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At the Bedside

People with Differences of Sexual Development: Can We Do Better?

Edmund G. Howe

ABSTRACT

This article discusses how careproviders of all types can help people with differences of sexual development (DSD): people with ambiguous genitalia, who used to be referred to as intersexed. Careproviders may be in a unique position to benefit these people by offering to discuss difficult issues that concern them, even when the discussions are brief. Specific interventions include learning about people with DSD, whether through the literature or in the clinic; treating them with optimal respect; raising difficult topics such as sex, fertility, and social stigma; encouraging them and helping them to meet others with DSD; and sharing the strengths that we can see that they have. We have come far, but have a long way to go.

In this issue of *The Journal of Clinical Ethics (JCE)*, in "On How Ploughing a Lonely Furrow Might Affect Youths' Sexual Health," Eva De Clercq discusses how we can better meet the needs of people who have differences of sexual development (DSD). Some refer to DSD as intersex conditions; affected infants are born with

ambiguous genitalia.¹ I refer to individuals with DSD as people, not patients, and refer to them as having differences of sexual development, not disorders, because I do not want to seem to imply that they have a medical condition.² In the past, this was often assumed to be the case. As infants and children, people with DSD often received genital surgery to "normalize" their genitals. It was generally believed that, with such surgery, they would naturally identify their gender as the gender of their genitals.³ But this did not always happen. Now it is recognized that children's gender identity may not follow that of their genitals. Parents of an infant with DSD are encouraged to wait, when medically reasonable, so that their child can later decide whether to have surgery.⁴ Parents are encouraged (or even required) to consult with multiple medical specialists, such as endocrinologists and surgeons, before they decide to pursue surgery for their infant. Children are urged to do the same as they grow up. Why the change occurred is not clear, but seems likely to have been based on careproviders' recognition that the prior approach sometimes caused irreparable harm.⁵

Problems remain for people with DSD, and more work remains to be done. In her article in this issue of *JCE*, De Clercq provides guidance on what we can do to most benefit people with DSD. She is assisted by "Emma," a young woman with DSD, whom she interviewed.

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In this article I will focus on how careproviders who are *not* experts or specialists can help people with DSD, if they feel they need help. They may see a careprovider for a need that is unrelated to their DSD. Careproviders may not have specialized training in psychological interventions, but may help immensely by discussing their concerns with them. Some interventions take only a little time, as I will describe.

Emma's insights are critical in this regard. I appreciate her openness and courage. She models the courage needed to take the initiative to bring up a difficult subject. I urge non-experts to bring up difficult subjects, even when that is a major change in how they practice. De Clercq writes, "Physicians, and in particular primary careproviders, are well placed to discuss sexuality with youth." Emma said, "If only my physicians would have been less prudish. . . ." We must muster the courage to bring up difficult topics such as sexuality, fertility, and social stigma, so that people will be more able to discuss these topics when it is important to them.

I will discuss what we can do to help in three sections. First, I will discuss how careproviders must establish sufficient trust to be helpful. Second, I will outline specific initiatives that careproviders should take: taking the initiative to discuss sexual intimacy and fertility, and keeping secrets during social interactions. These discussions should be appropriately geared to the age of people with DSD. In the third section I will discuss two general insights that we can offer: connecting people who have DSD with others who have DSD, and helping people with DSD to more fully know their own strengths.

It is inherently problematic to believe one can reasonably infer another person's needs. This especially so when the other person hasn't expressed any needs.⁶ Yet the possible benefits may be so substantial they may warrant the risk of stigmatizing people by asking about concerns they may not have. We might minimize the risk by asking beforehand if it would be okay to ask them about issues that other people with DSD have found concerning. At worst, they would only have the pain of saying, "No, thanks."

Many emotional concerns that people with DSD may experience are presented in the literature. In 2015, Georgiann Davis and Ellen Feder published articles by people with DSD.⁷ One author, Emily Quinn, has complete androgen insensitivity syndrome (CAIS). In her article she relates that she had been dating a man for sev-

eral months when "things became more serious." She was "head over heels. . . . I adored him." She decided to tell him about her CAIS, but had received no advice on how to do it. She writes, "When I told him a few months into the relationship, he broke up with me. I was devastated. . . . I was an absolute wreck." Fortunately, several months earlier, Quinn had met a specialist physician through a college course, and her first appointment was several days after the break up. She writes, "this one, perfect doctor literally changed my life. Having a doctor who understands your body, your variation, your medical needs, is the greatest possible gift for a patient."⁸

Before I go further, I will note that *JCE* published a special issue on ethics and people with DSD about two decades ago, and the articles were compiled and published in a 1998 book, *Intersex in the Age of Ethics*,⁹ edited by Alice Domurat Dreger. Dreger believes it is wrong to publish pictures of people with DSD naked in medical journals. She wrote, "Clinicians will need to develop ways to educate without making intersexed patients feel freakish and violated."¹⁰ She did more than this: to express her alliance with people with DSD, she "walked the walk" by adding herself to those who had been pictured naked. She included a picture of herself, unclothed, on the cover of her book, modelling the courage we can seek to emulate. Decades have passed since 1998, and we still have much to do. There are many reasons that we, as a profession, continue to get it wrong. One is that we may not ask people to say what they want, and may not "get it" when they do, because their experience is unlike our own. And then we may presume we know what they want.

