

Beyond Choosing Umbrella Terms : Two Psychologists Make Sense of 'Intersex' for Gender and Sexuality Studies Scholars

Hegarty, Peter; Lundberg, Tove

2020

<https://doi.org/10.25595/2205>

Veröffentlichungsversion / published version
Sammelbandbeitrag / collection article

Empfohlene Zitierung / Suggested Citation:

Hegarty, Peter; Lundberg, Tove: *Beyond Choosing Umbrella Terms : Two Psychologists Make Sense of 'Intersex' for Gender and Sexuality Studies Scholars*, in: Feldmann, Doris; Keilhauer, Annette; Liebold, Renate (Hrsg.): *Zuordnungen in Bewegung: Geschlecht und sexuelle Orientierung quer durch die Disziplinen* (Erlangen: FAU University Press, 2020), 197-217. DOI: <https://doi.org/10.25595/2205>.

Erstmalig hier erschienen / Initial publication here: <https://doi.org/10.25593/978-3-96147-302-1>

Nutzungsbedingungen:

Dieser Text wird unter einer CC BY 4.0 Lizenz (Namensnennung) zur Verfügung gestellt. Nähere Auskünfte zu dieser Lizenz finden Sie hier:

<https://creativecommons.org/licenses/by/4.0/deed.de>

Terms of use:

This document is made available under a CC BY 4.0 License (Attribution). For more information see:

<https://creativecommons.org/licenses/by/4.0/deed.en>

GenderOpen – Repositorium für die Geschlechterforschung: www.genderopen.de

Doris Feldmann, Annette Keilhauer, Renate Liebold (Hrsg.)

Zuordnungen in Bewegung:
Geschlecht und sexuelle Orientierung
quer durch die Disziplinen

FAU Studien Gender Differenz Diversität

Band 1

Herausgegeben vom Vorstand des Interdisziplinären Zentrums
Gender Differenz Diversität der Friedrich-Alexander-Universität
Erlangen-Nürnberg

Doris Feldmann, Annette Keilhauer, Renate Liebold (Hrsg.)

Zuordnungen in Bewegung:

Geschlecht und sexuelle Orientierung
quer durch die Disziplinen

Erlangen
FAU University Press
2020

Bibliografische Information der Deutschen Nationalbibliothek:
Die Deutsche Nationalbibliothek verzeichnet diese Publikation in der
Deutschen Nationalbibliografie; detaillierte bibliografische Daten
sind im Internet über <http://dnb.d-nb.de> abrufbar.

Das Werk, einschließlich seiner Teile, ist urheberrechtlich geschützt.
Die Rechte an allen Inhalten liegen bei ihren jeweiligen Autoren.
Sie sind nutzbar unter der Creative-Commons-Lizenz BY.

Der vollständige Inhalt des Buchs ist als PDF über den OPUS-Server
der Friedrich-Alexander-Universität Erlangen-Nürnberg abrufbar:
<https://opus4.kobv.de/opus4-fau/home>

Bitte zitieren als
Feldmann, Keilhauer, Liebold (Hrsg.). 2020. *Zuordnungen in
Bewegung. Geschlecht und sexuelle Orientierung quer durch die
Disziplinen*. FAU Studien Gender Differenz Diversität Band 1.
Erlangen: FAU University Press.
DOI: 10.25593/978-3-96147-302-1

Verlag und Auslieferung:
FAU University Press, Universitätsstraße 4, 91054 Erlangen

Druck: docupoint GmbH

ISBN: 978-3-96147-301-4 (Druckausgabe)
eISBN: 978-3-96147-302-1 (Online-Ausgabe)
ISSN: 2700-1261
eISSN: 2700-127X
DOI: 10.25593/978-3-96147-302-1

Inhaltsverzeichnis

DORIS FELDMANN, ANNETTE KEILHAUER, RENATE LIEBOLD

Einleitung..... 1

**I. Begriffe, Wahrnehmungen und Anerkennungen in
gegenwärtigen Aushandlungsprozessen 11**

DORIS FELDMANN UND JOCHEN HOFFMANN

Geschlecht oder Sex-Gender-Spektrum – sexuelle Identität
oder sexuelle Orientierung? Konzeptuelle Modellierungen im
Spannungsfeld von Rechts- und Kulturwissenschaft 13

