

Project SENS

- An international psychological research study conducted in **Scotland, England, Norway, and Sweden (SENS)**.
- We examined how diverse people make **SENSe**, in their own words, both of sex development that diverges from binary sex norms, and of the clinical interventions brought into play in relation to such development.
- We conducted in depth interviews with (1) young people, (2) parents and carers, and (3) medical professionals.
- We also conducted focus groups with naïve people, not personally or professionally involved with issues of diverse sex development.



Tove Lundberg,
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Peer Reviewed Articles from SENS Project

Vaginal Construction and Treatment Providers' Experiences: A Qualitative Analysis

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Making sense of 'Intersex' and 'DSD': how laypeople understand and use terminology

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ABSTRACT

Various umbrella terms refer to sex characteristics that do not fit typical binary notions of somatic sex. Key terms include *Intersex*, reclaimed by 1990s activists, and *Disorders of Sex Development (DSD)* used in medicine since 2006. Professionals across diverse disciplines express strong preferences for specific terms, making assumptions about what those terms do. Here, we draw on 10 focus group-interviews (41 participants without particular knowledge of Intersex/DSD), and semi-structured face-to-face interviews with 33 parents and 22 young people with personal experience of Intersex/DSD to examine how diverse laypeople understand and

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From Knowing Nothing to Knowing What, How and Now: Parents' Experiences of Caring for their Children With Congenital Adrenal Hyperplasia

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Shaping parents, shaping penises: How medical teams frame parents' decisions in response to hypospadias

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Introduction. Psychological research provides insights into how parents approach medical decisions on behalf of children. The medical decision of concern here is the surgical alteration of a hypospadiac penis, whose urethral opening does not appear at the tip. Hypospadias surgery is routinely carried out in infancy, despite criticism by international organizations concerned about children's rights. The focus of this study is on the framing of hypospadias surgery.

- All parties in the debates about medicalization and surgery agree that there is a distinction between “medically necessary” and “cosmetic” interventions on intersex characteristics.
- We found variability in how healthcare professionals “draw the line” between *medically necessary* and *cosmetic* interventions.