TO BE TRUSTED BY PEOPLE WITH DSD

People with DSD may share these difficulties: dissatisfaction with their body, difficulty in sexual functioning, and, sometimes, as a result, not feeling entitled to be in an intimate relationship. These are a few of the difficulties that may arise and persist in a context where they have experienced themselves as different from others, from an early age. They may have powerful, painful experiences of otherness from their childhood. We may misunderstand what they say because their experiences are so different from ours. Because of this, we should give exceptional attention to what they mean to say when they speak.

They may not share their views due to the exceptional angst they feel. For example, they may feel hesitant to disclose their concerns on whether to retain their capacity for fertility, especially since their choice may involve accepting significant risk, such as an increased likelihood of cancer. Such a reluctance to share may be another barrier to communication, and increase their vulnerability to social isolation.¹¹

Because people with DSD may experience this isolation, non-expert careproviders of all kinds may provide a precious opportunity to discuss these difficulties.¹² For example, ethics consultants may meet with people with DSD in other contexts, and be able to help them by being insightful and nonjudgmental. That may include discussions about sexuality, fertility, and their right to make choices, including the right to keep their options for fertility open.¹³

To be best able to assist people with DSD, we must be willing to bring up issues they may find uncomfortable and may not otherwise bring up. We can say, "Many people find it hard to discuss sexual intimacy, and people with DSD are among them. Would you like to discuss this with me?" To discuss these issues, people with DSD will have to feel sufficient trust. I will discuss the obstacles we may face when we take the initiative to raise these issues. Then I will discuss the changes in medical education that may be necessary to maximize the degree to which people with DSD may be able to feel trust.

A Reluctance to Discuss Sexual Issues

We may feel reluctant to discuss issues that we personally find to be sensitive. Patients' sexuality is a paradigmatic example. Patients may contribute to this reluctance. I recall, for example, telling a patient I was seeing for depression that changes in her sexual interest might be an indirect indication of the extent to which her depression was responding to treatment. She was offended by the suggestion. Her sexual life, she said, was private. Looking to my own experience, I sometimes feel such reluctance, myself. For instance, in my writing above, I paused longer than usual about whether to use the word "genitals" or "genitalia."

I think of what a female colleague said. Over decades as a patient, she had seen several male doctors. She noticed that most of the male doctors she saw slowed down their speech whenever they discussed sexually related topics, such

as menstruation. The price of such reluctance may be dear. For example, a patient was deciding whether to have a second mastectomy to reduce the risk that she would again have breast cancer. Due to her genetics and family history, she thought this would be wise. She wanted to retain feeling in her remaining nipple as a source of sexual stimulation, but when she consulted several physicians, none mentioned how a second mastectomy would affect her sexually. She was not comfortable with this omission and decided not to have the surgery.

Not bringing up a subject that patients may find pertinent may cause them to read into the omission not only possible relative negligence on our part, but that there may be some underlying reason we did not bring it up. Patients may fear that the reason is because there is something wrong with *them*. They may conclude that they should feel shame. Difference in nearly any context can pose the same risk: if the difference is not considered to be a "plus," it may become a source of lowered self-esteem.

In 2017, Heino F.L. Meyer-Bahlburg and colleagues interviewed 62 women with congenital genital ambiguity (CGA) about the stigma they experienced in medical settings. The authors report, "when physicians explicitly refer to possible future CGA-related problems . . . but noticeably evade providing details, patients may experience this withholding of information as aversive, presumably because it implies a prognosis of future differentness."¹⁴

People with DSD may not bring up delicate subjects on their own. A study published in 2017 by Caroline Sanders, Zoe Edwards, and Kimberly Keegan reports on interviews with 20 young persons with DSD (ages eight to 18) in the United Kingdom, 48 of their parents, and 37 health professionals. The authors report just 20 percent of the young people asked direct questions, and their parents spoke usually only when asked a direct question.¹⁵ Some parents said they did not ask questions because other parents were waiting to see the healthcare provider.

Given this, we should seek to overcome the reluctance people with DSD may have about initiating discussions, or, recognizing our own reluctance, we could acknowledge our own reluctance to them, and say that we know this is our limitation, and not theirs. Noting our own limitations may logically seem to reduce our credibility, but it may instead have a positive effect, as it may help them to see us as their equal. This

is always important in relationships that are asymmetrical in power, and may be especially important to people with DSD.