BEATE BINDER

Umkämpfte Felder: Kulturanthropologische Perspektiven auf
Geschlecht, Sexualität und Recht 41

**II. Zum Umgang mit geschlechtlichen und sexuellen
Normen in sich wandelnden Ordnungsentwürfen 61**

PETER BUBMANN

Binäre Schöpfungsordnung oder versöhnte Vielfalt?
Theologische Perspektiven auf geschlechtliche Identität und
sexuelle Orientierung 63

UWE SIELERT

Sexualpädagogik als Orientierungshilfe im Diversity-Trouble 83

**III. Anwendungs- und Fallbeispiele:
soziale Vergemeinschaftung, literarische
Transgression, filmische Multiplikation.....105**

RENAME LIEBOLD

Wissen – Milieu – Geschlecht: Die Perspektive der
soziologischen Geschlechterforschung..... 107

ANNETTE KEILHAUER

Literarische Inszenierungen von Transgender und Passing:
Monsieur Vénus von Rachilde 129

KATRIN HORN

Bewegte Bilder / Bewegte Vergangenheit: Queeres Kino
der USA 151

**IV. Zur Geschichte und Problematik von Inter-
Konzeptualisierungen 173**

NADINE METZGER

Als ‚Hermaphrodit‘ beim Arzt, 1671 – Vom Umgang mit
uneindeutigen Geschlechtsmerkmalen in Medizin und
Gesellschaft der Neuzeit 175

PETER HEGARTY AND TOVE LUNDBERG

Beyond Choosing Umbrella Terms: Two Psychologists Make
Sense of ‘Intersex’ for Gender and Sexuality Studies Scholars 197

Verzeichnis der Autorinnen und Autoren 219

Peter Hegarty and Tove Lundberg

Beyond Choosing Umbrella Terms: Two Psychologists Make Sense of ‘Intersex’ for Gender and Sexuality Studies Scholars

1 Introduction

We contribute to this interdisciplinary book series on Gender and Sexuality Studies as two psychologists immersed in the new area of intersex studies, aiming to orient unfamiliar gender and sexuality scholars to this field. This topic area is emerging in a context of stark disagreement between medical and human rights understandings. We focus on *language* as a point of entry for gender and sexuality scholars who are interested in intersex studies. We analyse the discourse of a recent important statement about what language terms should be used to describe sex characteristics that do not fit binary models. The focus on finding ‘correct’ umbrella terms has several limitations, and we consider what other understandings of language might imply for medical and psychological interventions aiming to promote well-being. Our own recent social psychological research contrasts how laypeople, without expert knowledge of intersex, understand ‘umbrella terms’ and how experts by experience of intersex conceptualize and use language to navigate social contexts. We argue for a *strategic anti-essentialist* psychology in this area and conclude by returning to an important analogy between language and gender drawn at a crucial juncture in the history of psychology’s engagement with intersex. That analogy underestimates the human capacity to be fully *bilingual* and, as a consequence, closes off important creative enactments of language and gender, which humans ordinarily show.

2 Background

Intersex traits are often described as physical sex characteristics that deviate from societal norms for male or female embodiment. The incidence rate of 0.5–1.7% of intersex traits is accepted by the United Nations (Monro et al., 2017, 3), whilst some biomedical scientists put the estimate closer to 0.3–0.5% (Lee et al., 2016, 159). Rather than resolving questions of incidence, this chapter orients towards long-standing and ongoing fundamental disagreement about what terminology to use to categorize embodiment beyond the binary norm, what features define this category, and whether or not this category is best defined by the presence or absence of features at all. We begin with a short outline of the history of intersex and the diverse ways that psychology and psychologists have been involved in this topic area.

Since the mid-twentieth century, a medical protocol developed in large part by the psychologist John Money prescribed early surgery on intersex traits to normalize appearance and an assignment of children to a sex of rearing. We will return to Money's conceptual understanding later but first focus on its historical effects. His and his colleagues' work justified a non-disclosure policy and faith in the belief that children would acquire the gender identity to which they were assigned irrespective of their underlying biology. This protocol was guided by an understanding that living openly with such traits was a psychological impossibility and faced no effective challenges for decades (see e.g. Reis, 2009).

