

Talking about intimacy and sex, fun, fulfilment, and connection with young people in the DSD clinic

Introduction

Research, experiences in clinic, and our own dsdfamilies work with youth consultants in 2020-2021 have made it clear that discussion in the DSD clinic with young people rarely moves beyond a medicalised approach to sex and sexual function.

The same research and youth work has highlighted that young people both **need** and **want** to have safer spaces and opportunities to talk with their healthcare professionals (and for many: their peers) about how their atypical body has developed, how to take care of their body and what this means for an intimate relationship, sexual connection, and pleasure.

We want to encourage professionals to think beyond 'sexual function' and to create a space to talk about other issues around sexual health, safe sex, and what 'good sex' may mean for the individual.

We acknowledge that talking about intimate issues does not come naturally to all professionals and have commissioned this piece by Dr Nina Callens (1). It aims to provide some guidance on topics and discussion points, and how to answer questions young people have around sex.

How can we, as healthcare providers, address sexual health topics with young people with different sex development and related conditions?

(by Dr Nina Callens)

Step 1: Self-reflect and evaluate

The research is clear: young people only go as far as we go. Our own inhibitions, even shame, fears, strengths and expectations permeate our work. Our sexual knowledge and comfort join us in our conversations. So, let us turn the lens on ourselves, the health care professionals, first.

- How do we define sexual health?

The real taboo may not be the mechanics of sex or the risks of it but the pleasure it may involve. Sexual health is characterised by both sexual safety and sexual pleasure. Sexual pleasure involves self-awareness and self-acceptance. It is like when you break an arm. It is not enough to remove the cast, but you need to learn to move the arm again, and to enjoy using it.

We are helping people not necessarily to have (functional) sex but think about what it means to have pleasurable experiences. How much of our work centres around pleasure and fun? And when we reduce sex to 'function', we also imply 'dysfunction'.

We want young people first and foremost to grant themselves the permission to explore the pleasurable dimension of life and experience sexual encounters in an atmosphere of curiosity and connection.

- Focus on genitals or performance?

How much are our conversations in clinic focused on reaching an end goal (functional sex) or having a sex script (this is what 'it' is and what 'it' is not) – that is preconceived, built on our own understanding of sexual intimacy, romance, friendship, pleasure.

Is the first step in developing a sense of self linked to understanding one's own body, its limitations and boundaries and having both the confidence and the language to describe what is happening physically and emotionally?

We make love with our whole body, not with our genitals alone (or even at all). We cannot always rely on our genitals to give us pleasurable experiences, they don't always behave like we expect them to behave; but we can rely on other body parts and senses, like our hands, smell, voice, which make the experience of sex meaningful and worthwhile.

How much do we focus on a competitive performance approach with the goal being penetration or orgasm? Or worse, the numbers game, whether it is frequency or time?

- What support do we have in place when working with young people?
Do you/we have colleagues or a peer supervision/consultation group to share young people's questions with? How do we go about finding one or setting one up?

The above questions are like holding a mirror up close and looking at various parts of ourselves and our work, so we can take note of our challenges and map the changes we would like to make. These will be important before we tackle adolescent-friendly conversations.

Hopefully, by starting a positive and non-judgmental dialogue around good, safer and pleasurable sex experiences, we can help young people with DSD continue to make informed choices and decisions about what feels right and pleasant for their bodies – also if that means they have given up on sex altogether. This is how we really (take) care.

Step 2: Leading conversations about sexual health

The words information and communication are often used interchangeably, but they signify quite different things. Information is giving out; communication is getting through. (Sidney J Harris)

We have developed a list of questions that health care providers could ask young people about themselves and their intimate relationships, to help young people explore their behaviours for themselves. The questions may help young people become more self-aware about their sexuality and sexual health. **The list of questions, and the possible answers we have shared to support the conversation, should be considered as a series of dialogues rather than a one-off encounter.** They are not a lecture. Be prepared for the possibility that the young person may not feel the same way or agree with you.

Research highlights the importance of the skills health care providers use to assess a young person's developmental stage and readiness or ability to engage in conversation. Further, listening skills are important as providers must create an opportunity to hear about prior experiences of young people. A combination of active listening and being compassionate allows providers to tailor their communication style and health messages appropriately.

Start out by saying that you are going to talk about something personal, but that it is important because you want to take care of their health and their wellbeing, and you want to make sure both of you are not missing anything.

If you sense that the young person may not be as forthcoming with their parent in the room, suggest or request that the parent leaves the room to allow the young person more privacy.

You can let the parents know, 'We're going to have a sensitive conversation and I want [your child] to be able to speak freely.'

1. Social life, diagnosis and body perception

We recommend asking young people about their social history, diagnosis and body first. You want to know what is going on around them and you want to know who their friends are, things they're interested in, but also how they see their diagnosis, and how they feel about their body.

Examples of questions:

- Can you tell me the name of your diagnosis / condition? What words would you prefer to use?
- Have you met other people with similar a condition? Do you question if you are getting the care (physical, emotional and support) you need from the people you see in the clinic?
- Are you comfortable with the medical team that you have (name here)?

