Research affecting outcomes for children born with variations in sex characteristics/intersex/DSD

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Background

- Long history of controversary around care
- 2006 beginning of change to health care
- Recommendations slow to happen
- Rise of Intersex activists and awareness
- More qualitative research involving lived experience
- More recognition resources needed
- Increasing frustration from advocates over lack of significant change
- Legislation





These are intersex children in an old medical archive, defaced and depersonalized as "pseudo hermaphrodites"





Research question



What are the elements influencing decision making for children born with a variation in sex characteristics (VSC) in Aotearoa/New Zealand





Research to Resources

Denise Steers	Gender mender, bender or defender
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vsc VSC - A Practical Guide for Parents in Aotearoa NZ

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Promoting healthy and positive outcomes for people born with a variation in sex characteristics (VSC)



Kia ora, nau mai, haere mai, welcome.

Rights-based framework

- Self determination
- Guidelines
- Delay non-essential surgery
- Training

- Self determination
- Avoiding past mistakes
- Honoring lived experience



- Self determination
- Bodily autonomy
- Valuing lived experience
- Communication and collaboration

- Self determination /Rangatiratanga
- Takatāpui, Ira tangata valuing Māori world view

How do we do better ?

- **1.** Use a Rights based framework
- 2. Listen to and acknowledge the lived experience of people living with an VSC
- 3. Work with Te Tiriti o Waitangi
- 4. Co-design with Māori and people with lived experience clear, flexible and accessible pathways of care
- 5. Recognise every encounter with the health system is inherently psychosocial
- 6. Pay explicit attention to psychosocial experience and outcome
- 7. Practice humility and "intellectual candour"
- 8. Remain emotionally aware and reflexive
- 9. Recognise collaboration and open communication is key to creating a better outcomes

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Resource https://vsc.org.nz/

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Steers, D. M. 2020. "Gender Mender, Bender or Defender: Understanding Decision-making in Aotearoa/New Zealand for People Born with a Variation in Sex Characteristics." PhD diss., University of Otago. https://ourarchive.otago.ac.nz/handle/10523/9986

Lee, P. A., C. P. Houk, S. F. Ahmed, and I. A. Hughes. 2006. "Consensus Statement on Managementof Intersex Disorders. International Consensus Conference on Intersex." Pediatrics 118 (2):e488–e500.doi:10.1542/peds. 2006-0738

Lee, P. A., A. Nordenstr€om, C. P. Houk, S. F. Ahmed, R. Auchus, A. Baratz, K. Baratz Dalke, L.-M.Liao, K. Lin-Su, L. H. J. Looijenga, et al. 2016. "Global Disorders of Sex Development Update since 2006: Perceptions, Approach and Care." Hormone Research in Paediatrics 85 (3):158–180. doi:10.1159/000442975

Cools, M., Nordenström, A., Robeva, R. *et al.* Caring for individuals with a difference of sex development (DSD): a Consensus Statement. *Nat Rev Endocrinol* **14**, 415–429 (2018). https://doi.org/10.1038/s41574-018-0010-8

New Zealand Human Rights Commission (NZHRC). 2018. Intersex Roundtable Report 2017: Ending the Practice of Genital Normalisation on Intersex Children in Aotearoa/NewZealand. https://www.hrc.co.nz/files/9615/2270/4142/HRC_Intersex_Roundtable_2017.pdf

Rich et al. The Increasing Prevalence in Intersex Variation from Toxicological Dysregulation in Fetal Reproductive Tissue Differentiation and Development by Endocrine-Disrupting Chemicals. Environmental Health Insights 2016:10 163–171 doi: 10.4137/EHI.S39825

Sandberg DE, Gardner M, Kopec K, Urbanski M, Callens N, Keegan CE, Yashar BM, Fechner PY, Shnorhavorian M, Vilain E, Timmermans S, Siminoff LA. Development of a decision support tool in pediatric Differences/Disorders of Sex Development. Semin Pediatr Surg. 2019 Oct;28(5):150838. doi: 10.1016/j.sempedsurg.2019.150838. Epub 2019 Sep 13. PMID: 31668291; PMCID: PMC6911706.

Suorsa-Johnson KI, Gardner MD, Brinkman W, Carley M, Gruppen L, Liang N, Lightfoot S, Pinkelman K, Speiser PW, VanderBrink B, Wisniewski J, Sandberg DE, Stacey D. A survey of healthcare professionals' perceptions of the decisional needs of parents with an infant born with a disorder/difference of sex development. J Pediatr Urol. 2022 Sep 28:S1477-5131(22)00380-1. doi: 10.1016/j.jpurol.2022.09.015. Epub ahead of print. PMID: 36244898.

Chawla R, Weidler EM, Hernandez J, Grimbsy G, van Leeuwen K. Utilization of a shared decision-making tool in a female infant with congenital adrenal hyperplasia and genital ambiguity. J Pediatr Endocrinol Metab. 2019 Jun 26;32(6):643-646. doi: 10.1515/jpem-2018-0567. PMID: 31145695.

Gramc M, Streuli J, de Clercq E. Multidisciplinary teams caring for people with variations of sex characteristics: a scoping review. BMJ Paediatrics Open 2021;5:e001257. doi:10.1136/bmjpo-2021-001257