If we feel uneasy in these conversations, we can refer people with DSD to a careprovider who can discuss these topics more easily. Medical students may gain greater ease with these topics by practicing doing interviews with actors.

We can comment in advance that people with DSD often gain from discussing sex and other intimate issues with others who have DSD. Doing so may help them to validate their needs or wants that are idiosyncratic. We may add that some people do not want to have such discussions, which may make it easier for those who do not want to have a discussion to decline.

Not Traumatizing People with DSD

Dreger's concerns about protecting the dignity of people with DSD includes publishing pictures of them without clothes in medical journals. Many people with DSD report that, when in the hospital for a procedure, medical students and younger physicians are routinely brought to their bedside to see their genitals, to learn. People with DSD find this traumatizing, and accordingly, many strongly dislike going to a medical clinic. In the study by Sanders, Edwards, and Keegan, young people with DSD said that what happened to them in clinics was "crap," and described them as the "pull my pants down clinic."¹⁶ When they were asked, as part of the study, to be examined, they were "horrified and angry."¹⁷ Stacy, a young person with DSD, said when she had an exam in the hospital, "I was the new thing on the block. . . . They [medical residents] had to check it out. . . . Some people were going to take advantage of that and try to see the difference, I guess, in the genitals. . . ." She concludes that the residents "kind of blew it out of the water pretty bad."¹⁸ This last phrase is noteworthy, and I will refer to it later. Her comments express humor, objectivity, and an understanding of the residents' need to learn, even though she found what they did to be disconcerting. This is a kind of acquired wisdom. Such a capacity for humor and her ability to care about herself indicates that she and others with DSD may have rare gifts they may give to others, for example, medical residents and their own careprovider. I will suggest that we should try to let people with DSD know they have this acquired wisdom, if they don't know it already.

We can, as an organizational issue, decrease opportunities for this kind of trauma. We can, before we do anything, share our concerns with people who have DSD, and state unequivocally that we do not want them to feel traumatized by an appointment or exam. Eve, a young person with DSD who is quoted in the article by Sanders, Edwards, and Keegan, said "we were seen as a medical curiosity as opposed to [medical students'] . . . caring about how you actually felt about what they were doing to you."¹⁹ To avoid this, we can ask people with DSD what they want. They may want only one person to examine them, but be okay with the use of a video camera. Or they may want to choose who will examine them. Finally, we should make clear that regardless of what they initially say they prefer, they can change that at any time.

THREE INITIATIVES WE MAY TAKE

In this section I will discuss three concerns that may trouble people with DSD: sexual intimacy; fertility, including carrying a child; and disclosing to others that they have DSD. These may not be all, or even most, of their chief concerns. Rather, they should be regarded as paradigmatic of other concerns. These may be the most difficult issues for people with DSD. Thus, I will discuss only these three. We should pursue them to the extent that people with DSD want. But, like the patient who was considering a second mastectomy who did not ask about the sensitivity of her remaining nipple, people with DSD may not bring up these topics themselves. We may have to muster our courage to raise them, or we can refer people with DSD to a careprovider who can take the initiative to ask them whether they want to discuss these concerns.

Sexual Intimacy

People with DSD may have many concerns regarding sexual intimacy.²⁰ Their process of coming to experience intimacy with a partner may involve, for example, informing their partner about their condition and fearing rejection. A core overall approach we can take is to ask people with DSD about their meaningful relationships that are not solely contingent on sexual functioning. It may help to open their eyes that such relationships are possible.

Emma reported that she and her partner were able to overcome their sexual limitations be-

cause they cared so much for each other. She stated that surgical interventions may be premised on the notion that facilitating a normal sexual life must mean “facilitating coitus,” but she disagreed with that assumption. Instead, she noted, sexual intimacy may include other intimate exchanges such as anal intercourse and oral sex. When people feel cherished, as Emma reported she did, their capacity to respond sexually may be heightened.²¹ Our brains are more malleable, more plastic, than we realize. There are, in reality, many different ways that people may be able to experience heightened sexual sensations, including orgasm. Neuroanatomists have determined that there are nerves in many different parts of our body that lead to a final, common nerve pathway in our brain that gives us heightened sexual sensations.²²

People who care deeply for each other, as Emma and her boyfriend did, may be able to feel heightened sexual sensations with each other in ways that they hadn’t imagined. They may do best by relaxing, finding meaning in their relationship, and expressing their caring for each other. When people relax, their parasympathetic nervous system takes over. This allows them to maximally respond. Remaining in a state of sympathetic arousal, marked by continuing to feel tense, may prevent their maximal response.²³

Rejection

Like Emily Quinn, who wrote about being rejected by a boyfriend, people with DSD—as any of us—may find rejection to be “devastating.” They may feel hurt and rage. Those feelings may become crippling and impair their capacity to engage fully in other relationships. As careproviders, we may be able to help them regain their emotional resiliency. If we can help them to *understand* what happened, it may help them to accept the rejection and move on. There are two possibilities we could raise, and both may help people feel less devastated. But first, we should ask them whether they want to discuss it, and we can say it could be helpful to them, because it could help them to move on.