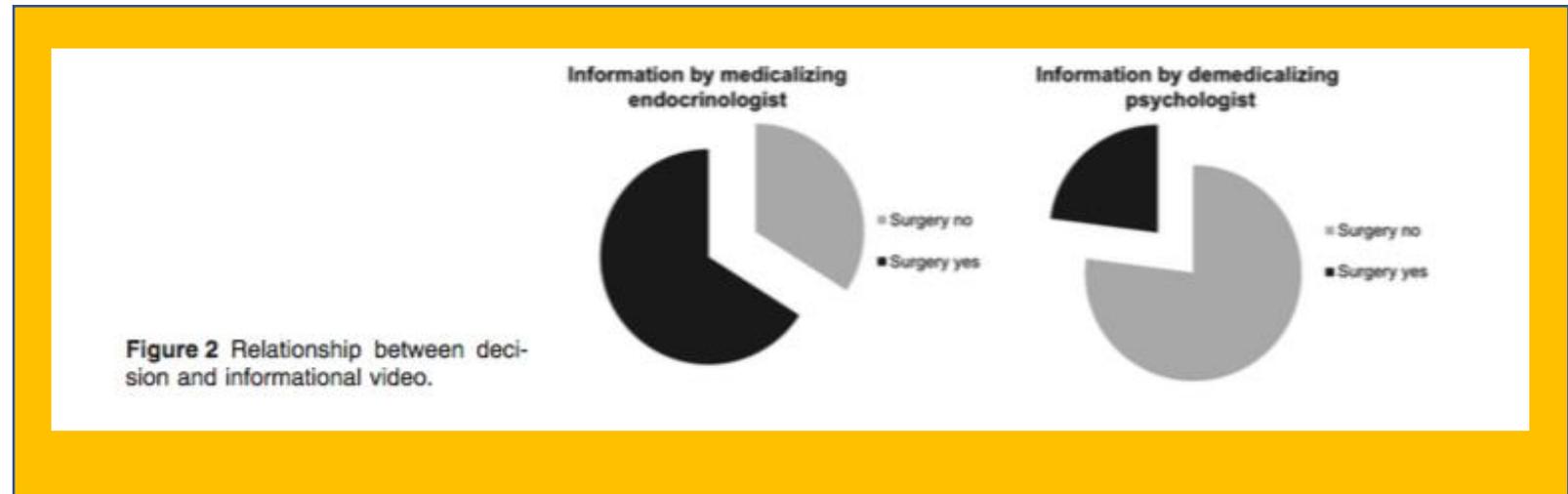
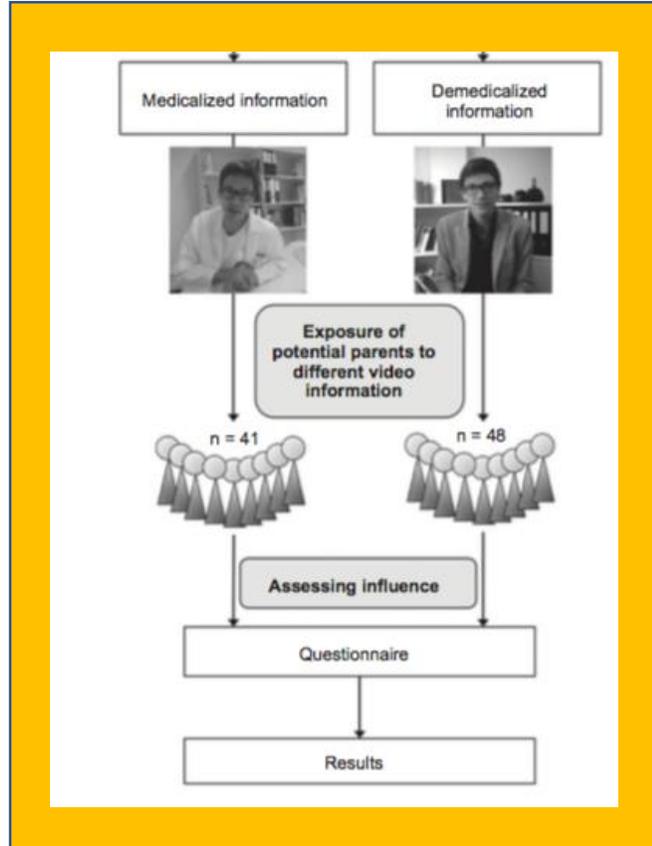
- All parties in the debates about medicalization and surgery agree that there is a distinction between “medically necessary” and “cosmetic” interventions on intersex characteristics.
- We found variability in how healthcare professionals “draw the line” between *medically necessary* and *cosmetic* interventions.
 - **CLINICIAN 1:**
 - ***Ah, give the young person an opportunity to, you know, particularly as a boy to, you know, be continent to not least stand up at the urinal with his pals and pee in the pot at the same time rather than, so you know. You know if you’re talking about hypospadias I think it, my own personal view is one should try and sort this out early in life.***

- All parties in the debates about medicalization and surgery agree that there is a distinction between “medically necessary” and “cosmetic” interventions on intersex characteristics.
- We found variability in how healthcare professionals “draw the line” between *medically necessary* and *cosmetic* interventions.
 - **CLINICIAN 2:**
 - ***In hypospadias, 99.9% of families would have surgery, even for the mildest, because they think that, you know, their child will grow up with a stigma, you know with a problem. Will be teased when other boys see their penises they'll tease them and the reality is that doesn't happen, because children these days do not look at other people's, other children's penises, they just don't do that. So, I'm not sure whether it's medically essential.***

The “Natural Attitude” of a Gender Binary System.

1. There are two and only two genders.
2. One's gender is invariant.
3. Genitals are the essential sign of gender.
4. Any exceptions to two genders are not to be taken seriously.
5. There are only *ceremonial* transfers from one gender to another.
6. Everyone must be classified as a member of one gender or another.
7. The dichotomy is a natural one.
8. Membership in one gender category or another is something “natural.”

