-up questions in subsequent interviews.
- **c.** Tell me more about [*topic suggested by participant*] …
- **d.** I heard you say [*reflect topic suggested by participant*] …
- **e.** We'd like to get your thoughts on how you discuss the diagnosis and what it means with (your patients / your child / your peers, etc).
- **f.** [Potential prompts – use whichever fits the flow of your conversation best (or use your own variations)]:
  - **i.** What are some of the things you say to patients and when?
  - **ii.** What are some of the things you've said to your patient / your child about his / her condition? How old were they then?
  - **iii.** Can you remember some of the wording you've used when you've talked to your patients / child?
  - **iv.** Okay, so, say at age 5, what are some of the words you might use to explain a patient's CAH (or MRKH, hypospadias, etc...) to them? At 10? 15? 20?
  - **v.** When do you start talking about biology? Genetics? Karyotype? Fertility? Sexuality? Relationships?
- **g.** Prompts for clinicians / those involved in clinical decisions and treatments:

- **i.** Can you think of an example of a decision that you had to make about care / treatment that you might be willing to share?
    - **1.** What are some of the things you had to think about or struggle with at the time? How did you come to a decision in the end? Looking back, what have you learned from that decision process? What did you learn / can you teach us?
- **ii.** As a provider, what do you see as your role / responsibility in ensuring successful outcomes for patients?
    - **1.** [Consider prefacing this next question to acknowledge that it may be difficult, but is also important]: How would you know if you achieved success?; How would you know if you failed a patient?

h. Prompts for mon-medical stakeholders, like Bioethicists:

- **i.** Can you think of an example of a difficult decision / issue faced by a patient or family with DSD that your team was (or that you were) consulted on or involved with? What did you learn / can you teach us...?

i. Prompts for patients / families:

- **i.** Looking back, can you think of an example of a difficult decision you (your parents) had to make that was relevant to your child's (your) condition? What are some things you (they) had to think about / struggle with? What helped? What didn't help? What can we learn from you? What would you like medical providers who care for people with DSD to learn or know?
- **ii.** As a parent, what do you see as your role / responsibility in ensuring a successful outcome for your child?
- **iii.** [*Summarize what participants have stated about successful outcomes*]; if you had to rank these in most to least important, what is at the top of the list? The bottom?
    - **1.** Is [*one thing mentioned by participant*] more or less important than [*other thing mentioned by participant*]?
- **iv.** What haven't we talked about yet in terms of ways of achieving those outcomes?

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Summary Figure.

Identified Themes.

Note. DSD = difference of sex development

Table 1.

Stakeholder participants (n = 110).

Stakeholder Group	Participants (n)
Individuals with a DSD (15–40 years)	
Recruited through DSD clinics	20
Recruited through patient SAOs	4
Parents of individuals with a DSD	
Recruited through DSD clinics	15
Recruited through patient SAOs	4
Healthcare providers	
Endocrinology	6
Genetics, genetic counseling, genomics	6
Pediatric & adolescent gynecology	4
Primary care & adolescent medicine	6
Psychology	5
Pediatric urology & general surgery	4
Other: Child life, neonatology, nursing	6
Other Stakeholders	
Chaplaincy / pastoral care	7
Clinical research	5
Healthcare administration	4
Law	2
Medical ethics	4
SAO leadership	4
Social science researchers	4

Note. SAO = Support or advocacy organization.

Table 2.

Participant demographics.