In the early 1990s, feminist scholars drew attention to the ways in which the assumption that there were two, and only two, gender or sexes was enforced through this medical protocol (Kessler, 1990; Fausto-Sterling, 1993). Whilst these criticisms were not initially engaged with the lived experience of people who had been made subject to these protocols, intersex-identified people quickly built a social movement that challenged the rationale for early intervention. They narrated their lived experience as the proof of harm being caused by the shame and secrecy required by existing medical protocols (Chase, 1998; Dreger, 1999). Medical ethics fell short here, in part because psychological research focused overwhelmingly on the gender and sexual identities of people with intersex traits rather than negative psychological effects on individuals and families. In particular, people

with Congenital Adrenal Hyperplasia were routinely studied as a 'natural experiment' used to answer nature/nurture questions about gender and sexuality, to the exclusion of psychological questions about the effects of medicalization, spectacularization, and shame (Stout et al., 2010). Some clinicians called for a moratorium on surgeries, mindful that some children did not adjust to their sex of rearing as Money predicted (Diamond, Sigmundson, 1997), including David Reimer. Reimer had been John Money's most celebrated case study and it was later revealed that this case had involved both psychological abuse and scientific fraud (Colapinto, 2001).

In the 1990s, Gender and Sexuality Studies courses began to address intersex more frequently. Psychology of gender textbooks had long discussed intersex people as 'natural experiments' along the lines discussed above, but intersex was not frequently mentioned in Gender and Sexuality Studies otherwise. A few psychology of gender textbooks began to break this mould and to discuss intersex movements (e.g. Crawford, Unger, 2004). However, in a review of Gender and Sexuality Studies curricula in the 1990s, Koyama and Weasel (2001) found that intersex continued to be described as an *example* that demonstrated the social constructedness of gender and sex categories. Fausto-Sterling (1993) was the most frequently used text, and Koyama and Weasel (2001) conclude that the voices and writings of intersex people were rarely referenced. This critique describes well the experience of the first author as a PhD researcher in California (1993–1999). He first read Money's work to understand the politics of nature/nurture arguments about homosexuality, was introduced to the work of Fausto-Sterling and Kessler by anthropologists and sociologists in gender studies contexts, and gave a presentation at a Gender Studies conference in 1996 that made precisely the errors described by Koyama: an overemphasis on the insight that categories of gender and sex were socially constructed and a neglect of the priorities foregrounded in narratives of lived experience.

During the early 2000s, research and activism diversified and an emphasis on the lived experience and expressed needs of people with intersex variations became more evident in diverse contexts. Academically, Preves (2003) published the first large sociological study drawing on interviews with intersex-identified people in North America and she used stigma theory and the history of LGBT movements to analyse the

current state and project a bright future for the intersex-identified community. A support group based in the UK, AISSG, also adopted a more collaborative approach to improving medical care. They also afforded access to social scientists who described how medicine colluded with norms for gendered embodiment affecting women with Androgen Insensitivity Syndrome or AIS (Alderson et al., 2004). The British Psychological Society journal *The Psychologist* published a special issue on intersex in 2004 (Liao, Boyle, 2004).

Discussions of the use of language, terminology, and classifications were an important part of the changes that happened during the early 2000s. Davis (2015) describes how the strategy of ‘collective confrontation’ by intersex movements in the 1990s diversified to a wider array of both confrontational and collaborative relationships with medical groups in the early 2000s, and we rely on her account of these shifts here. In 2000, Chase was invited to speak at the Lawson Wilkins Pediatric Endocrine Society. This event signalled the increasing recognition of intersex movements within medicine during the early 2000s. Together with medical and bioethics colleagues she later called for a revision in taxonomy, arguing that “the current taxonomy does *not* represent a division into what philosophers of science call ‘natural kinds’” (Dreger et al., 2005, 730). These authors were reacting against the perception that the histology of gonads was a feature that could ground diagnostic categories labelled as ‘hermaphroditism’. They challenged both the misleading and stigmatizing associations of the term, the conflict between this conceptual system and other forms of scientific knowledge, conflating a person with a condition, and creating a ‘hierarchy of authenticity’ among intersex people (Dreger et al., 2005, 732). They argued for a two-level category system that recognized distinct conditions and the umbrella term ‘disorders of sexual differentiation’ (DSD) in clinical medicine. Later in 2005 at a Consensus Meeting of paediatricians, the term ‘disorders of sex development’ was introduced at a “rushed final plenary session” (Davis, 2015, 44). The Intersex Society of North America (ISNA), which Chase had founded in the early 1990s, quickly adopted the term in place of ‘intersex’ in its communications, and the term ‘DSD’ was presented as the correct one to use over ‘intersex’ and ‘hermaphrodite’ in the 2006 Consensus Statement on the Management of Intersex Disorders (Lee et al., 2006). This statement continues to frame biomedical understanding and practice

