**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:**

**Health Professionals**

- N=22

**Parents**

- N=18

**Young people with VSC/DSD**

- N=10

**Methodology:**
- Iterative thematic analysis (Braun & Clarke 2006)

**Demonstrations**

- Gender
  - Female N=9
  - Male N=6
  - Non-binary N=1

- Age Range
  - 14 - 23 yrs
  - under 20 yrs N = 5
  - over 20 yrs N =5

- Variation
  - Congenital Adrenal Hyperplasia (CAH) N=2
  - Swyer’s /Gonadal Dysgenesis N=2
  - Mayer-Rokitansky-Küster-Hauser syndrome (MRKH) N=3
  - Complete Androgen Insensitivity Syndrome (CAIS) N=1
  - Cloacal Anomaly (CA) N=1
  - 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.

**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”

**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”

**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”

**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