

# Gender Mender or Defender?

## Understanding decision making in Aotearoa/New Zealand for people born with Variations in Sex Characteristics

Denise Steers<sup>1</sup>, Esko Wiltshire<sup>2</sup>, Angela Ballantyne<sup>3</sup>, Maria Stubbe<sup>3</sup>, Sunny Collings<sup>1</sup>

<sup>1</sup>Suicide and Mental Health Research Group, <sup>2</sup>Department of Paediatrics & Child Health, <sup>3</sup>Department of Primary Health Care & General Practice, University of Otago.

### Background:

People born with a variation in sex characteristics or Difference of sex development (DSD/VSC) face the challenge of having atypically sexed bodies. This qualitative study recruited young adults with DSD/VSC; parents of children with VSC; and health professionals

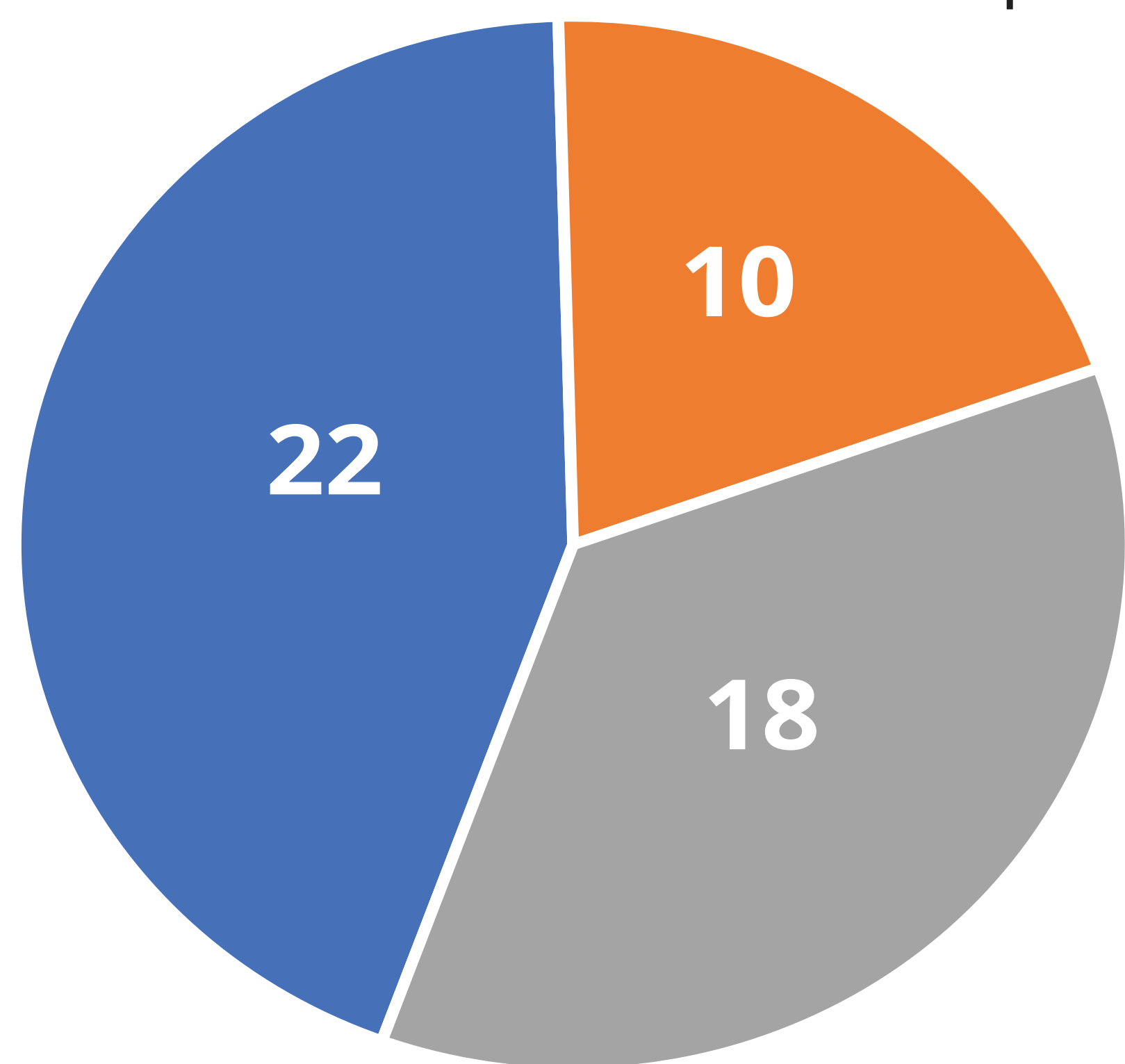
This study was conducted in collaboration with the Intersex trust of Aotearoa/New Zealand (ITANZ).

### Aim:

To identify key themes regarding participants' experiences of decision-making in the health care setting.

### Methods:

Research participants N=50



- Young people
- Parents
- Health professionals

Methodology: Semi-structured face to face interviews with participants

Iterative thematic analysis (Braun & Clarke 2006)

### Research originality:

This research is original and innovative in three ways – it demonstrates close collaboration between activists and academics through all stages of the research design and conduct; it provides a unique 360-degree perspective integrating the views of clinicians, parents and young people; and it fills a gap in the literature by capturing the voice of current young people living with VSC.