	Individuals with a DSD & Families		Providers	Other Stakeholders
	Individual	Parents		
Group n	24	19	37	30
Age, years				
Mean (SD)	22.1 (7.1)	37.8 (6.9)	46.1 (9.4)	49.9 (12.2)
Range	15–39	25–52	28–68	32–78
Gender identity, n (%)				
Boy / Man	1 (4.2)	6 (31.6)	7 (18.9)	14 (46.7)
Girl / Woman	22 (91.7)	13 (68.4)	29 (78.4)	15 (50.0)
Other	1 (4.2)	0	1 (2.7)	1 (3.3)
Race, n (%)[a]				
African American / Black	3 (13.0)	1 (5.3)	1 (2.7)	1 (3.7)
Asian	0	0	5 (13.5)	1 (3.7)
Caucasian / White	16 (70.0)	17 (89.5)	30 (81.1)	24 (88.9)
First Nations / American Indian or Alaskan Native	0	0	0	0
Hawaii Native / Pacific Islander	0	0	1 (2.7)	0
Other / More than one	4 (17.4)	1 (5.3)	0	1 (3.7)
Hispanic ethnicity, n (%)	5 (20.8)	3 (15.8)	1 (2.7)	0[b]
Sexual orientation, n (%)[a]				
Straight or heterosexual	14 (63.6)	15 (93.8)	34 (91.9)	22 (84.6)
Lesbian, gay, or homosexual	3 (13.6)	0	3 (8.1)	1 (3.8)
Bisexual	3 (13.6)	1 (6.3)	0	1 (3.8)
Other	2 (9.1)	0	0	2 (7.7)
Education completed				
Junior high / partial high school (>9th to 11th grade)	7 (29.2)	1 (5.3)	0	0
High school graduate	3 (12.5)	1 (5.3)	0	0
Partial college or >1 year specialized training	6 (25.0)	5 (26.3)	0	0
College graduate	7 (29.2)	9 (47.4)	2 (5.4)	2 (6.7)

	Individuals with a DSD & Families		Providers	Other Stakeholders
	Individual	**Parents**		
Graduate/professional training	1 (4.2)	3 (15.8)	35 (94.6)	27 (90.0)
DSD diagnosis/category[c,d]				
Source: electronic medical record				
Congenital adrenal hyperplasia	5 (20.8)	2 (10.5)		
Complete androgen insensitivity syndrome	4 (16.7)	0		
Cloaca / cloacal exstrophy	2 (8.3)	4 (21.1)		
Complete gonadal dysgenesis	2 (8.3)	0		
Partial androgen insensitivity syndrome	2 (8.3)	1 (5.3)		
Mayer-Rokitansky-Küster-Hauser syndrome	2 (8.3)	0		
46,XY DSD (not otherwise specified)	2 (8.3)	0		
45,X/46,XY mixed gonadal dysgenesis	1 (4.2)	0		
Hypospadias	0	3 (15.8)		
Ovotesticular DSD	0	2 (10.5)		
5α-reductase deficiency	0	1 (5.3)		
17β-hydroxysteroid dehydrogenase deficiency	0	1 (5.3)		
Source: Participant-reported				
Congenital adrenal hyperplasia	2 (8.3)	1 (5.3)		
Cloacal anomaly with imperforate anus	1 (4.2)	0		
Mixed gonadal dysgenesis	1 (4.2)	0		
Ambiguous genitalia	0	2 (10.5)		
Müllerian anomaly	0	1 (5.3)		

Note.

[a] Percentages adjusted for missing data

[b] 1 participant declined to answer and 1 missing

[c] For those recruited through clinic, diagnoses were derived from chart review; for those recruited through support or advocacy organizations, diagnoses were self-reported

[d] For parent participants, “diagnoses” reflect their child’s DSD condition; SD = standard deviation; DSD = difference of sex development.

Table 3.

Selected quotes to illustrate successful outcomes and how to achieve them.

