

# **Abstracts of papers presented at the EuroPSI Inaugural Conference**

**London - 17 September 2014**

## **Between the Intersexed Body and the Powerful Secret**

**Limor Meoded Danon**, PhD - Dept. of Sociology and Anthropology, Ben Gurion University of the Negev, Beer-Sheva, Israel

In many western countries, intersexed bodies are still very much "in the closet," concealed, and kept secret. My lecture focuses on the connection and interaction between the intersexed body and a powerful social agent—the secret. The connection between these two players—the intersexed body and the secret—begins in the medical system, which seeks to normalize the intersexed body and, through medical practices, to conceal it from the public eye, keeping it rare and unfamiliar, and controlled for the most part by medical professionals. In time, the intersexed body and the secret surrounding it become one, with the secret playing a significant role in the lives of intersexed people, in their familial life and in their everyday social and medical interactions. The immanent connection between intersexed bodies and the secret causes intersexed people to feel absent and present at the same time, caught in an in-between state, not here, but not there, experiencing physical and social alienation and a sense of estrangement. This lecture reveals the dynamic and the paradox of the secret that surrounds intersexed bodies and to explore each "agent of secrecy,"—the bio-medical experts, the parents, and intersexed people themselves.

## **Early findings on communication issues from a UK study of DSD MDTs**

**Caroline Sanders** - Alder Hey Children's hospital, Liverpool, UK

[Abstract not available]

Contd.

## Ordering by Disordering: A Critique of Sexed Kinds and Natural Purpose

Natalie Delimata - Institute of Technology, Sligo, Ireland

This is a brief summary of the presentation given at the EuroPSI inaugural meeting held on the 17<sup>th</sup> of September 2014 in London in which I argued against the use of the term ‘disorder of sex development’ on the grounds that the term implies that certain *kinds* of sex *ought* to exist while others ought not which, initially at least, suggests that nature operates with intent. I will use David Hume’s is/ought distinction to contest the application of ought concepts (disorder) to physical things (sexed bodies) (Hume, 1969).

To describe a body as ‘disordered’ implies that there exists an order according to which all bodies ought to adhere. However, within philosophy, particularly scientific and biological philosophy, applying ‘ought’ concepts to physical ‘things’ is highly contentious. The first philosopher to identify the problem of applying ought to physical phenomena was David Hume. According to Charles Pigden, Hume argued that it is not possible to derive moral or evaluative conclusions from non-moral or non-evaluative premises without first introducing a moral or evaluative premise (Pigden, 2011). This means that we cannot claim that objects or things are good or bad in themselves but only relative to a particular evaluative premise. For Hume the premise of evaluative claims could only be based on personal experience (Hume, 1969). Thus from a Humean perspective the term ‘disorder of sex development’ is rational only where the individuals to whom the term is collectively applied experience their bodies as disordered and therefore adopt the term to describe their experience.

In their book *Establishing Medical Reality: Essays in the Metaphysics and Epistemology of Biomedical Science* Harold Kincaid and Jennifer McKittrick explain that ‘within philosophy there has been a growing interest and appreciation for the connections between issues of value and issues of fact in science [...]. Biomedical science is a paradigm instance where the two intersect’ (Kincaid and McKittrick, 2007:1). Thus biomedical facts are informed by ideals. Though this would appear to contradict Hume, it can be argued that biomedicine is simply reflecting society’s collective experience of ill health justifying the use of evaluative terms to describe physical conditions which it is attempting to eliminate or alleviate. Thus health becomes the premise supporting biomedical evaluation of bodies. While this may be broadly acceptable, biomedicine must be careful to reflect experience when assigning and defining illness and not simply evaluate bodies through the lens of heteronormative social ideals.

Western biomedicine recognises sex as beginning with an androgynous undifferentiated foetus that differentiates into one of two sexes, male and female, which through the act of copulation form a reproductive unit. Though now viewed through the lens of science, this androgynous singularity/sexed duality/reproductive unity trope has informed social myths and ideals for thousands of years. From 2500 BCE Indo-European, Sumerian and Egyptian cosmic creation myths describe the universe as beginning with an androgynous unity that divided into a male and female entity which copulated to bring forth the sun, sea, earth and sky. In later Babylonian, Greek and Abrahamic human creation myths 1000 BCE - 800 AD the first humans were created from an androgynous ball of earth which was then divided in two to form the first male and female, who through copulation brought forth all of humanity. Traces of this trope can be found in Genesis, the Qur'an, Jewish myths and Plato's *Symposium*. Later Henry Rousseau invoked this trope to argue against equal rights for women on the grounds that women were not men's equal but their 'complement' within the socio-reproductive unit (Schiebinger 2000: 46). In 1997 John Finnis, professor of law at Oxford argued against homosexual marriage on the grounds that their sex organs cannot constitute a reproductive unity and therefore cannot actualise 'the two-in-one-flesh common good and reality of marriage' (Finnis 1997: 10). In *Man & Woman, Boy & Girl*, Money and Ehrhardt present the 'complementation principle' as a founding premise underpinning gender identity development which describes how since the 'reproductive anatomy is dimorphic, therefore, it is foreordained, if a species is to reproduce, that sexual behaviour must be sexually dimorphic enough to permit conception to take place' (Money and Ehrhardt 1972: 65). Money used the *complementation principle* as an underlying premise supporting the pathologization of bodies, behaviours and identities which did not conform to this trope. I believe that it is this trope rather than collective personal experience which continues to act as an evaluative premise informing Western ideals and biomedical practice in relation to sex. There is sufficient anecdotal evidence to suggest that the term 'disorders of sex development' does not reflect collective personal experience. Bodies are not good or bad, ordered or disordered. Labelling bodies as disordered when the collective embodied experience is not disordered is not only irrational but is likely to cause harm.

