

DisRUPTing THE NORM

Giving a voice to young people with Differences of Sex Development (DSD) or Variations in Sex Characteristics (VSC)

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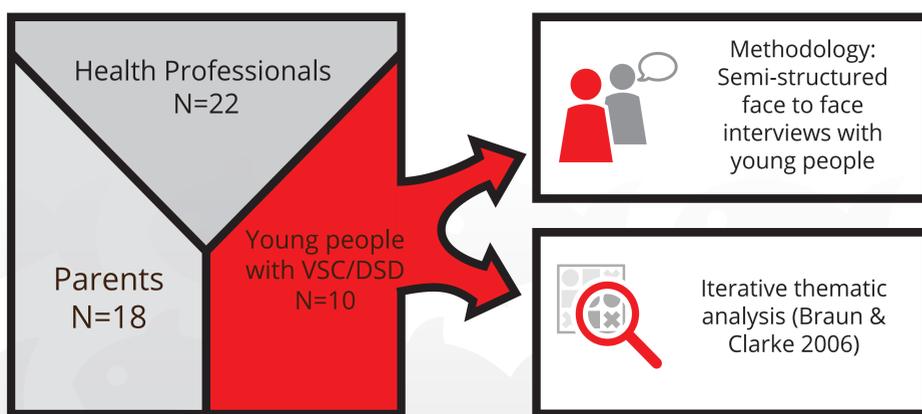
Background:

The experience of older people with a VSC/DSD is relatively well documented. But medical practice is changing rapidly, so we need to understand the recent experience of younger people with VSC/DSD.

Aim:

Qualitative research designed to document the experiences of young people with VSC/DSD living in Aotearoa/New Zealand.

Methods:



Demographics

Gender	Age Range	Variation
Female N=9 Male N=0 Non-binary N=1 (gender queer)	14 - 23 yrs under 20 yrs N = 5 over 20 yrs N = 5	Congenital Adrenal Hyperplasia (CAH)N=2 Mayer-Rokitansky-Kuster-Hauser syndrome (MRKH) N=3 Complete Androgen Insensitivity Syndrome (CAIS)N=1 Cloacal Anomaly (CA)N=1 Swyer's /Gonadal Dysgenesis N=2 Turners syndrome N=1

Findings:

- Variety in individual experiences – positive and negative
- Diversity of support offered to young people by health professionals underpinned positive experiences

Conclusion:

- Many young people could embrace diversity and accept their difference when supported to consider the option of thinking beyond the confines of “the Norm” and disrupt long held binary stereotypes
- Participants found this support amongst peers with VSC, but rarely from health professionals
- We recommend improved communication skills and bias training for health professionals, and delaying non-life/organ threatening interventions to enhance bodily autonomy

References

Virginia Braun & Victoria Clarke (2006) Using thematic analysis in psychology, *Qualitative Research in Psychology*, 3:2, 77-101

Acknowledgements

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Main themes

Challenging the Norm

“I’m sick of the old norm, I am the new Norm and the new normal starts now”

“I just believe that if we start to like accept abnormal bodies as normal, then like this is not so much of a problem”

Bodily Autonomy

“I can see both sides, I can see why you wanna do [genital surgery] earlier but I think it would be better to wait for the person to decide for themselves”

Bias

“I think a lot of medical professionals aren’t aware of how much they’re buying into standard stuff... majority of doctors are ...Cis and straight and not intersex, right?”

“no matter how much corrective surgery you perform on someone, you’re telling them that there’s an ok body and there’s a not ok body and ...the fact that they have to intervene early tells you that, you know, ...you couldn’t possibly live this way”

Communication

“no one wants to talk about us as people really, they want to talk about us as case studies and not think about our feelings because doctors don’t deal with feelings.”

“[information given by doctor] needs to be so much clearer so ...that people feel ...I can still be normal and live in this body the way that it is...”

Support

“there’s [no services] to really address ...the way you feel about it in yourself or how it’s affecting you now, all that kind of stuff, the psychological part of having it”

“I used to think that it was really rare... we’ve found [other peers with VSC]... it’s nice to know that it’s like not only me”

Identity

“as much as it challenged my identity in the beginning, it almost like reaffirmed my identity towards the end, like knowing who I was and being ok with not being normal, you know...”

“We are all 100% human”

Implications

Education and training for health professionals

Foster caring communities for young people by:

- Peer support -encourage contact with online support groups
- Parent support – help parents access resources and offer different points of view
- Psychological support - explore young people’s feelings around difference
- Developing sense of identity that supports diversity and acceptance



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