Themes / Subthemes	+/−	Exemplar Quotes
Understanding diagnosis and self-efficacy in management are necessary but complex		
Patient understands DSD condition	+	“From a baby’s standpoint, identifying what the problem is early and then making sure the parents understand it and know what is going on. In terms of young kids, introducing it to them early; not telling them when they are 16…17. And not going into so much detail and not completely overwhelming them, but giving them the general idea of what is going on with their bodies.” (*teenager with DSD*)
	−	“I just wish that things were maybe explained in more detail and didn’t sugar coat it because then I would have had so much more information about my disorder.” (*adult with DSD*)
Patient experiences sel-fefficacy for living with DSD	+	“I would say successful outcome looks like a patient who feels confident and prepared just for their life, living with whatever they have to deal with physically or possibly mentally.” (*child life specialist*)
Patient receives genetic basis for DSD	+	“People argue against medicalization of intersex, and I agree with them. But, I think a solid diagnosis of any medical condition is critical. And, for me, when they finally said ‘look, here’s your genetics,’ and it explained everything. […] I mean; it really did explain so much.” (*adult with DSD*)
	−	“I’m kind of wondering where you are in terms of, does a person need a full complete genetic diagnosis, or can it stop at karyotype? Kind of where your thoughts are with that?” (*interviewer*) “Me, personally, once I heard I was XY, I said that’s all I’d need to know. […] The detail of exactly where [the genes] went wrong or things happened or whatever, didn’t necessarily, wasn’t my biggest [concern]- no.” (*adult with DSD*)
Patient and family psychological well-being		
Patient achieves well-being living with DSD	+	“To me a successful outcome would be his [the child’s] happiness. If he decides he wants to find someone and have a relationship, then I hope that he can find that. Or if he wants to find someone, have a relationship, and have a family, in whatever form that takes, I hope that he can find that. So I guess just his overall happiness and well-being becomes a successful outcome to me.” (*parent*)
	+	“You want to go through life feeling good. You want to go through life feeling healthy. You want to go through life feeling that your life is not at risk and that you can enjoy life and do things. So this whole time I am growing up and doing stuff, I never stopped my life. I stopped that piece of it, but I have traveled; I have built a career. I mean I have done everything except the piece where surgery was involved. So to me, if I hadn’t been able to do that, and I didn’t have that quality of life to support what I wanted to do, I don’t know… It would be really tough… it would be really tough to live like that.” (*adult with DSD*)
Patient maintains normalcy without experiencing stigmatization	+	“I originally thought that this was like a completely life changing thing where I am not going to be able to live like a normal person. I don’t know why I felt that, because that wasn’t true at all. And I found out pretty quickly, easily within a month, that it doesn’t mean I am different from other people and that I have to act different.” (*teenager with DSD*)
Parent achieves well-being / satisfaction	+	“Usually my immediate concern is: ‘how is [this] going to affect the new parents of this baby?’ […] And how do we support them through something that is potentially very difficult that they weren’t prepared for?” (*neonatologist*)
	−	“But I feel like maybe the emotional support from the medical staff was lacking, other than that nurse. And I feel like that is something that down the road, they need to consider expanding the horizons of the medical care staff and letting them know that this is an emotional thing that parents go through.” (*parent*)
Positive mental health	+	“I think it is critical. That is why we get started at a very young age with them interviewed and counseled by psychology to see how they are adjusting and give us advice and make recommendations on what we do. We don’t do anything without [the psychologist’s] input on these patients.” (*urologist*)
	+	“I think it’s finding out what the concerns are and trying to normalize it: ‘we see lots of kids who have medical conditions that can impact how they feel about themselves, and that is why we would want your child to see if we can work on strengthening their self-esteem or having less anxiety about X or Y.’” (*primary care provider*)