## References

Finnis, J. (1997) 'Law, Morality, and "Sexual Orientation"'. In John Corvino (ed.), *Same Sex: Debating the Ethics, Science, and Culture of Homosexuality*. Lanham, New York, London: Rowman and Littlefield. Accessed online from:

[http://nw18.american.edu/~dfagel/Class%20Readings/Finnis/Finnis\\_LawMoralitySexualOrientation.pdf](http://nw18.american.edu/~dfagel/Class%20Readings/Finnis/Finnis_LawMoralitySexualOrientation.pdf)

Hume, D. (1969) *A Treatise of Human Nature* (edited by Mossner, E. C.). England, USA, Australia: Penguin Books

Kincaid, H. and McKittrick, J. (2007) 'Introduction'. In Kincaid, H. and McKittrick, J. eds. *Establishing Medial Reality: Essays in the Metaphysics and Epistemology of Biomedical Science*. The Netherlands: Springer

Money, J. and Ehrhardt A. A. (1972) *Man & Woman: Boy and Girl*. Baltimore and London: The Johns Hopkins University Press

Pigden, C. R. (2011) 'Hume on Is and Ought'. First published in *Philosophy Now*, issue 83, March/April. Accessed online from: [https://philosophynow.org/issues/83/Hume\\_on\\_Is\\_and\\_Ought](https://philosophynow.org/issues/83/Hume_on_Is_and_Ought)

Schiebinger, L. (2000) 'Skeletons in the Closet: The First Illustrations of the Female Skeleton on Eighteenth-Century Anatomy'. In Schiebinger, L. ed. *Feminism & The Body*. Oxford, New York: Oxford University Press

### **Patient-centred or decentred care? Challenges for clinical practice**

**Tove Lundberg** MSc (clinical psychologist), PhD-fellow - University of Oslo, Norway,  
Visiting PhD-fellow, University of Lund, Sweden (2014-2015)

Patient-centred care has become an essential standard in medical practice in general (Stewart, 2003; Laine, 1996) as well as within the field of Intersex/DSD (Asciutto et al, 2011; Liao & Simmonds, 2013) in recent years. However, very few have explicitly discussed how patient-centred care should be carried out when it comes to supporting people with experiences of atypical sex development. I argue that the concept is all-encompassing and needs to be broken down and discussed in detail if we are to make effective use of it in practice. This paper is an attempt to address some of the concerns connected to this important clinical standard.

Firstly, I understand the framework of patient-centred care as a contrast to the evidence based medicine-paradigm and the attempts to combine these two are not very convincing yet.

Secondly, there are tensions between patient-centred care in theory and in practice that we need to address. Drawing from social psychology for example, mechanisms of diffusion of responsibility might happen in clinical settings that might risk health care to become decentred rather than patient-centred. Finally, there is a gap between the value of and

ambition to carry out health services in accordance with patient-centred care and the research that is being done within larger contemporary research collaborations.

Hopefully EuroPSI, in its endeavour to “bring tangible psychological benefits, not just to affected people but also to their advocates and care providers” via “innovative and critical psychosocial knowledge frameworks” (EuroPSI, 2014) can provide a constructive platform from where we can develop these ideas together in the future.

## References

Asciutto, A. J., Haddad, E., Green, J., & Sandberg, D. E. (2011). Patient-centered care: Caring for families affected by disorders of sex development. *Exp Med Biol*, 707, 135-142.

EuroPSI. (2014). Who are we? - Aims. Retrieved 15th of August, 2014, from <http://www.europsi.org/Aims>

Laine, C., & Davidoff, F. (1996). Patient-centered medicine: A professional evolution. *JAMA*, 275(2), 152-156. doi: 10.1001/jama.1996.03530260066035

Liao, L-M., & Simmonds, M. (2013). A values-driven and evidence-based health care psychology for diverse sex development. *Psychology & Sexuality*, 1-19. doi: 10.1080/19419899.2013.831217

Stewart, M. (2003). *Patient-centered medicine: transforming the clinical method*. Oxon: Radcliffe Medical Press.

## Controversial Dialogues in Paediatrics

**Dr Julie Alderson** - Bristol Children's Hospital, UK

Diverse Sex Development raise lots of questions for families and health workers around a new-born child. Health workers are advised to choose their words carefully and not say the ‘wrong’ thing. This presentation suggests that in doing so health teams inadvertently begin a process of under-communication and suppression of information. New parents are commonly advised not to say much to their families who are eagerly waiting for news of the baby. The whole system around the child seems to be waiting for something definitive to say; a certainty that may remain elusive.

A further suggestion is that parents might beneficially be encouraged to talk about the little that they know and the process of waiting, how it feels and to seek support of their loving family and interested close friends via opening up and describing the situation that faces them and their child.

Health teams expect parents to adhere to their advice of being discrete about their child's yet to be established sex or the development of their genitals. Julie suggests that this sanctioned reticence can seed shame and hamper adaptation to the challenges of the long term implication of the condition.

She concludes that health teams might be encouraged to support parents to be open about what is not known about their infant. In addition health teams should be open about what they don't know about their management. We don't know whether surgery will be helpful in the long term. Nor do we know whether seeing a psychologist will be helpful in the long term either. Perhaps one clear message to new parents of a child being investigated for a suspected DSD is that as parents they have responsibility for saying as much or as little about the child as they wish. - This situation asks a lot of you. We will help as far as we can.

### **Why do we need to differentiate between sex assignment and gender allocation?**

**Hertha Richter-Appelt** - UKE Hamburg, Institute for Sex Research and Forensic Psychiatry,  
Hamburg

[Abstract not available]