(Davis, 2015, 46), as does the claim that 'disorders of sex development' is a less confusing, less pejorative, modern, descriptive term that incorporates scientific advances and is meaningful for the people that it names and their family members.

3 Language Since the Chicago Consensus in 2006

Since Chicago, psychologists and social scientists have repeatedly asked whether or not medical practices have substantively changed as a result of new norms in favour of parents' and patients' active involvement in medical decision making, multi-disciplinary teams working together, including psychological care, acknowledgment of the harms risked by surgery, silence and spectacularization, and the shift in language towards DSD (see the papers in Liao, Roen, 2014). A self-report survey of European physicians showed that the uptake of the DSD language was rapid and widespread, but only half of clinics self-reported a decline in the most controversial of surgical interventions, which is the reduction of clitoral size (Pasterski et al., 2010). Evidence of such a decline in surgical rates remains lacking in multiple countries, such as the UK (Creighton et al., 2014).

Important attempts to answer the questions mentioned above include the 'Ten Year Global Update' (Lee et al., 2016) to the 2005 Chicago Consensus Conference, which convened fourteen working groups to consider progress since 2005. Nineteen diverse professionals in one working group focused on prescriptions for nomenclature and debated the functions and effects of DSD and other language in a corpus of emails of 80,000 words in 2014 to 2015. The corpus was then subjected to thematic analysis and reported by six working group members (Delimata, Simmonds, O'Brien, Davis, Auchus, Lin-Su, 2018). Four other contributors were listed as 'unconditional affiliates', five as 'conditional affiliates', and four were not listed at all. The contributors' variable agreement with this analysis of their own exchange attests to the difficulty of achieving their goal of defining consensus around language, even ten years on from Chicago. Similarly, our critiques of the limits of this conversation should not be read as critiques of any of the individuals who participated in it.

After Chicago, several surveys on different continents show that experts by experience, defined as people with intersex variations and their family members, rarely use DSD and very often perceive it as pathologizing (summarized in Lundberg et al., 2018). Aware of these surveys, the authors of the nomenclature-paper (Delimata et al., 2018), including Lin-Su who had conducted such surveys, made the point that surveys demonstrated that DSD was experienced as pathologizing. However, DSD was also described in their conversation as a valuable term because of its *aims* to avoid attributions of sex ambiguity (which were assumed to be harmful) and because it named the biomedical “reality, reflecting the patient’s condition, thereby helping them to come to terms with, and adapt to their circumstances” (Delimata et al., 2018, 101). We note here the conflict between two approaches to science: an understanding based on a realist view that linguistic signifiers can be mapped directly onto clear-cut realities whose existence is beyond question versus an understanding emphasizing the empirical study of what people say language terms mean to them. In sum, the experts’ diverse opinions about DSD resonated well with John Austin’s distinction between the locutionary meaning, related to the reference of a term, and the perlocutionary social *function* of a speech act (1962).

The experts noted that Dreger et al. (2005) had never called for an end to the use of ‘intersex’ as the later Chicago Consensus had done. They also used Dreger et al.’s (2005) metaphor of the *umbrella* term to describe ‘DSD’ and discussed the merits of ‘umbrella terms’ at length. Their discussion drew upon a limited understanding of humans’ abilities for reasoning with categories. Contradicting the idea that ‘DSD’ mapped onto a ‘reality’ that would be harmful to deny, Delimata et al. (2018, 102) reference an unresolved “debate among various endocrine societies and individuals regarding what conditions ought to be included under the term.” A *desire* for a clear-cut category is more apparent in this discussion than the *recognition* of the existence of any such category, let alone a neutral word to describe it.

