

Clinician perspectives on management of Disorders/Differences of Sex Development (DSD) in Aotearoa/New Zealand: a qualitative study



WELLINGTON

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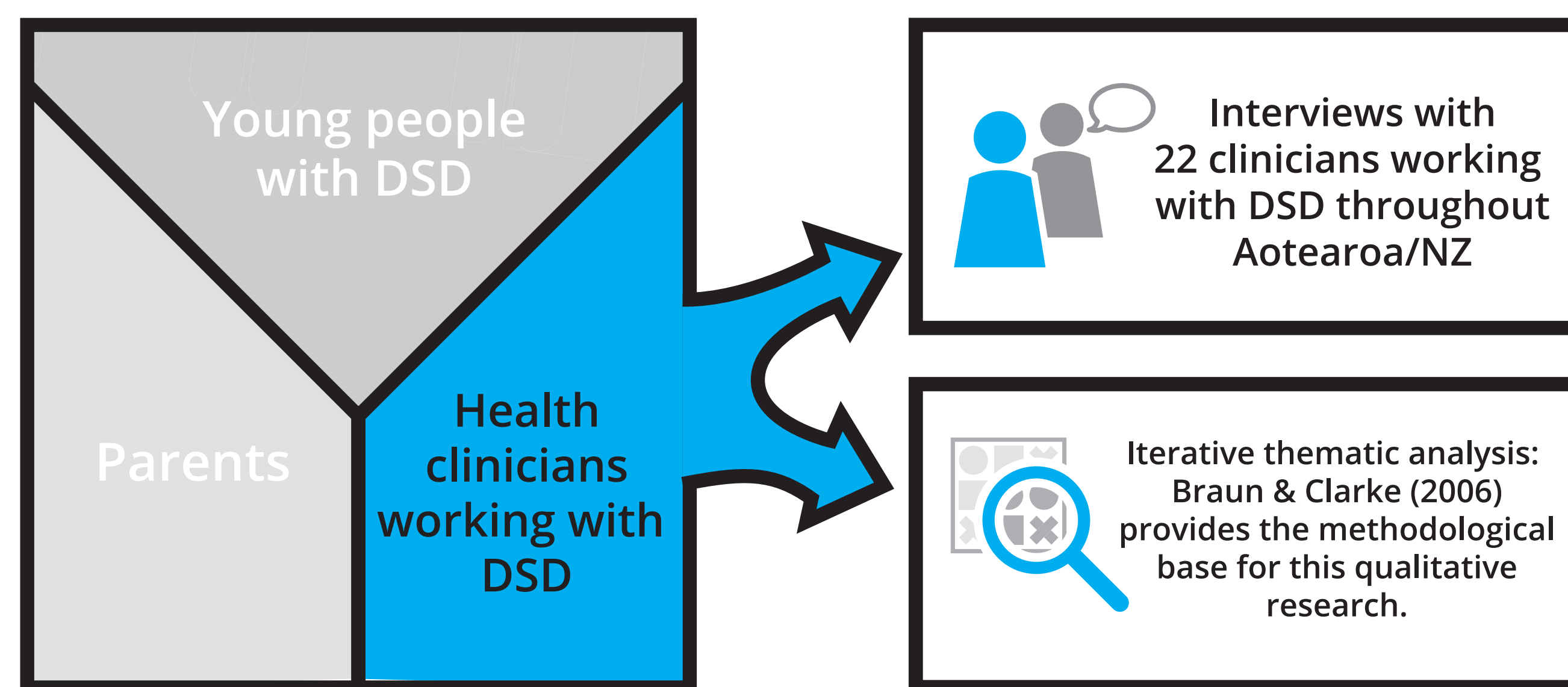
Background:

- Gender is usually seen as a binary construct based on biology
- This is challenging for young people with DSD
- Clinical management & decision making:
 - are challenging, complex and often controversial
 - are ethically complex
 - involve multiple decision points
 - have divergent and sometimes uncertain consequences

Research Question:

What influences decision making for young people with DSD from a clinician's perspective?

Methods:



One component of larger qualitative study

Gender Female N=9 Male N=13	Age Range 36-45yrs N=10 46-55yrs N=4 56-65yrs N=5 66-75yrs N=3	Clinicians Endocrinologist N=11 Surgeon N=8 Allied Health N=3
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Findings:

The clinicians considered that overall, decision making is shared. They felt a responsibility to provide clear clinical information and guidance to parents, but that it is the parents who are ultimately responsible for the final decision.

Influences on Decision making:

Recognition of past mistakes/ learning from patient experience

"well medicine in general is a lot less paternalistic than it used to be... and health professionals hopefully realise that it's important to involve patients and families in their own care... and that they have a right and should be involved in the decision making process rather than just being told what to do by someone in an ivory tower with a stethoscope around their neck" HP5

Great expectations'- social norms and stereotypes

"I think well you have to think about what parents want and what their expectations are..." HP22

"It's just a peer pressure and having a normal child, you know that's as simple as that and especially in situations where you've got, you know your child's genitals are exposed to other people in day care centers and nurseries and things like that, that it's got to be really difficult to handle" HP13

Communication Challenges

"the thing that makes or breaks your future relationship with the family and the patient is your communication right at the beginning and your respect for them and for what they're having to deal with and so I think that that's really paramount and most ethical guidelines don't talk about that at all" HP5

"so it's not always easy as the health professional to have the conversations and you understand very well when you're on the other end of the table, you don't always want people to raise things so you're trying to do a good job and you're trying to think of the entirety of the issues" HP20

"Availability of any psychological support as in professional psychologists, you know and getting that or trained social workers who would be willing to come in, involved in that situation is, from my perception on zero..." HP15

"My job's a hormone doctor, I'm not a head doctor" HP2

Unintended Bias

"I mean what are the schools going to do in the future? They going to have a male a female and another toilet for those who don't quite know?" HP2

"it's more a fashion statement than a true orientation... [that high school girls] are attracted to the same sex, they're more heterosexual [laughs]" HP19

"I try and say do you have a partner (and I just forget) ... look I'm just a product of my generation, you know it's just, yeah and I shouldn't be" HP21

"No I don't think it's correct to give parents a list of options because that's Sophie's choice, I mean they don't know what to do, I think you need to give them an educated clinical opinion..." HP15

Some clinicians were aware of bias:

"...always being careful that our own personal opinions aren't overriding everything. And again, that's why I think all of these patients are best managed within a group setting, so that... you know, someone's personal preference or bias isn't colouring the advice you're giving to the families." HP17

Conclusion:

Clinicians are motivated to facilitate informed, shared decision making. However, this is difficult to achieve in practice.

What does this mean for you?



What's needed?

Targeted professional development and reflective practice to help clinicians:

- increase their awareness and insight
- reduce unintended bias
- develop advanced communication skills
- understand patient perspectives
- address ethical issues

Health system improvements:

- Multi-disciplinary teams including psychologists and patient advocates
- Specialist national centre in Aotearoa/NZ

References

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

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