Themes / Subthemes	+/−	Exemplar Quotes
Parent is comfortable with their child’s gendered behavior / Patient is comfortable with their gender identity	+	Going along with what I’ve said at the very beginning about [how] success is having the person be able to live the life they wanna live and that should be the goal. I think that includes being accepting and welcoming of whatever gender identity they have.” (*adult with DSD*)
	+	“I was definitely tomboyish growing up but there was definitely nobody that really told me that: ‘You need to start acting more girlish.’” (*teenager with a DSD*)
	−	“I can’t re-train a family in the middle of their first hospitalization with their new baby that gender and sex aren’t the same thing. And even if we box this child into one assortment of genitals, that doesn’t mean that that’s gonna match the gender. I might not be able to convince the family during this hospitalization that gender and sex are two different things, and that sexuality is completely different, and that love is actually something different from that.” (*chaplain*)
Patient is comfortable with their sexual orientation	+	“But I would say certainly as a teenager, […] feeling okay about your sexual orientation, feeling that it can be communicated to the degree that you want it to be with your family is pretty important.” (*psychologist*)
	−	“And I would say that heterosexual orientation would not be on my list [of important outcomes] at all.” (*bioethicist*)
Support from others versus being stigmatized		
Patient comfortable / confident interacting with others; does not experience shame	+	“For me, thinking of a child that […] makes good friendships.” (*primary care provider*)
Patient shares information about DSD with significant others (family / friends)	+/−	“For me, when I’m vulnerable, that creates intimacy with someone. Not necessarily relationshipwise, but: this is my friend; I’m sharing this with them. But I, personally… I’ve been vulnerable to someone before and that hurt me. And so I just kinda don’t.” (*teenager with DSD*)
Patient supported by family (versus being rejected)	+	“I don’t like telling people about myself. That’s not my thing. I often just end up keeping it to myself. The people I tell the most, though; again, family. I cannot stress that enough: how important it is to have a great family.” (*teenager with DSD*)
	−	“For me there is a lot of secrecy still in my family surrounding my disorder. My siblings don’t really know about it. They know almost nothing about it. They know that I have a disorder; they know that I take medications; they know that I travel for it. But in their minds, they honestly probably think it’s a lot more serious than it is and they know nothing about the sexual aspect of it.” (*adult with DSD*)
Patient seeks peer support organization, as needed	+	“I think offering support systems sometimes is a really good way for the doctors to help, whether that be […] telling them about a support group that meets at the hospital, or maybe a camp that they can go to, like Youth Rally, so that they can go and experience firsthand that there are other people like them, other kids.” (*adult with DSD*)
	+/−	“I am not one for it [reaching out to support groups/advocacy organization]. But if the patient wants that, then I would say go for it; if they don’t, don’t force them to.” (*teenager with a DSD*)
	+/−	“And I learned about it [support group] the first time when I was probably 13 or 14, but we didn’t have any money to do it. And I didn’t hear about it again until I was 21. It was kind of pushed away. I remember wanting to go, but it just kind of got pushed out of mind or whatever.” (*adult with a DSD*)
Patient has good physical health and accepts the implications of their condition for their body		
Minimize health risks / maintains good physical health	+	“And I would say, also, with age, making sure the children are taking care of themselves beyond their DSD’s. So, not […] misusing drugs or alcohol; eating healthy, not becoming obese and getting all the sort of chronic illnesses of adulthood we see in people who, maybe haven’t been prepared to take care of themselves to the best of their ability.” (*clinical researcher*)
	+	“We did what we had to do to make sure [our daughter] stayed healthy.” (*parent*)