- Do you talk to family about private stuff, or is there anyone else you would want to talk to instead?
- What do you think is the most challenging aspect of talking about your condition?
- Who are your close friends? How would you like them to understand what is going on?
- How would you describe how you are feeling right now? Do you know of a or a poem that captures that feeling?
- When do you feel most safe?
- When do you feel most free?
- What is a great compliment about you and your body that you'd like to receive? What is the best part of your body? When do you feel most beautiful?
- How comfortable are you with nudity, e.g. in a changing room at the gym?

2. Relationships, love and sex

You want then to move on to relationships (friends/partners). Because sexual health is a part of that, you would want to know if and in what ways sex is part of those relationships.

Examples of questions:

- Do a lot of your friends already have romantic or sexual relationships?
- Are you in love right now? How does that feel? Have you ever been in love or felt romantic? How does that feel? **it is possible that young people will tell you that they have no romantic or sexual attraction at all.* [ACES and AROS -asexual and aromantic - may not be terms you have heard before. For a number of young people with and without DSD there is a growing community and research area focused on changing the gender social narrative].' Ace: What Asexuality Reveals About Desire, Society, and the Meaning of Sex, by Angela Chen can be an interesting book to review]
- Have you been hurt in love? Have you ever been loved the way you would like to be loved?
- If you talk about sex and relationships with your friends, at all, what are some of the things that typically come up in your conversations?
- What is something that you perhaps have questions about and (would want) talk to them about? Who can you approach when you have a question about sex and relationships? Where do you find your information?
- Are you ever worried about sharing information about yourself – in the moment, by mistake, when in an intimate space?
- Do you think that other people can tell you've got 'it' by looking at you?
- Have you ever experienced pressure from peers and friends to engage in sex or in an intimate relationship?
- Have you ever asked another person with DSD how they told others about their body?
- Do you currently have a partner?

IF YES:

In 2-3 sentences, what are some of the things that you appreciate about your partner?

In 2-3 sentences, what do you think your partner appreciates about you?

If you could change or improve something about your relationship, what would it be?

How do you think your romantic/ sex life with this partner is influenced by (knowing your) diagnosis? What are some challenges? What do you need to overcome them?

IF NO:

Is being in a sexual/romantic relationship with someone else something you want? Why (not)?

In 2-3 sentences, what would you like your partner to be like?

In 2-3 sentences, what would your partner need to appreciate about you?

How do you imagine your romantic/sex life with this person? Does your diagnosis has an impact, if at all? What are perhaps some challenges? What do you need to overcome those challenges?

3. Sexual health, level of sexual experience and communication

“Is this normal? Will it ever change? Am I doing it wrong? How do I address this with my partner? Am I asexual? What is asexuality? Why is (the lack of) sex giving me so much anxiety? How do I fix this?”

In this final category of ‘Sexual health, level of experience and communication’ a lot of questions can pop up. Sometimes young people will bring their own. Often you as a health care provider will need to be the conversation starter.

Treat this subject like anything else . . . saying: ‘Yes, talking about sex can be a bit nerve-racking, but don’t worry, I discuss this with all clients/patients, when they are ready to talk about it’. Teenagers and adolescents are always afraid of ‘being the only one’ so in a way you are addressing and validating that feeling.

We have created a long list of questions/areas for discussion, as well as some answer examples. In an ideal caregiving/healthcare environment, we would like you to address all of them in your consultations and have the time to explore them with young people. The responses you get will give you lots of information about the young person in front of you, which will inform your care. But more importantly, you ‘role model’ a practice of connection, exploration and curiosity, a practice we want young people to become familiar and safe with.

If you are not in an ideal caregiving/healthcare environment, go through the list and highlight the ones *you* are most uncomfortable with. Those are the ones we specifically want you to practice and try out in your consulting room -not just in words, but emotionally and psychologically as well. *The experience of initial awkwardness is a good reminder of how much courage it takes from young people to voice their questions and concerns.* And when the tension eases up a bit, know that this is what it is all about: creating a positive and different atmosphere. Slow down and connect. Our practice with a focus on respect, communication, consent, and pleasure, influences young peoples' emotional and physical experiences of sex. So, prepare well because how you approach this matters.

Examples of questions:

SEXUALITY

- If you were the author of a book on sexuality, what would the title be?
- When you think of sex, what comes to mind?
- Is there something sexual you would like to experience, something you long for?
- What motivates you to have sex and/or what do you want to get out of it?

Answer example: People long for sex or engage in it for very different reasons. Some people long for love and emotional intimacy with someone else, others want to find a special physical connection. Some people engage in sex because they want to play and enjoy their bodies. Other people are motivated to explore because they want to understand why so many books, and songs and films are made about sexual excitement. Some people want to feel their body work and feel normal through sex. Other people want to explore their gender through sex. Some people look for surrender in sex, others long for control in sex. These are just examples. What do you hope to find in sex? Are there things in your sexuality that scare you?