The first possible reason people might reject a person with DSD is because they are not willing to see whether love can move them to discover new kinds of sexual intimacy with their partner. If they don’t care enough to consider new kinds of intimacy, will they be a good partner in the longer run? People with DSD may want to consider this aspect of their relationship.

Raising such long-range considerations with people who have been rejected may seem grossly insensitive and may risk losing their trust. Still, if we warn them in advance, they may be open to discussion, and it may help. We can say, “Would you be open to discussing how this relationship might have turned out if it continued? Even though I expect this is the last thing you want to think about now.” It may seem that such conversations could take place only with a specialist over a length of time, but that may be all that’s needed to spark new thinking.

The second reason that people with DSD may experience rejection is more subtle. If they hadn’t thought of this possibility, considering it may help. Their partners may have rejected them for reasons that were largely or completely outside their control, *and even outside their awareness*. The partners’ response may stem from experiences they had, but then repressed, so that they were not consciously aware of them.

For example, a patient of mine was deeply in love with a man she wanted to marry, but she had an uncomfortable response when she was with him that she could not overcome. She said he had a facial feature that would “intrude.” I performed with her an “affect bridge,” a type of hypnosis.²⁴ I asked her to recreate the uncomfortable feeling in her mind, in my office, and then go backward in her life and see what came to mind. “Oh my God,” she said. “My boyfriend has a feature just like a boy in my elementary school who bullied me!” Getting in touch with this truth “set her free.” Her discomfort diminished and she married him shortly after that.

The point here is that a partner may reject a person with DSD not because of how the person is, but because the partner has a limitation created by a previous relationship. In a later section I will explain how one of the most important insights we can suggest to people with DSD, and other individuals, is that they may have not recognized another person’s limitations.

Rage

But what about the anger or even rage we may feel toward a person who rejects us? These feelings may limit what people could positively feel for another in the future. One possibility is to try to forgive, if we want to. We may want to forgive when we are able to consider the other person’s limitations. One approach that may be helpful is to suggest they try to recall a time in their life when they felt they wanted to reject

someone. If they can, it may evoke an awareness that they share more in common with the other person than they thought. It may be a way to be more able to forgive the other person. Having done this, it may be more possible move on.

Discussing their Worldview

Like anyone who has been traumatized, people with DSD may ask, “Why me?” This question may occur after a profound trauma. What each of us experience as a profound trauma may greatly differ. Rejection may rekindle the question of “Why me?” from the first time people learned they had DSD. What people understand to be the answer to this question may shatter their worldview. People with DSD, like anyone else, may have believed that life is fair and safe, but, after rejection, they may not know what to believe—as anyone else would, in that instance. This is where careproviders may have a role. Some people, after trauma, find the shattering of their worldview to be so painful that they reject it. For example, a man was mugged in an alley at dusk and rejected the power of this “new reality” by repeatedly returning to the same alley, at the same time of day. That may seem irrational. But, in a way, it was not. Unconsciously, he may have wanted to restore his prior worldview, that his world is safe. If he could take the same walk, night after night, and still be okay, maybe his world *is* safe after all, as he had imagined it to be.²⁵ One trouble is that, psychologically, this approach may not work. Our brain may remember what happened, and may continue to know better. What to do then? When people with DSD are rejected, we can inquire regarding their responses, and, as they construct a new worldview, they may not feel so alone.

Fertility

No area of pediatric endocrinology may engender more controversy than DSD, as they affect reproduction.²⁶ It is important therefore for us to take the initiative to discuss remaining fertile and/or retaining the capacity to carry a child through pregnancy, if and when that is possible, with people who have DSD. Remaining fertile may have no small cost; people with some DSD are at a higher risk of cancer.²⁷ Knowing this risk, family members and friends may discourage or even demean them for wanting to have or carry a child under these conditions. “But you can adopt!” they may say. These are situations in which people with DSD may greatly need our

support, so that they will be as freely able choose what they want as anyone else.

They may want to remain fertile not for themselves and their own wants, but because they can envision meeting a partner who would want to have a biologically related child with them, who might see not being able to do this as a “show-stopper.” Family and friends may demean them for this desire, so again our support may be essential in enabling them to choose what it is they want to do, in the same way that others, who do not have DSD, may choose.

Who Should Know, and When?