Themes / Subthemes	+/−	Exemplar Quotes
	+/−	“In some respects, if you present them head-to-head ‘cancer versus fertility,’ cancer is lifethreatening. And if you’re not alive, you’re not going to be able to reproduce.” (*psychologist*)
Fertility preservation / patients with infertility accept alternative ways of defining family	+	“And preserving fertility, I think, is important to a sufficient number of people that I think that is an important outcome. […] For some women it’s not just being fertile, but the ability to achieve and maintain a pregnancy. And that is a separate issue. So there are women who, with an egg donor, could become pregnant. And so I think it’s not just preserving. You’d have to figure out how you are defining fertility. But I would define fertility as: the ability to have a biological offspring. And, in particular, given the multiple fertility preservation techniques, I think that there are multiple ways to achieve fertility.” (*bioethicist*)
	−	“The hardest part for me was finding out that I couldn’t have children.” (*adult with DSD*)
	+	“I advise parents of my patients who I know have a risk of potential infertility to start conversations early on about different ways to be a parent. Because I feel that parents may think it’s so early to have a conversation about fertility, but many kids as they grow up whether its consciously or subconsciously will have some expectation about how they will be a parent in the future just based on what they see around them.” (*endocrinologist*)
Accepting / normalizing genital appearance	−	“I think, ‘why are they gonna do [surgery] just to look different?’ I think that’s not good. [To have surgery] just because they want it.” (*teenager with DSD*)
	+	“It’s all in how the [genital] difference is framed. […] In some respects, there will be circumstances where a child’s atypicality may be observed by others; for example, daycare providers or a babysitter, other family members, those kinds of things. But […] there’s a range of normal, and sort of helping families to understand that this is an aspect of their child, but it’s not their whole child and who they are.” (*psychologist*)
Achieving optimal urogenital function	+	“But we do hope that she has a vibrant sexual life. It’s part of life. And so we hope that she can have fulfilling intimate relationships, part of which may be physical. But again, we don’t know what kind of relationships she’ll be interested in, and whether that would require any kind of surgical alteration to her genitals. And also one of the surgical procedures that we were presented with was a clitoral reduction, which is a big source of pleasure for many women, and so the idea of cutting that or altering it didn’t make a whole lot of sense to us since we want her to enjoy sex if she decides to have it.” (*parent*)
Surgery	+	“The ideal outcome would be: the overall acceptance of the condition and then compliance with either a hormonal regimen and/or if surgery is ever indicated, surgical intervention.” (*nurse*)
	+/−	“I’m willing to say, if we’re looking at […] what’s the priorities now, I would say no surgery. But I think that, that would be really hard on parents in the absence of a lack of change in terms of the language that is used and in terms of the team providing the information right.” (*social scientist*)
Complexities in DSD decision making		
Family and / or patient involved in decision making	+	“My training is that I’m non-directive. I don’t make decisions. I help the family make decisions that are best for them. So, I don’t tell them when to test. I tell them about the options for testing and, what we can get covered by insurance. But then they decide if they want testing or not. So, I don’t make a ton of decisions.” (*genetic counselor*)
Providers supporting parents / patient to make informed decisions (process)	+	“There should definitely be more pressure on doctors to absolutely present all of the necessary options because parents don’t know the right questions to ask when [their child is] given a diagnosis like this. Most of these disorders can be diagnosed at birth and so, [parents] are thrown into an entirely new realm. And so I think access to educational resources immediately should be [the doctor’s] number one priority, so when parents are thrown into a situation like this and it’s sink or swim, they should be able to swim.” (*adult with DSD*)
	+	“I personally think that [explaining the purpose of tests] should be done. But, I actually don’t know how common or routine that is, in terms of why different tests are being ordered.” (*psychologist*)
Parents / patient have clear understanding of treatment options or care plan to provide informed consent (outcome)	+	“I would let patient know fully and make sure they understand completely what their decisions are so, that way, when it comes to surgery, if they need it, they can make a decision clearly and open mindfully.” (*teenager with DSD*)