### Demographics:

Group	Gender	Age Range	Variation
Young people	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
Parents	Female N=13 Male N=4	28 - 49 Years	Children's variation Congenital Adrenal Hyperplasia (CAH)N=5 Severe hypospadias N=3 Partial Insensitivity Syndrome (PAIS) N=3 Complete Androgen Insensitivity Syndrome (CAIS)N=1 Cloacal Anomaly (CA)N=1 Denys Dash N=1 Turners syndrome N=1 46,XY N=1
Health professionals	Female N=9 Male N=13	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

### Findings:

Four common elements across the three participant groups influenced decision making: communication, bias, norms and support

There were two additional themes for each participant group.

- Health professionals: recognition of the past and expectations
- Young people: bodily autonomy and identity
- Parents: what's right and future worries

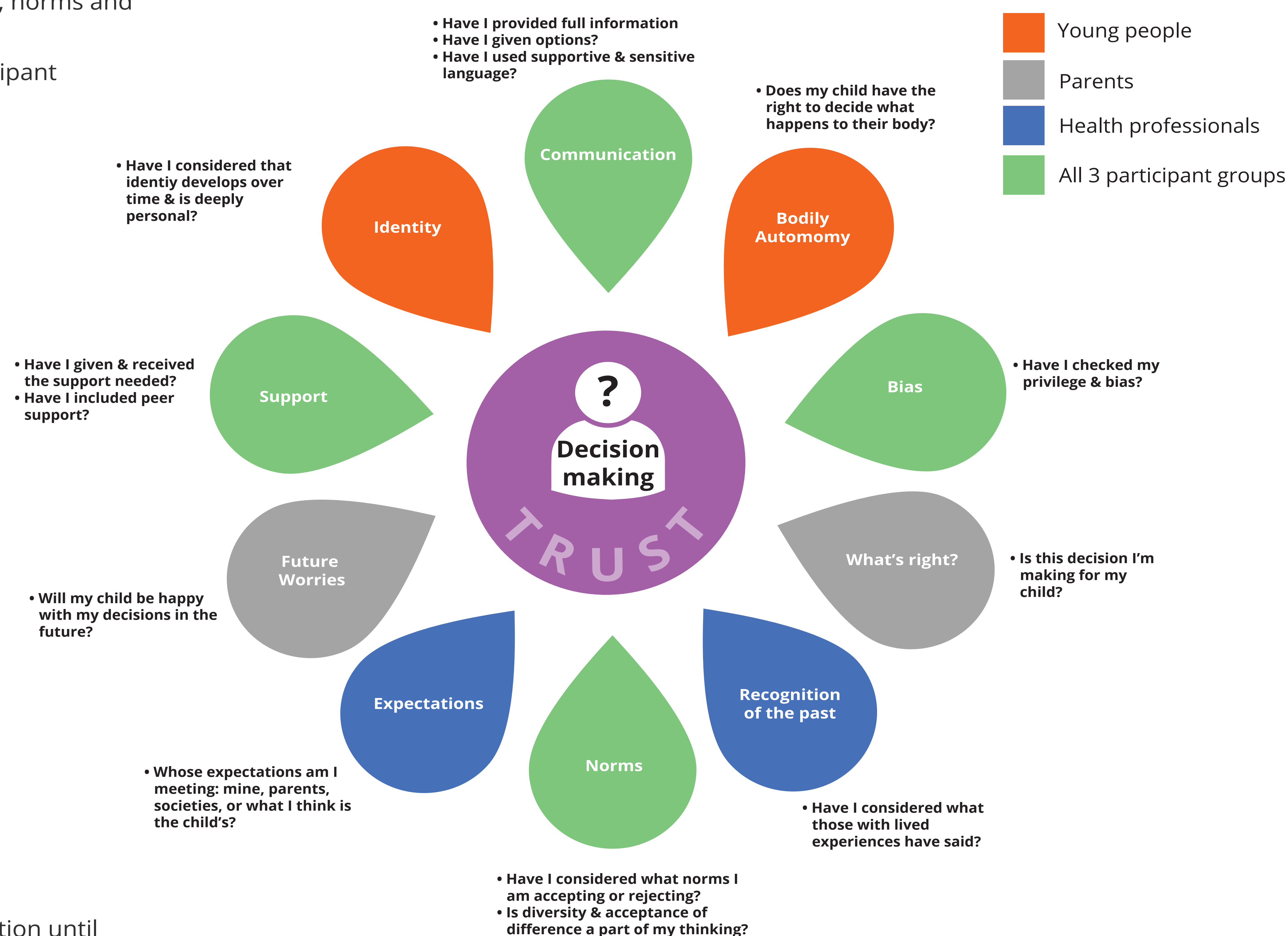
All these elements underpinned the overarching element of trust. These elements of influence could be experienced as either positive or negative depending on the circumstance (e.g. the way information about diagnosis was communicated could be sensitive or insensitive, psychological/peer support could be offered or not)

### Conclusion:

Better health care is needed and change can be supported by:

- Providing enhanced training and education for health professionals regarding communication skills and implicit bias
- Developing better supports for parents and young people, especially peer support and specialist psychological support
- Championing bodily autonomy, recommend delaying appearance based surgical intervention until a young person can have agency to decide for them selves
- Challenging the norm, and accepting that difference is part of a diverse society
- Always including people with a VSC in service development and delivery
- Ongoing research supporting active change

### Decision making process using research elements influencing decision making



### References

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

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### Contact

Denise.steers@otago.ac.nz



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