Fears about proceeding without such a category centred on concerns that harms that clinicians might inadvertently create if they were to wrongly generalize between very different patients will “[result] in the individual’s needs not being correctly identified” (Delimata et al., 2018, 102). This relationship between the debates about categories, which

medical professionals continue, and the shared desire for a simpler mapping of bodies to categories is very relevant to a long-standing fantasy of *genetic futurism* in medical approaches to intersex (see Griffiths, 2018). Griffiths narrates histories of medical faith that future research would 'sort out' category ambiguity, taking moral ambiguity about medical practice away with it and particularly the question of whether Klinefelter's and Turner's syndromes sit under that umbrella or not. The history of competing interests in the earlier category of 'intersex' narrated by Griffiths (2018) is continuous with the call for a two-level category system in Dreger et al. (2005) and the description in Delimata et al. (2018) of ongoing expert disagreement about who falls under the DSD umbrella, "depending on the perceived source of concern, whether sexual, reproductive, genetic, gonadal, genital, hormonal or morphological" (102). At the start of this chapter we resisted answering the question about the incidence of intersex. We point out now that we did so to avoid giving our readers the false impression that there is more certainty and agreement in medical discourse about what the range of *any* umbrella term in this area might be than actually exists.

The irony we wish to point out here is that whilst DSD is described as a reality with which patients must come to terms and which practitioners must use to organize clinical practice and research, there is also an opposing desire that the signifier 'DSD' can remain *open* to reinterpretation, at least for some people in some contexts. Delimata (2017) has critiqued the application of an essentialist philosophy to intersex, and Thorne and Hegarty (2019) have described how cognitive psychology research on categorization applies to intersex. Both note the failure of essentialism to describe how humans reason with categories, and how people often construct, and reason with, categories whose members lack shared essential features. We reason as such when we construct categories to achieve certain *goals*, such as 'things to bring on a camping trip', for example (Barsalou, 1983). Later in Delimata et al. (2018, 105), it becomes clear that DSD was discussed as a *goal-directed* category constructed to *achieve* particular *performative* effects. Criticism of DSD and considerations of alternatives lead the authors to list eight goals that any good umbrella term should achieve: (1) highlight health implications, (2) clarify the purpose of umbrella terms, (3) avoid pejorative effects, (4) not employ 'disorder' (for that

term implies something to be fixed), (5) not employ ‘sex’ as this term could increase existing anxiety, (6) accurately reflect biomedical issues, (7) be simple enough to ease communication, and (8) emerge from, or at least be tolerated by, those to whom it is applied. A similar list was offered by Dreger et al. (2005). Umbrella terms are asked to achieve a lot more goals than only to describe essential features.

Thorne and Hegarty (2019) summarize the arguments made by others that humans sometimes *appear* to reason as if their categories had an essentialist grounding more than they actually do (Medin, 1989), but evidence a very ordinary *lack of explanatory depth* in the sense that they cannot point to those essentialist features when they are demanded to do so (Hampson, 2010). The discussion of Delimata et al. (2018) clearly shows a lack of explanatory depth among contemporary experts, and we should not expect neo-essentialism to change the epistemological landscape here any time soon. Rather, in institutional and cultural contexts where categories such as diagnoses are implemented, people very commonly shift between understandings of those categories as having clearly defined or fuzzy boundaries. Such flexibility is often necessary to make institutions work (Bowker, Star, 1999). As the original Chicago Consensus statement put it: “Disorders of Sex Development [...] nomenclature should be sufficiently flexible to incorporate new information yet robust enough to maintain a consistent framework” (Lee et al., 2006, e488). Whilst insisting that DSD reflects a reality with which patients must come to terms, medical experts seem to retain the privilege of keeping the signifier ‘DSD’ open to do a wide range of things for multiple contexts and diverse audiences. This assumption of the privilege to both remain anti-essentialist whilst insisting that reality is grounded in essences with which others must come to terms is the point of departure for our own work on sense-making in this area.

