

Developing a 'notepad' tool to guide clinical conversations with young women with difference in sex development



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With thanks to DSD Youth Ambassadors, dsdfamilies Trustees and Dr Williams

About dsdfamilies



Dsdfamilies is an information and peer support charity for families. Established in 2011 the Charity has developed a range of resources and been involved in many different aspects of work with policy, health and national partners.

Problem: Young people had questions about their body

Consultation with Young People

Dsd families commissioned work (2020-21) led by a youth advisor who engaged young people to explore what issues were important to them.

Young People

The young people decided they would act in a consultancy role to develop and review information/resources with others

Funding

This work has developed further resulting in several outputs

- 1) Insta-account developed and led by young people
- 2) the notepad and supporting resources
- 3) Podcast stories, and
- 4) Study with the Centre for Appearance Research

Notepad



Close the gap

Why think about a Notepad idea

Target

Those working with Young People in transition services of adult clinics

Goal

To open up conversation about topics that can be sensitive for the young person and or the provider

Easy to use

Simple design that gives all parties the opportunity to ask questions

Designing the Notepad

Questions

The youth consultants captured their conversations and share their idea with the study team

Building Questions

The questions generated from the topic areas young people highlighted

Tested

The questions were reviewed by young people and dsdfamilies panel of experts to provide feedback

Re Building Questions

The questions were re-ordered and refined in light of feedback and re-circulated to the youth consultants



This Notepad and these questions have been produced to help open up a conversation about what matters to you. Revisit these questions and add your own at any time.

MY BODY AND ME

- Does my condition have a name, how did it happen? How often does it happen?
- How is my body different to that of my friends?
- What does this mean for my health and everyday life, and can I do all the same things as my friends and peers?
- Is there someone else in this clinic who I can talk to about how this makes me feel?
- Do I need to tell my school/college about my condition?
- Is it normal to feel sad or down because of my condition or feel anxious and lonely because of my condition?
- Will I be able to have a 'normal' life?

Questions around medication (may not apply to all)

- Do I need to take medication because of my condition and to stay healthy? Or is this medication optional/aesthetic (e.g. to grow a bigger chest if I lack hormones to do so)?
- Do these medications have any side effects? Will I be on them forever?

Questions around vaginal dilation (may not apply to all)

- Why dilate and how do I know when I am ready?
- What do I do if I can't find a private place to dilate?
- Can I change my mind and decide to have surgery if I started dilation myself?

'BE OUTSPOKEN. BE UNAPOLOGETIC.'

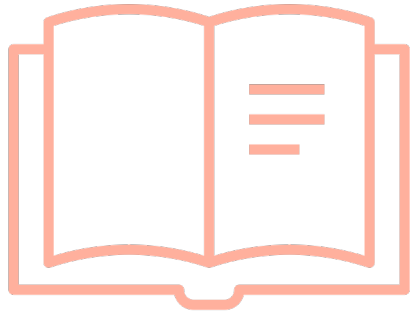
RELATIONSHIPS, FRIENDSHIPS AND PEER SUPPORT

- How can I explain this to my family and friends?
- How can I explain it in a way that pays attention to my culture, and ethnicity?
- My family never talks about sex and private body parts - What if I cannot talk to them about this? What if they do not understand how this can have happened to me?

Why Paper (QR)

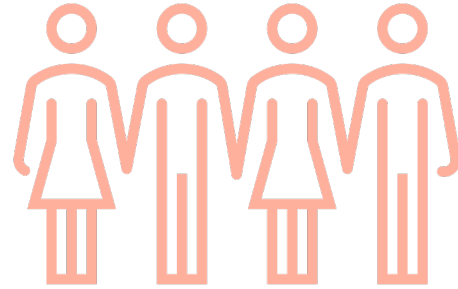
The consensus was there was a hope that by using a paper document there was an opportunity to use this as a tactile resource in the clinical space.

The Notepad: Supporting Documents



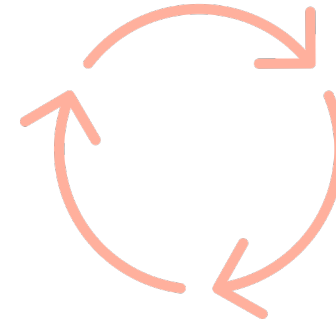
How to use the Notepad

The decision was to develop a tool that could be used in clinic



Knowledge

Young people were aware that providers may not wish to talk with them in clinic – development of a talking about intimacy tool to support providers



Design

Youth consultants developed the resource format and colour choice

Resources



Part 1

Why the Notepad
and How to Use it



Part 2

the Notepad



Part 3

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



Part 4

Through my eyes -
learning about and
living with a DSD
(MRKH) from a
Black point of view



Summary