An ongoing, painful dilemma for many with DSD is deciding whether they should tell anyone, and, if so, when. Questions regarding secrecy may begin with their parents. Parents may want their child to have early surgery primarily to avoid others’ questions. Parents may choose a child’s name for the same reason. They may choose a name that is clearly only for one gender, rather than one that could apply to either binary gender.²⁸ Limor Meoded Danon describes this pressure as follows: “There are no support groups and I also wonder whether there can be, since many times I have felt that parents want so much to distance themselves from this issue that they don’t even want to define themselves as being part of this thing. . . . In most of the families I’ve met, most of the parents have a hard time acknowledging that we’re talking about what we call intersex but then it’s not even possible to talk to them about intersex.”²⁹

Children may struggle with this same question as they grow up. They may feel embarrassed or even ashamed, for example, if their clitoris is especially large. This may be apparent in a locker room or through a bathing suit. It may be the pre-eminent factor that moves parents and children to seek surgery.³⁰ If teens have surgery, they may feel isolated and lie about why they are in the hospital, because they fear telling others why they are there.³¹ Some make up stories to lead others to believe they can menstruate or become pregnant when they can’t. A person who uses only the name Amanda says, “I also had crafted some pretty good covers for my AIS [androgen insensitivity syndrome], including stories about when I first had my (fake) period, or how I acted fearful about a pregnancy scare in college when a partner’s condom fell off (which was a breeze thanks to beer), or the creation of various hiding spots for my estrogen pill containers.”³²

There may be little we can do to help people with DSD who fear the reactions of others, but sharing the concept of “fawning” may be helpful. Much has been written about how, when individuals are stressed or fearful, they may fight, flee, or freeze, called the “three f”s. Now there is a “fourth f,” called “fawning.”³³ In this alternative, individuals may seek, above all, to please persons they fear. If we are prone to fawning when we feel fearful, it may not be helpful to be told that we do this. It may seem impossible to change. I have been told that therapists sometimes have patients who are “addicted to fawning” get on an elevator with others and then push all the elevator’s buttons to try to help them overcome their compulsive need to please others.

We may be able to help people who fawn when they are stressed or fearful to have better control over their responses. They may benefit from understanding that they are vulnerable to acting in this way, and the result may be that they feel freer to act in a more authentic way.³⁴

Guidelines have been published to help parents and people with DSD deal with these issues. For example, in response to a common question that parents have, “What do we tell our friends and family while we wait for the gender assignment?” the guidelines suggest, “This is important. We strongly recommend being open and honest about your child’s situation. Even if you don’t intend to, lying or withholding information will create a sense of shame and secrecy.”³⁵ Of course, it may be a challenge for parents to convey this information nonjudgmentally.

TWO APPROACHES TO HELP

We may be able to help people with DSD by taking the three initiatives described above. There are two more general ways that may help, perhaps to even a greater extent: helping them to connect with other people with DSD and to more clearly see their strengths.

Mentors and Others with DSD

It is said that people need three things when they are faced with a challenge: a person who has overcome the challenge that they face, a person who has experienced what they are experiencing, and a person who has expertise and can tell them what is going on. Some institutions now offer all three to people with DSD. Emma Quinn, quoted above, is an example of a person with DSD who has done well. Her success, as a

real person who has DSD, may provide hope in a way that careproviders cannot. Careproviders have not “walked the walk,” and people with DSD may see careproviders’ efforts to increase their hope as “part of their job.” We still may provide needed information to people with DSD, and doing so may be critical not only in their decision making, but also to their confidence and feeling that they are more in control.

Edge-of-the-field institutions make mentors and people like Emma Quinn readily available to people with DSD. Careproviders at these places are able to say to parents, for instance, “We know this is challenging, but lots of families like yours are raising happy, healthy children. May we share your contact information so one of these parents can get in touch with you?”³⁶ Some institutions have arrangements so that people with DSD are immediately available, in person or by phone.³⁷ Ideally, when considering surgery, parents and young people should have access to people with the same DSD who had surgery and people with the same DSD who rejected it.³⁸

Helping People See their Strengths

One way to help people with DSD may be singularly beneficial: to help put them in touch with their own strengths.³⁹ This can be done with a person of any age. I will give examples of these for young people who have AIS. First, we can provide them with information about AIS. Second, we can tell them about having the gift of laughter and how they can give it to others. Third, we can share with them about the acquired wisdom they have, and how they are able to share their wisdom with others.