4 Diversifying Expertise with Language Use

Borrowing from Griffiths (2018), we describe the attitude to language in biomedicine as one of *linguistic futurism*; a persistent faith that, in spite of all evidence and logic, research will one day bring about clear, value-free signifiers (expressed as medical terminology). We do not share this faith but keep in mind the purported overarching goal of

medicine in this area, the health, wellbeing, and flourishing of people with intersex variations within their families, social contexts, and societies. From this perspective, medical contexts and their accompanying discourses are some, but not all of the contexts that people with intersex variations must navigate during their lifetimes. We are thus oriented to the question of how experts by experience use language to perform certain everyday actions and whether or not the linguistic tools they have available work for them in the ways that people who lack their expertise by experience correctly anticipate and understand. In a recent empirical paper (Lundberg et al., 2018), we drew on different data sources to explore these questions. We drew on twenty-two interviews with young people and interviews with twenty-four mothers and nine fathers (representing twenty-five families), the so-called 'experts by experience'. We also drew on ten focus groups (including a total of thirty-one women and nine men) with adults without any particular knowledge, or experience, of intersex.

We were aware of surveys across Europe, Australia, and the USA which show that people with intersex variations and their family members are only very rarely content to use the DSD language. An exception to this pattern is the European DSD-LIFE study (Bennecke, De Vries, 2016), but this team also was unique in using the language of DSD exclusively in its recruitment materials. In an Australian survey, which used more diverse recruitment materials, intersex and intersex-related terms were the only terms preferred by a majority of participants (Jones, 2017). Pushing past votes for particular terms, we wanted to understand and describe experiential expertise in what Austin (1962) might call 'doing things with terms' in everyday life.

In our study, experts by experience and lay focus group participants had distinct preferences for terms. 'Intersex' was preferred by more people in both groups than was 'DSD', but more of the focus group participants preferred both of the umbrella terms 'intersex' and 'DSD'. All groups commonly noted – often quite quickly – that DSD was a pathologizing term, but the focus group participants more commonly voiced optimism that as a *medical* term, DSD might have positive normalizing effects. Focus group participants were also more optimistic about any benefit from the association between 'intersex' and sexual and gender minority groups than experts by experience, who more often voiced concern about the risks of such associations. These group

differences suggest to us that people new to this area could quickly frame debates about language as one between the benefits of ‘intersex’ and ‘DSD’, whilst experts by experience may find this conversation less relevant to their day-to-day life than others presume. More details about the interview and focus group questions that elicited these data are provided in Lundberg et al. (2018).

Parents and young people did not use existing terms descriptively but did things with respect to language in their day-to-day lives that a debate about umbrella terms could risk precluding. For example, some avoided all such terms, and one parent expressed doubt about there ever being an adequate umbrella term noting that:

“Intersex and DSD’s, is, is such a, so many different kinds [...] and different manifestations of, [...] it’s hard to get an umbrella term [...] it depends on the situation or [...] who we’re talking to.” (Lundberg et al., 2018, 169)

This quote exemplifies something very ordinary; that the language that people are using when they talk about their or their child’s embodiment or social identity needs to do things that vary by audience and context. Social psychologists consider these matters to be so well evidenced that they can be assumed (Potter, Wetherell, 1987; Tajfel, Turner, 1986), but such regularities of social life run counter to the desires of linguistic futurism – that is, to name the reality with which different people must come to terms by using only one unified signifier. Day-to-day life demands more flexibility than linguistic futurism desires. A different approach to those demands is not to avoid umbrella terms but to use them in conjunction to express something individual and particular. As one young person said:

“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.” (Lundberg et al., 2018, 167)

Survey research on other continents shows that people with intersex traits use the term ‘DSD’ when interacting with clinicians but not in other social contexts (Davis, 2015; Jones, 2017). Such code-switching could be demanded by talking DSD language in clinical contexts whilst limiting the impact of a diagnosis on self-definition in other areas of life (Lundberg et al., 2016, 340–341).

