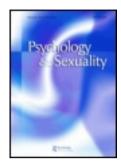
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# Intersex/DSD post-Chicago: new developments and challenges for psychologists

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#### **EDITORIAL**

## Intersex/DSD post-Chicago: new developments and challenges for psychologists

The title of this special issue reflects the significance of a landmark, if dilemmatic, development in research and practice relating to atypical sex development. The *Consensus Statement on the Management of Intersex Disorders* (Hughes, Houk, Ahmed, & Lee, 2006) was the outcome of an invitation-only meeting. The meeting took place in Chicago and resulted in a document sometimes called 'the Chicago consensus statement'. The document was not intended as a clinical guideline. Rather, it was a professional response to a troubled and troubling area of medicine and a strategic development to facilitate basic science research on the horizon. The name of this special issue signals, first of all, our chosen focus on current (i.e. post-Chicago) issues rather than the more familiar topics of the past and, second, a recognition of the widespread impact of biomedical perspectives, even for workers approaching the topic from non-clinical standpoints. The collection of articles aims to provide an update on the diverse linguistic frameworks, conceptualisations, practices and experiences relating to intersex/'disorders of sex development' (DSD). The aim is achieved via contributions from service users, advocates, medical specialists and psychologists.

In their contribution to this special issue, Ahmed, Gardner, and Sandberg outline the key clinical themes of the statement for a psychological readership. The consensus statement is one of a series of clinical documents over the past decade that call for the involvement of psychologists in the health care provision for people affected by intersex/DSD (see also: Ahmed & Rodie, 2010; Brain et al., 2010; Hughes, Nihoul-Fekete, Thomas, & Cohen-Kettenis, 2007). This then, may be an ideal time for psychologists to take a greater interest in intersex/DSD and to draw attention to pertinent psychological concerns.

The consensus has been followed by research attempting to assess the extent to which the call for psychological input had been taken up (Pasterski, Prentice, & Hughes, 2010). This research shows that many specialist teams working with intersex/DSD draw on a level of psychological expertise. There remain, however, fundamental gaps in psychological knowledge. What specific questions should psychologists prioritise about intersex/DSD? What are the strengths and weaknesses of the works so far and how should they develop? How can psychologists most usefully contribute to this field via research and practice? These questions emerged early in the development of the current special issue and resonate through the final product.

A major task facing the consensus group was revision of the nomenclature. The introduction of DSD to replace 'intersex' has split service users, advocates and clinicians into those who hailed it as a success, those who responded with dilemmatic acceptance, and those who resisted it outright. A snapshot of the range of reactions is available in the responses to the publication of the consensus statement (e.g. Clune-Taylor, 2010; Diamond & Beh, 2006; Feder, 2009; Hughes, 2008). Every term is bound to fail to be inclusive

of, and recognisable to, those to whom it refers, and to be user-friendly to the children and adults who continue to negotiate their bodily differences, identities and embodied experiences in their intersecting social contexts.

The irreconcilable tensions are explicit in this special issue. Some authors have sought to bridge the chasm that has opened up between *disorder of sex development* and *intersex* by making alternative use of the acronym: DSD. This acronym may, for example, be used to mean *divergence of sex development* (Reis, 2007), *divergences of sex development* (Schweizer et al., this issue), *differences of sex development* (Tamar-Mattis et al., this issue) and *diverse sex development* (Liao & Simmonds, this issue). Other authors, while being vocal in their support of intersex political goals, have chosen to accept *DSD* as a term that could 'normalise' intersex, 'directing attention to appropriate and ethical treatment' that 'promot[es] human flourishing' (Feder, 2009, pp. 240–241). The question of naming is taken up in more detail in this issue, where Davis reports empirical research with people who use the terms intersex or DSD in referring to their own identities and medical conditions.

Some of the most strident developments post-Chicago have taken place in the laboratory. Within basic science, intersex/DSD is framed in terms of a biological deviation that provides opportunities to learn more about 'normal' development. Large biomolecular projects are at an advanced stage of development (see: http://www.eurodsd.eu/en/publications-1.php and http://www.eurodsd.eu/en/the-project.php). Examples of current molecular themes that preoccupy scientists are found in the overview provided by Conway for this special issue.

Away from the laboratories, the debate on elective genital surgery on children remains the central concern for some clinicians and bioethicists. In their contribution to this issue, Creighton, Michala, Mushtaq and Yaron, four surgeons working with children and adults, expertly scour the medical literature for glimpses of changes in surgical practices that reflect the more cautious approach advocated by the consensus group. Their search appears to have led them to lean on the side of pessimism. The article by Tamar-Mattis, Baratz, Dalke and Karkazis represents a response to medical interventionism by elaborating upon the process of informed consent.

The research with service users reported in the contribution from Schweizer, Brunner, Handford and Richter-Appelt highlights the inadequacy of the binary categorisation of gender in the consensus statement and current medical practice. Their empirical data suggest that many service users do not experience and express their gender in binary terms. The authors convincingly argue that, rather than aiming to fit people into a narrow understanding of gender by modifying their bodies — a project that may be destined to fail — clinical care should aim to maximise psychological well-being by validating expressions in non-binary terms.

Recent implicit and explicit calls for less 'brain gender' and more psychosocial research (Karkazis, 2008; Stout, Litvak, Robbins, & Sandberg, 2010) seem to have resulted in some fledgling, if also floundering, strands of descriptive psychosocial end point research with clinic attendees diagnosed with intersex/DSD conditions. Some of this work is detached from clear social and psychological frameworks and is difficult to interpret. In their contribution as providers of professional and peer psychological support, respectively, Liao and Simmonds challenge clinical psychologists and health care researchers with a bold proposal for a multi-layered programme of specific works.

Psychologists working in the intersex/DSD field clearly draw on diverse ideas and produce very different (and sometimes incommensurable) understandings. Neuroscience experiments involving animals and humans to further the goals of brain organisation theory

have been privileged for some decades. Studies that aim to locate 'masculinised' gender development in the 'masculinised' foetal brain of females proliferate in clinical literatures, perhaps due to their accessibility to medical doctors and scientists. More recently, psychometrics has been applied to evaluate psychosocial end points. Many psychologists have chosen to develop norm-critical approaches. They argue for alternative ways of conceptualising intersex/DSD, and aim for a reduction in pathologisation and stigma and for more systemic moves to improve the care of atypically sexed children in the contexts of their families and communities. The rift between potentially irreconcilable psychological accounts is taken up by Roen and Pasterski who, in their article, examine how recent psychological research is expanding diverse understandings of intersex/DSD. This research seeks simultaneously to provide a knowledge base for psychologists working in the intersex/DSD field, and to expose the contingent nature of such knowledge.

This special issue owes its breadth to the expertise of the authors from many disciplines and agencies. However, by no means does it capture all relevant perspectives. For example, it falls short of a discussion of endocrine treatment and prevention of aspects of intersex/DSD. Even so, the collection of articles has usefully explored and exposed some of the pluses and minuses of the Chicago consensus, whose status as a progressive clinical and scientific statement will continue to be tested in the years to come. In informing and updating our intended psychological audience on the multiple perspectives and signposting to some of the challenges, we hope to encourage many more psychological voices on the wide range of topics relating to intersex/DSD.

We thank all of the contributors for the generous offers of their expertise and all of the reviewers who have made important contributions without taking any credit. Our appreciation goes also to the editors of Psychology & Sexuality, especially Meg Barker, with whom the idea of this special issue was first conceived on a warm evening in the week of the LGBTQ Psychology Summer Institute organised by Peter Hegarty, Abby Stewart and Nicola Curtin, at the University of Michigan, August 2010.

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