Informing Teens about AIS

This is an example of a careprovider who provided unparalleled care. She was seeing a teenage girl who had AIS. People with AIS have XY chromosomes, those of a male, but their body is not able to respond to testosterone. In almost every way they are female, but they cannot bear a child or carry a child because they lack eggs and a uterus. When the girl was 12, her careprovider told her that all embryos are initially girls and, thus, the building blocks that enabled her to grow had merely been mislabeled. They had an XY on them as opposed to an XX. After this explanation, the careprovider showed the girl a video of a mother with AIS happily raising adopted children.⁴⁰

The Strength of Having and Giving Laughter

Should we provide care for a person with DSD, we can point out any and all strengths we observe. Here are two examples from Emma, the young woman De Clercq interviewed, regarding her relationship with her boyfriend: "After a year of foreplay, we were both dying of desire [laughing] but I did not want to make love before saying something. It did not make any difference to him, he told me he loved me and the same evening we tried to make love, which did not work." She continued, "Vaginoplasty has been practiced for 50 years, yet it is still full of bugs! [Laughing.]" Emma said she and her partner tried to have sex after using self-dilation and lubricants but "his penis was just too big." The experience she described was probably painful physically and emotionally, but her laughter conveys her capacity for humor and her ability to benefit others by sharing it. She has the gift of irony.

Other people that I've quoted in this article show their gift to evoke laughter. Stacy said medical residents "blew it out of the water" with their curiosity about her anatomy. Amanda said, "I also had crafted some pretty good covers for my AIS," and "I acted fearful about a pregnancy scare in college when a partner's condom fell off (which was a breeze thanks to beer)." Why is a capacity for humor such a strength? First, humor is a learned skill and may be the most effective way to instantaneously help someone feel at ease. It helps people who are feeling pain to transcend it. As Carol Tavris, a therapist and expert on anger writes, humor "makes outrage tolerable." Psychologists use "humor therapy," therefore, she points out, to treat patients with "anger problems."⁴¹ Second, humor is a gift we can give others. This was noted by John L. Sullivan, a comedy film writer, who saw prison inmates roaring with laughter when watching slapstick cartoons: "There's a lot to be said for making people laugh. Don't you know that's all some people have? It's not much, but it's better than nothing in this cockeyed caravan."⁴²

Having Wisdom after Experiencing Struggles

Wisdom often is produced by struggling. We may acquire a better understanding of the bigger picture. We may be able to come to see others' unfortunate behavior as the result of their own struggles, which allows us to feel less prematurely or unjustifiably judgemental. Feeling more accepting, we may be more able to love.⁴³

The quotations I have included from people with DSD model this type of love. Why might

they have wisdom more than most other people? They have struggled throughout their lives, since childhood. Emma, interviewed by De Clercq, shows this wisdom. She is aware that she has it, and that she has a right to it. She said that she once thought there was something "monstrous about what she had," but she later described herself to her boyfriend as having "the sex of an angel." What a great example of wisdom after a struggle. Her laughter, recorded by De Clercq, shows she is amused by her own story, and she invites us to laugh with her. This is an example of wisdom, and perhaps we too see her as an angel. Rather than feeling bitter and blaming, she shares her laughter. Some people with DSD may not know they have this kind of wisdom, at least not fully. Thus, when we see this wisdom, we should share that with them. It may be especially important because they are likely to have had instances that challenged their self-esteem.

It may require courage on our part to bring up some of the topics discussed here. Some people may not welcome it, feeling that they don't need it. Lih-Mei Liao, a clinical and health psychologist, writes, "And so the wall of shame remains. We need to learn from doctors who seem more able to role model shame-free communication to positive cascading effects, and from the doctors in the narratives who, I presume, were sufficiently unafraid of the rage of the hitherto poorly served individuals to engage with and assist them."⁴⁴ As Liao suggests, we need to learn how to recognize and authenticate the ways in which, even if hidden, these people are exceptional. When we have the opportunity, if possible, we should try to absorb and bear with them their shame, rage, pain, and fear, to the limited degree we can.

CONCLUSION

De Clercq sums up what she and Emma hope to convey. She says, "By moving away from preconceived notions of what is 'normal' in sex, healthcare providers can encourage intersex persons to explore their existing capacity for sexual relations and enjoyment." I have elaborated on this by discussing our hesitancy to discuss sexuality; our need to change how we learn from people with DSD; the initiatives we can take to discuss sex, fertility, and secrets; and the importance of letting people with DSD know about their strengths, particularly their capacity to experience and give laughter and the wisdom that this reflects.

It is fitting to end this discussion with a quotation from Alice Domurat Dreger from 1998: “All theory aside, in real life sexual variation blends imperceptively one kind into the next. The treatment of people born with notably unusual anatomies isn’t going to be resolved by the discovery of some gene that reveals the ultimate nature of sexual identity. . . . In the end all intersexuals are now asking is to be treated according to the same ethical principles as everybody else. This volume seeks to explore what this would mean.”⁴⁵

De Clercq, in an article she co-authored with Michael Rost and Bernice Elger on pediatric autonomy, presents an overarching aim that they urge for all children: “Therefore, parents have to empathize with the child, have to become aware of the child’s attempts to express her or his needs and, finally, have to respond to them.” “Otherwise . . . the child renounces and betrays her or his true self, desperately adapts to the external world, and surrenders to the will of others to earn their (conditional) love.” Their request is remarkable: “Respond unconditionally to children’s needs and feelings, [and] thereby enhance their capacity to experience them.”⁴⁶

MASKING

The names of people with DSD have been masked, with the exception of Emily Quinn, who publishes under her own name.