Experts by experience dispreferred umbrella terms but did report other experiences with language more commonly. When we asked young people how they talked about their sex development, they commonly told us that they do not talk about it at all, speaking to a lack of accessible linguistic resources for self-definition among people who are receiving medical intervention. Shame is frequently mentioned in intersex people's stories and the difficulties it presents are often cited as the reason why medics "have to do something" via surgical intervention (Roen, 2008, 53–54). Elsewhere we have described how parents of such young people must develop knowledges about how and when to talk about their child's diagnosis. These can be understood as forms of situated expertise that are not given by knowing the diagnosis itself (Lundberg et al., 2017, 523–524). The need for such resources and expertise in everyday life settings also informs the need for psychological interventions that enable people to find and use self-determining language in this area. The opportunity for young people to say "I am intersex" or "I have intersex characteristics" could make a huge difference to exploring diverse ways of making sense of their embodiment and themselves, particularly if "I am abnormal" and "I have a disorder" are the only other options for self-identification that the social context has offered thus far. Although, since Chicago, the validity of multidisciplinary teams in this area has depended upon the inclusion of psychologists, in reality, the inclusion of psychological expertise and of psychological care in these teams remains unclear. The potential lack of psychologists' representation is highly problematic and may be justified by fantasies that medicine can bypass emotional suffering, whilst it never produces emotional suffering (Liao, 2016). Medical professionals could realize that patients may need more time than they are often allowed so that they can flexibly formulate thoughts and questions in language that are relevant to their experiences (Roen, 2019).

Many experts by experience whom we interviewed – 63.6% of parents and 45.5% of young people – reported a preference to use what we categorized as *descriptive terms*, whilst only 17.7% of the lay focus group participants without experience did so (Lundberg et al., 2018). Parents reported that they sometimes said things like "her adrenal glands don't work" as part of a strategy to communicate necessary information whilst maintaining privacy (see also Sanders et al., 2012). Medical intervention in the lives of children with intersex traits can

risk their right to an ‘open future’ to self-determining choices later on (Carpenter, 2016; Kon, 2015). Similar to medical interventions, some parents reported using these descriptive explanations as linguistic strategies to keep future options for identification open. Others pursued the same kind of ends by different means, using multiple umbrella terms – both ‘intersex’ and ‘DSD’ – as a deliberate strategy of keeping several linguistic choices open for their children down the line.

Ours is not the only qualitative study that addresses the experience and expertise of young people and their family members. In an excellent synthesis of such studies conducted in multiple countries by scholars in multiple disciplines since Chicago, Roen (2019) emphasizes clear evidence of emotional costs of medical interventions. Roen argues there is insufficient time for emotional processing of events that unfold in medicalized environments and for building the supportive relationships required to develop such collaborations. This evidence calls for a critical psychological approach that assumes that *how we talk and know* in this area has material consequences, according to Roen.

5 Possible Routes for Gender and Sexuality Studies

Lundberg et al.’s (2018) focus groups were a rare attempt to respond to Liao and Simmonds’ (2014) call to understand how people without expertise, by virtue either of profession or experience, make sense of experience. These focus group participants in some way remind us of Koyama’s critique (in Koyama, Weasel, 2001) of addressing intersex only as an illustration of the social constructedness of gender. Experts by experience often encounter people whose understanding of intersex is limited to gender, framed by umbrella terms, and which consequently provides limited concepts for understanding their own lived realities. When experts’ definitions of terms diverge from those of people they are talking about, psychological research can help by describing the associations that key terms in the discourse bring to mind, to better understand the concepts that lie behind them (Kelley, 1992).

Accordingly, Hegarty et al. (under review) asked 271 UK and USA participants to list their associations to three umbrella terms, namely ‘DSD’, ‘intersex’, and ‘hermaphrodite’. Most participants had heard of

the term 'hermaphrodite', fewer had heard of 'intersex', and only a minority reported that they had heard of 'disorders of sex development'. These umbrella terms had overlapping associations and distinct referents. 'DSD' referred more to biomedicine, to children, and to family contexts. 'Intersex' prompted more references to gender minority identities. 'Hermaphrodite' prompted unique references to non-human entities, including plants, animals, and mythical characters, as feared by Dreger et al. (2005). These 'umbrella terms' do not have identical prototypical *referents* (children vs. adults vs. non-humans) and they are not equally familiar to non-experts. Accordingly, people, in everyday contexts, should be expected to use these somewhat different linguistic tools because they imply different referents to different audiences and can be assumed to be part of the *common ground* in conversations with others to a greater or lesser extent. For example, Hegarty et al. (under review) included 'hermaphrodite' in the survey, with an awareness that the term had been described as pejorative, because they had to use it to develop common ground regarding their research goals with University Ethics Officers, who had not heard of either 'intersex' or 'DSD'. Accordingly, they included 'hermaphrodite' on the assumption that it might access aspects of public understanding that the other terms might fail to prompt.