- Have you ever been hurt sexually? Has anyone ever touched you or asked you to touch them in a way you didn't like?
- Do you feel confident exploring your sexuality? If yes, what helps? If not, what would help?
- How do you feel about being a woman?
- What is your favourite sense when it comes to sex? Seeing? Smelling? Hearing? Touching? Tasting?
- What do you personally consider as a vulnerability in your sexuality or sex life? Vulnerable here can mean worrying about something linked to sex - but it can also mean being vulnerable and trying something outside your comfort zone, but not outside your safe zone, which can support sexual exploration and result in new experiences.
- What do you personally consider as your greatest strength in your sexuality or sex life?
- What is an aspect of your sexual experiences that you would like to keep and what is an aspect of your sexuality that you would like to change?

- What is more difficult for you: to think and talk about sex or to engage in it?
- Are there changes in your sexuality due to health concerns or medication?

MASTURBATION

- Have you tried to touch yourself and are you enjoying that? Would you want tips to increase pleasure during masturbation?
- If you are taking hormone medication – do you think this makes a difference? Have you any questions about hormones and masturbation or arousal?

Answer example:

Self-touch, whether it is through massage, masturbation or tuning in to the way the sun or wind for example feel on your skin, can have lasting effects on the relationship we have with ourselves. Self-touch naturally soothes us and is a powerful tool for self-care.

Masturbation as just one form of self-touch, is a great way to explore and learn about what gives us pleasure and what doesn't. It doesn't need to end in orgasm but is a way to feel physically and emotionally connected to our body. When we masturbate, we are reminding ourselves that we deserve to feel good, to relax, to be turned on, to take time for our own pleasure. We are not dependent on a partner, nor do we need penetrative sex for it.

What could work for you? Turn your computer off, put your phone away. Try thinking of someone you feel attracted to or of a sexual experience you have had that was really good, or an idea of what you think might feel good for your body. Try to sit or lay in different positions. Try using different speeds, motions, or pressure. Have you tried the shower yet? You never know what works for you until you try it. You can use your hands or also use props while masturbating.

READY FOR SEX?

- How do you know when you're ready for sex with someone else? Think about what you want to give and what you may want to receive.

Answer example: This can be exciting, but scary nonetheless! So, what steps should you take mentally and physically? First, you need to ask yourself if the individual you're about to have sex with, is someone that respects your body and someone you trust. Do you also know their sexual health status? Safe sex is great sex! But more importantly, have pulse checks with them, and conversations about your readiness together. Communicate. What is it that you would like to get out of sex together? What does currently stand in the way? What do you need to overcome that obstacle? By remaining curious and open in these conversations, we are asking ourselves and the other: who are we as sexual beings? We don't have to understand ourselves or our partner right away, but those conversations do create a space of acknowledgment and room for exploration and play.

- What do you do to protect yourself from sexually transmitted infections?

LIKES AND DISLIKES

- How do you know what you like, especially if you have not had sex yet?

Answer example: Do you need to be in a relationship with someone to know whether you like them or not? Likewise, with sex, you sometimes just know what turns you on or not. But it is also about exploration and finding out what you like. Be mindful and attentive to what your body tells you and responds to. Hearing about it or reading about already makes you feel warmer? Then you may be interested in trying it out!

All sorts of non-penetrative sex are good ways to see what gives your pleasure and what doesn't. Finding out what you like should be a fun experience. And remember, what you (and your partner) do should be consensual.

- Are you comfortable discussing what you like and don't like with your partner or potential partner? Do you feel perhaps insecure because they had more bed partners than you (ever) had?

Answer example: Everyone is starting with a blank slate with each new partner because we all like different things. So, this may reduce the insecurity or anxiety around the number of partners you have had compared to your partner.

Is your partner actively making you feel insecure, and tells you he/she is better because they had more partners? If that is the case they don't seem to have your best interest at heart, and you might want to think about whether he/she values you.

Talking about sex can be tricky – especially when you have never talked about it before. However, good communication is at the heart of good sex. Frequently, there is the fear that if we talk about what we like or don't like, our partner may not know how to deal with it or possibly 'shame' us. Our partner may also think or worry that we are not happy with what they are currently doing. Start by reassuring them that you enjoy what you do have and open up the dialogue: "I'm really curious about what you like. Are you open to talking about what turns you on?" Or what really turns you off? You can add that you have never really talked about this before and that this makes you nervous. The earlier you open up this dialogue in a relationship, the easier it is.

Dr Nina Callens is a clinical psychologist working with people who feel they want to explore what good sex and relationships can mean for them. Nina has worked with and supported dsdfamilies since 2015, e.g., as a co-author of the dsdteens website and the 'Top Tips for Dilation' booklet (available to download on the dsdfamilies website). She has published extensively around DSD care incl.: Callens, N., Kreukels, B. P., & van de Grift, T. C. (2021). Young voices: Sexual health and transition care needs in adolescents with intersex/differences of sex development—A pilot study. *Journal of Paediatric and Adolescent Gynaecology*, 34(2), 176-189. <https://doi.org/10.1016/j.jpaga.2020.11.001>