Themes / Subthemes	+/−	Exemplar Quotes
	+	“Knowing what the risk actually is for the choices I make was important. You know, the doctors I spoke with had said, “you have a 2% risk of cancer right now, and that’ll go up, but that’s where we are right now.” And so knowing that, like “oh, this isn’t really imminent right now,” helped me; it gave me room to make my own choice through it all.” (*adult with DSD*)
Decision making driven by parents’ desire to minimize anticipated patient burden / stigmatization	+/−	“There are still parents who are making decisions to do these surgeries to their children. Who have their children’s best interest at heart, but in reality it is just founded on a notion of there being a binary and their kid’s not going to fit in. That, right there, is not […] really a good reason to surgically alter somebody -- to make them fit in.” (*adult with DSD*)
Parents and patients gather narratives (from peer support in DSD community) as one source to inform decision making	+	“I did talk with other women who have AIS about the paths they’ve taken and the rationale for doing so -- which I honestly think was the most helpful.” (*adult with DSD*)
	−	“Some of the girls that I met [at the support organization meeting], the parents that I met there… their conditions were much worse than my daughter’s. Some didn’t have ovaries; their ovaries were in different anatomical places; they had one kidney, you know. And in the parent group, meeting a lot of the young girls… Well, several of them, their mothers spoke, that their daughters became very promiscuous and it… Part of me felt like I didn’t relate to a lot of what I experienced there.” (*parent*)
Providers and family (parents / patient) align DSD management goals	+	“There may be time[s] when the family feels like they know what’s gonna make their kid the most happy and healthy and that may be different from [or] may not always align with what the medical team’s recommendation is.” (*pediatric endocrinologist*)
	+	“It goes back to ‘I wish I’d ask more of what their goals are,’ because if our goals are not aligned, then we should be finding out how we can compromise.” (*urologist*)
Providers and parents wait to make treatment decisions with the patient	+	“I think that success in an earlier stage would be to preserve the opportunity as best as one can. As widely for the child, while waiting for the child to get to the point of: they can have meaningful engagement. I’m not saying it’s the age of consent, but meaningful engagement about their care and who they are; their care and what they would like.” (*primary care provider*)
Providers and family (parents / patient) delay surgical decisions	+	“Yeah, [I had] like a 15-year gap [in DSD medical care]. And then a few years went by [after reestablishing care with a urologist], because I still wasn’t ready for surgery.” (*adult with DSD*)
	+/−	“If you are choosing to wait for surgery, like a lot of people are advocating for nowadays, that might be more socially acceptable in Chicago or San Francisco… And I think it should be that way everywhere, don’t get me wrong, but that’s just not the world that we live in. And the other thing that I think plays into this is you make a decision based on what you think is going to be best for your child.” (*adult with a DSD*)
	+/−	“I think that maybe the surgery should not be done as a baby. But then again, if the person doesn’t have insurance later on in life to fix what is going on, then they might need it as a baby.” (*adult with DSD*)
Providers and family (parents / patient) aware of contextual circumstances influencing decisions	+	“There’s a law in California to try and pass; to ban unnecessary surgeries. I’m definitely in support of that.” (*adult with DSD*)
Roles and expectations		