Medical and Psychology Framing & Decision-Making About Early Surgery



Making Sense of “Intesex” and “DSD”

- Express Complexity about the Self:
 - *Um, I think DSD just describes physically how my sex development has been different and intersex just describes how I feel like my gender identity is maybe not a 100% female. (Young Person speaking on “Intersex” and “DSD”)*
- Maintaining Privacy:
 - When I describe it, I just say her adrenal glands don't work [...] And I'm not going into too many details [...] I don't tell them, oh she has more male hormone or, so [...] because I think they don't need to know (Parent of young person)

YouTube Videos About Lived Experience



Intersex Youth Advocacy Group:
What's It Like to be Intersex.
(2015).
Approximately 93,000 views per
month.

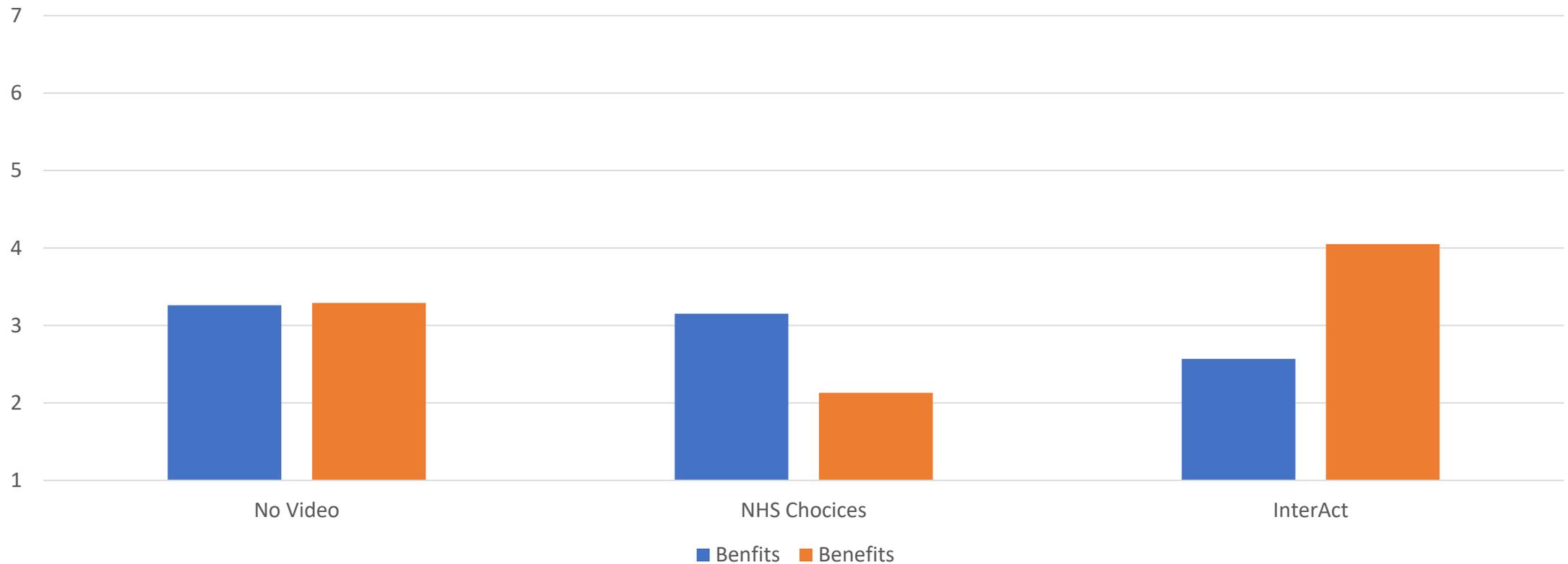


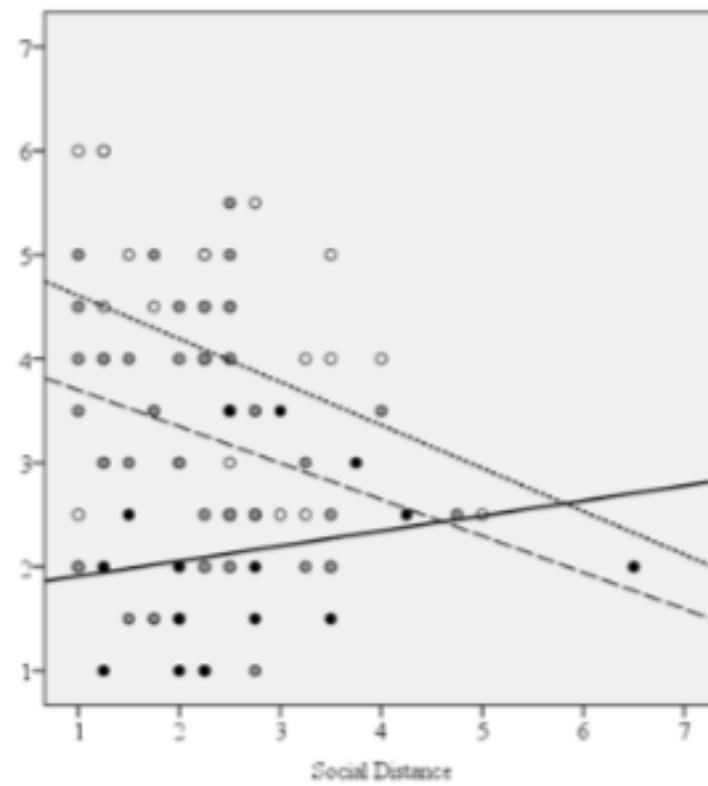
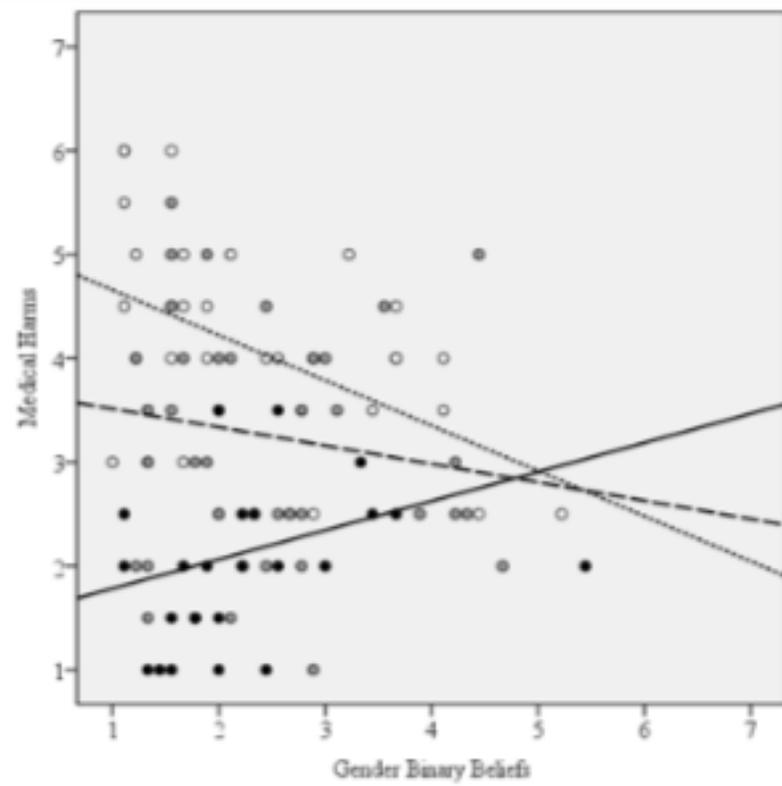
NHS Choices: *Disorders of Sex
Development (DSD)* (2011).
Approximately 1,000 views per
month.

Hegarty, P., Smith, A., & Bogan-Carey, T. (in press). Stigma as framed on *YouTube*: Effects of personal experience videos on students' beliefs about medicalizing intersex. *Journal of Applied Social Psychology*.

YouTube Videos About Lived Experience

Beliefs about Medical Benefits and Harms





- - - Social Video
 — Medical Video
 - - - Control

YouTube Videos About Lived Experience

Beliefs about Normality, Optimism about Inclusion and Interest in Learning More

