

Through my eyes - learning about and living with a DSD (MRKH) from a Black point of view: inform care and guide the Notepad use in clinic

Introduction

Our MetroCharity/Comic Relief funded 2020-2021 work with dsdfamilies youth consultants from black and Asian backgrounds highlighted the need to get across -urgently and clearly- the distinct challenging experience of young British women from black and Asian backgrounds learning about and living with a DSD.

Our objective as part of our BritSpag funded Notepad project had been to produce a series of recommendations but after reading Gabrielle N.'s written piece, we decided that this work is bigger than what dsdfamilies can deliver. *Seeing this through Gabrielle's eyes should make us all stop for a moment and question what we are doing, and how we are doing it.*

We call on BritSpag, other DSD related professional societies and NHS partners to prioritise working with dsdfamilies and especially our youth consultant Gabrielle to address the specific challenges faced by our youth from different cultural backgrounds and their families.

Through my eyes

by Gabrielle N

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As a black female who grew up in a west African household, I can wholeheartedly say the experience I had learning I had a DSD was completely different to my White counterpart. I'd like to make it clear that race aside no experience is the same – however, the hardships and difficulties people of colour with DSD's face is something that many need to take into consideration when talking to/approaching parents from different cultures and countries.

It's important to understand that people from different backgrounds are not open to talking about this topic. For some it's against their beliefs and for others it's an uncomfortable topic as they do not have the type of relationship with their child where they can openly talk about something so private.

When it comes to African and Asian households, it is important for most but not all parents to ensure their children are 'perfect', they want their kids to have the best education and get a good job then eventually get married and have kids of their own. Anything that stops this could be considered a problem or curse or deformity which can result in more trauma to be done to the child.

Key issues:

Access to a therapist, psychologist: When talking about DSD's and how to come to terms with it; we often mention support, not everyone has the support that others have. However, *as a black female with a DSD I think it is important to understand that it's common for young people from Black and Asian community to have no support at all.* This really affects our mental health which is something the community struggles to deal with.

In many households' mental health is ignored or hidden and a lot of parents don't believe in using therapists or psychologists at all. Instead, they will turn to their religion however, this again, could affect the young person.

Support: Again, with support, many young people from Black and Asian households may not receive any support from their families. Many of us find it hard to talk about our DSD as we were raised to not talk about such private things. In many of these households it's hard to talk about certain issues with parents such as sex because it can be seen as disrespectful. For many, having a DSD will be ignored by the family because it is 'embarrassing' for the parent. I think this all needs to be taken into consideration.

Access to information: Another issue would be gaining access to information. Again, if your parents or carers are from another country or background, they could genuinely find it difficult to find help, as already mentioned, most families from these backgrounds prefer to be private and would not confide in other family members. For the young person it's different. *Finding help can be difficult, when searching online and looking at forums it can be very overwhelming, especially if most people you see offering help and support look nothing like you.* Most people find it more comfortable to talk to people who look like them, as they most likely have a lot more in common. It feels uncomfortable to talk to a middle-aged white female about dilation and sex when you've never even talked to your own mother about it. Not only that but when it comes to dilation you are usually offered the option to have surgery or told to find a private space, get comfortable and do it naturally. *What if you don't have a private space? What if you share one bedroom with four sisters? What if you're scared to ask about surgery because your parents are against it?*

Lack of sex education: In many ethnic minority households, religion is extremely important. A lot of parents avoid talking about sex or anything around the subject. It's very taboo and can be frustrating for those of us who have a DSD. *How can we communicate openly if we must avoid certain subjects?* Many Black adults grew up without receiving sex information from their own parents. It's tough to replicate experiences that weren't taught for them, and many of today's

Black parents grew up with incorrect and negative messaging about sex. The desire to protect their daughters from racism and white supremacist beliefs about Black sexuality has traditionally affected Black parents' apprehensions about discussing sex with their daughters. Black people were stereotyped as being hypersexual and morally ambiguous in the past. These historical misconceptions still exist, which may explain why some Black parents and caregivers avoid the topic.

Related topics: A lot of people with DSD's call themselves intersex which is often tied with the LGBTQ community, another taboo in the Asian and Black community. Although many support, there is still a lot of traditional households who don't 'believe in it' and don't agree with it. A lot of us understand this which is also a big worry for us. As some parents will misinterpret DSD's for being gay etc. It does sound weird, and it may not make sense, but this is really how some people think which is why I do think the way how we explain these things and the language we use is important.

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