Themes / Subthemes	+/−	Exemplar Quotes
Expectations of providers' roles and responsibilities	+	"Moral decisions and stuff like that should not be made by doctors if they don't need to. This isn't life or death. This is not their own agenda that should be enacted onto their patients. That's not their role, that's not their job." (*adult with DSD*)
	+	"We have to really have is this willingness to… when parents are reacting adversely, to try to do the best we can to not let them push our buttons. And to try as best we can to remember that ultimately - to the extent that we're 'the professionals' - that means that […] we're there to serve them." (*bioethicist*)
Expectations of parental roles and responsibilities	+/−	"You are going to have to start dealing with some weird and uncomfortable questions that are really private for your kid, but that, as much as I'm sure your kid wants to keep them secret or whatever, at some point they need to be discussed. And making sure that you are comfortable with that, making sure that you are making it as comfortable as possible for your child to come to you about anything, really. And just being an open resource for support and helping them to seek the answers that they need." (*adult with DSD*)
Parents reconcile mismatch - between expectations and realities (e.g., prenatal ultrasound incorrectly predicts a girl)	−	"In many of our deliveries, parents have had an identification of the sex of the baby before the baby is born and the baby has a name, and a wardrobe, and a room that is decorated in a certain color palette. And I think there's a lot of the consternation meeting these people and starting them on their journey when some of the strong assumptions you made about your baby might not hold." (*neonatologist*)
	+/−	"Maybe [surgery would be unsuccessful] if their expectations are not met. So, maybe they're expecting, uh… It's hard to say because I think it's dependent on everyone's personal expectations. So they could have a positive or a negative feeling about results." (*child life specialist*)
Knowledgeable providers and multidisciplinary teams are essential but barriers persist		
Parents / patients have access to multidisciplinary team at a center of excellence	+	"In regards to where you go for care, I would say having a multiple-disciplinary team would probably be more important than like a large medical center. Although I would argue that most multiple-disciplinary teams are likely going to be in larger medical centers. Just because like for the hospital to support a team of that nature, they kind of have to be, I would assume, an academic center and recognize the value, have the funding, and all of those things." (*genetic counselor*)
	+	"I was able to see a team of doctors a couple of times and I thought it was really helpful." (*adult with DSD*)
	+/−	"[Getting care from a large medical center] has its pros and cons. I mean there's a lot more people there. […] They're not limited to a short supply of resources. […] You have everybody there versus a small amount kind of deal. More variety of knowledge, I guess. […] I mean the cons for us, specifically, it is quite a bit of a drive." (*parent*)
Parent / patient has access to highly knowledgeable and experienced providers	+	"I think just having my doctors be so positive and knowledgeable was very comforting, and knowing that they know a lot about it, and I think having them be so positive about it." (*adult with DSD*)
	−	"And this September [my integrated practice physician] closed his office. So I had to find another primary care. And so I went to the PA who had handled one of my anaphylaxis reactions. And after hearing my medical history, she said 'I can't. It's just too complicated. I can't do this.' She said, 'You need specialists.' I said 'Where? There aren't any, you know?' I live in a town of less
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	−	“And this September [my integrated practice physician] closed his office. So I had to find another primary care. And so I went to the PA who had handled one of my anaphylaxis reactions. And after hearing my medical history, she said ‘I can’t. It’s just too complicated. I can’t do this.’ She said, ‘You need specialists.’ I said ‘Where? There aren’t any, you know?’ I live in a town of less than 10,000 people. And, yeah, I can go to [US city], but I just had a genetics appointment there […] and they don’t know about intersex.” (*adult with DSD*)
Good (candid and open) communication from providers	+	“Good communication with a team and a very single clear message is really important - certainly in the beginning.” (*genetic counselor*)
	−	“When you are exposed to so much and you are going from one doctor to the next doctor, everybody is going to say something different. One doctor may not take into account what the other doctor is doing.” (*adult with DSD*)
Parents / patient feel supported by and have a positive relationship with care team	+	“Number one, the doctor has to be supportive. They have to understand where the patient is coming from, and where the parents are coming from, because […] we’re all thinking different things.” (*teenager with DSD*)
	+	“I would […] say that it’s probably the family satisfaction, and sort of the working relationship with the team, is the area that we have the best shot at trying to really have a positive outcome with.” (*psychologist*)
The process of giving or receiving care occurs over time	+	“We have this sort of checklist that we follow, where we present some information to the family at each visit over the course of potentially a year, if it’s any baby with CAH. And then we kind of reinforce that information at the end of the visit and at the next visit as well, so repetition really helps families comprehend everything.” (*clinical researcher / provider*)
	+	“And so, I guess that brings me to: we just need to slow down and take our time over multiple clinic visits talk to these families and support them.” (*urologist*)
Patients have continuity of DSD care into adulthood	−	“I felt like, because I was no longer a child or what they consider pediatrics or whatever, that there wasn’t anything for really adults. I felt that support my whole life, but then, that transition to adult and where it is I need adult care. […] There was nowhere I could go where they understood me, so every time I went to a doctor I’m like, ‘Ok, this is my condition.’ […] Had I had some, transition plan or something or recommendations of who to see or be able to see the same people, maybe not as frequently, but something to where I still felt that support. Because for me, I felt I still need that medical support as well as the mental health.” (*adult with DSD*)

Note. “+” identifies a quote that is in support of the subtheme or is a positive example; “−” identifies a quote that is a not in support of the subtheme or shows a negative example.