NOTES

I thank Norman Quist for numerous insights he gave me on this article.

1. E. De Clercq, “On How Ploughing a Lonely Furrow Might Affect Youths’ Sexual Health,” in this issue of *The Journal of Clinical Ethics* 32, no. 1 (Spring 2021).

2. My use of the word “people” seems uncomfortably impersonal, but it is preferable to other words that seem to medicalize people with DSD. At a recent meeting of Public Responsibility in Medicine & Research (PRIM&R), the word “people” was used to refer to persons who were transgender (or gender fluid or gender nonconforming). L. Bitterman, “Situational Vulnerability Considerations When Exploring Gender Identity, Social/Economic Challenges, and At-Risk Behavior,” Annual Meeting of PRIM&R, 8 December 2020.

3. A.D. Dreger, “A History of Intersex: From the Age of Gonads to the Age of Consent,” in *Intersex in the Age of Ethics*, ed. A.D. Dreger (Hagerstown, Md.: University Publishing Group, 1998). *JCE* published a special issue on this issue in volume 9, no. 4, Winter 1998. Julie A. Greenberg, whose work De Clercq cites,

wrote the sole law review article on this subject at the time. At my invitation she came to Washington, D.C., to present our argument to an eminent legal group to offer these children greater legal protection. The group did not act on our argument.

4. D.E. Sandberg et al., “Interdisciplinary Care in Disorders/Differences of Sex Development (DSD): The Psychosocial Component of the DSD-Translational Research Network,” *American Journal of Medical Genetics Part C: Seminars in Medical Genetics* 175, no. 2 (June 2017): 279-92.

5. “Advocates and clinicians recommend team and communication skills training for health professionals to advance well-being.” P.A. Lee et al., “Global DSD Update Consortium: Global Disorders of Sex Development Update Since 2006: Perceptions, Approach and Care,” *Hormone Research in Paediatrics* 85, no. 3 (2016): 158-80, 167-70; C. Sanders, Z. Edwards, and K. Keegan, “Exploring Stakeholder Experiences of Interprofessional Teamwork in Sex Development Outpatient Clinics,” *Journal of Interprofessional Care* 31, no. 3 (May 2017): 376-85.

6. H.F.L. Meyer-Bahlburg, J. Khuri, J. Reyes-Portillo, and M.I. New, “Stigma in Medical Settings as Reported Retrospectively by Women With Congenital Adrenal Hyperplasia (CAH) for their Childhood and Adolescence,” *Journal of Pediatric Psychology* 42, no. 5 (June 2017): 496-503, 499.

7. G. Davis and E. Feder, “Normalizing Intersex: The Transformative Power of Stories,” *Narrative Inquiry in Bioethics* 5, no. 2 (Summer 2015): 87-9.

8. E. Quinn, “Standing Up,” *Narrative Inquiry in Bioethics* 5, no. 2 (Summer 2015): 109-111.

9. Dreger, *Intersex in the Age of Ethics*, see note 3 above.

10. *Ibid.*, 19.

11. Lee et al., “Global DSD Update Consortium,” see note 5 above.

12. *Ibid.*

13. R. Markosyan and S.F. Ahmed, “Sex Assignment in Conditions Affecting Sex Development,” *Journal of Clinical Research in Pediatric Endocrinology* 9, supp. 2 (2017): 106-12, 108; E. Magritte, “Working Together in Placing the Long Term Interests of the Child at the Heart of the DSD Evaluation,” *Journal of Pediatric Urology* 8, no. 6 (2012): 571-5; K. Schützmann et al., “Psychological Distress, Self-harming Behavior, and Suicidal Tendencies in Adults with Disorders of Sex Development,” *Archives of Sexual Behavior* 38 (2009): 16-33.

14. Meyer-Bahlburg, Khuri, Reyes-Portillo, and New, “Stigma in Medical Settings,” note 6 above, p. 499.

15. Sanders, Edwards, and Keegan, “Exploring Stakeholder Experiences,” see note 5 above, p. 380.

16. *Ibid.*, 379.

17. *Ibid.*

18. Meyer-Bahlburg, Khuri, Reyes-Portillo, and New, “Stigma in Medical Settings,” note 6 above, p. 499.

19. *Ibid.*

20. R. Chawla, M. Rutter, J. Green, and E.M. Weidler, "Care of the Adolescent Patient with Congenital Adrenal Hyperplasia: Special Considerations, Shared Decision Making, and Transition," *Seminars in Pediatric Surgery* 28, no. 5 (October 2019): 150845; J. Raza, S.Z. Zaidi, and G.L. Warne, "Management of Disorders of Sex Development: With a Focus on Development of the Child and Adolescent through the Pubertal Years," *Best Practice & Research: Clinical Endocrinology & Metabolism* 33, no. 3 (June 2019): 101297.
21. C.V. Moura, I.M. Tavares, and P.J. Nobre, "Cognitive-Affective Factors and Female Orgasm: A Comparative Study on Women with and Without Orgasm Difficulties," *Journal of Sexual Medicine* 17, no. 11 (November 2020): 2220-8; J.A. Dickenson et al., "Understanding Heterosexual Women's Erotic Flexibility: The Role of Attention in Sexual Evaluations and Neural Responses to Sexual Stimuli," *Social Cognitive and Affective Neuroscience*, 15, no. 4 (June 2020): 447-65; D.C. de Jong, "The Role of Attention in Sexual Arousal: Implications for Treatment of Sexual Dysfunction," *Journal of Sex Research* 46, no. 2-3 (March-June 2009): 237-48.
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23. A.K. Johnson, A.J. Johnson, D. Barton, and G. Elkins, "Hypnotic Relaxation Therapy and Sexual Function in Postmenopausal Women: Results of a Randomized Clinical Trial," *International Journal of Clinical and Experimental Hypnosis* 64, no. 2 (2016): 213-24.
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27. S. Rowlands and J.J. Amy, "Preserving the Reproductive Potential of Transgender and Intersex People," *European Journal of Contraception and Reproductive Health Care* 23, no. 1 (February 2018): 58-63.
28. Raza, Zaidi, and Warne, "Management of Disorders of Sex Development," see note 20 above.
29. L. Danon, "Intersex Activists in Israel: Their Achievements and the Obstacles They Face," *Journal of Bioethical Inquiry* 15, no. 4 (December 2018): 569-78.
30. D.P. Merke and D.P. Poppas, "Management of Adolescents with Congenital Adrenal Hyperplasia," *Lancet Diabetes & Endocrinology* 1, no. 4 (December 2013): 341-52.
31. Meyer-Bahlburg, Khuri, Reyes-Portillo, and New, "Stigma in Medical Settings," see note 6 above, p. 500.
32. Amanda, "The Truth in Writing," *Narrative Inquiry in Bioethics* 5, no. 2 (Summer 2015): 98-100.
33. J. Virzi, "Fawning: The Fourth Trauma Response We Don't Talk About," *yahoo/life*, 2 January 2020, <https://www.yahoo.com/lifestyle/fawning-fourth-trauma-response-dont-202416242.html>.
34. This may be like the gain from awareness during a panic attack. Patients may fear they are having a heart attack and/or are dying and may repeatedly go to an emergency room. Once they are aware of what is happening, they can tell themselves they are having only a panic attack, have much greater control, and, accordingly, respond differently.
35. Consortium on the Management of Disorders of Sex Development, *Clinical Guidelines for the Management of Sex Disorders in Children* (Whitehouse Station, N.Y.: Accord Alliance, 2006), 38; Accord Alliance, "DSD Guidelines," dsdguidelines.org.
36. Children's Hospital in Denver, Colorado, is "successfully piloting this model." Lee et al., "Global DSD Update Consortium," see note 5 above, p. 160.
37. *Ibid.*, 160.
38. Phoenix Children's Hospital offers the option to meet with an individual with congenital adrenal hyperplasia (CAH) who had surgery and an individual with CAH who chose to defer surgery, so that both perspectives can be gained. R. Chawla, M. Rutter, J. Green, and E.M. Weidler, "Care of the Adolescent Patient with Congenital Adrenal Hyperplasia: Special Considerations, Shared Decision Making, and Transition," *Seminars in Pediatric Surgery* 28, no. 5 (October 2019): 150845.
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41. C. Tavris, *Anger: The Misunderstood Emotion* (New York, N.Y.: Simon and Schuster, 1982), 148.
42. Z. Hitz, *Lost in Thought* (Princeton, N.J.: Princeton University Press, 2020), 173. I thank Norman Quist for making me aware of this book.
43. M. Plews-Ogan, J.E. Owens, and N. May, *Choosing Wisdom* (W. Conshohocken, Pa.: Templeton Press, 2012), 4.
44. L.M. Liao, "Stonewalling Emotion," *Narrative Inquiry in Bioethics* 5, no. 2 (Summer 2015): 143-50.
45. Dreger, "A History of Intersex," see note 3 above, pp. 20-1. This article seeks do likewise.
46. M. Rost, E. De Clercq, and B. Elger, "Arno Gruen's Understanding of Autonomy in Children: Experiencing and Integrating One's Own Feelings and Needs," *Swiss Medical Weekly*, 26 October 2018.