We conclude with points for gender and sexuality scholars about how such terms might serve to bridge their own expertise and this area. Gender and sexuality scholars in cultural studies who focus on classical literature are most likely to use 'hermaphrodite' as a point of entry. Hegarty et al.'s (under review) results remind those scholars that 'hermaphrodite' continues to imply the doubly-gendered, the mythical, and the non-human. Zajko (2009) has recently revisited Ovid's storytelling of Hermaphroditus and Salmacis through engagement with a range of queer and intersex scholars, concluding that considering Hermaphroditus as *queer* might alleviate "prejudice surrounding the intersexual by providing the modern phenomenon with an ancient etiological myth" (197). While Zajko is cautiously optimistic about Ovid's tale, Groves' (2016) more recent reading of Ovid's poetics suggests that intersex people who continue to call for recognition of their lived experience (e.g. DuBois, Iltis, 2016) may not be satisfied by it. As Groves (2016) very cleverly explains, Ovid's poetic narration in *Metamorphoses*

produces a sense of after-the-fact surprise in discovering Hermaphroditus identity toward the end of the story, similar to that afforded by viewing earlier sculptural representations of Hermaphroditus. This available experience of surprise falls short of the storytelling and -listening that is demanded in intersex studies now, as Zajko (2009) recognizes. Lundberg et al. (2018) found no evidence of people using this ancient myth to make sense of their embodiment, identity, or themselves, or as a term that enabled communication with others. However, ancient texts can remain very relevant in the lives of many people, as when Christian intersex people gain a narrative resolution of intersex and Christian identity when reading about ‘eunuchs’ for the kingdom of heaven in the Christian New Testament (Cornwall, 2010, 136–137).

We expect that the term ‘intersex’ will appeal to a broader range of scholars in gender and sexuality studies, as both Hegarty et al. (under review) and Lundberg et al. (2018) show that laypeople often analogize intersex to gender minorities and to LGBT. A recent response to the Council of Europe Human Rights Commissioner’s Issue Paper on Human Rights and Intersex People critiqued the representation of intersex issues by existing LGBT groups on the grounds that those organizations had not worked in partnership with clinical services or with parental support service groups, whilst “the assumption that intersex is per se related to sexual orientation and gender dysphoria or confusion (...) has a detrimental effect on societal understanding of variances in sex development and undermines the efforts of many people working towards optimal outcomes” (Cools et al., 2016, 408). Carpenter (2016, 2018) has also voiced caution about LGBT organizations ‘adding the I’, but his concerns centre on the ways that organizations of intersex-identified people, not medical teams or parents, can be pushed to the side in the process. We agree with Carpenter (2018, 497) that claims about identity between these groups are poorly grounded and risky and with his point that a *historical* connection exists because of long-standing stigmatization, the use of intersex people to investigate how to undo homosexuality, and contemporary cisgenderist concerns about the gendered behaviour of some children with congenital adrenal hyperplasia (see also Stout et al., 2010). From this historical vantage point, Cools et al.’s (2016) claim that it is the very recent entry of LGBT organizations to intersex that has created the “detrimental effect on societal understanding” by

suggesting “that intersex is per se related to sexual orientation and gender dysphoria or confusion” (407–408) requires an enormous effort of will to completely forget the last 150 years of medical history in this area. It also requires us to consider the systematic cisgenderist and heterosexist frameworks which evidently still organize the thinking of contemporary clinicians (Roen et al., 2018; Roen, Hegarty, 2018).

Finally, we note with interest that whilst these critiques centre on LGBT *organizations*, Hegarty et al. (under review) further found that self-identified sexuality (not heterosexual vs. heterosexual) was the single largest demographic determinant of opinions about early surgery on intersex traits and human rights challenges to the legality of those surgeries (see Carpenter, 2016 for a cogent summary of such challenges). Apart from the politics of ordinary representation, this empirical finding suggests that LGBT people and heterosexual-identified people may have systematically different affinities with people born with intersex traits and the risks that they face from early medical intervention.

We have little more to say about ‘DSD’. Delimata et al. (2018) and other recent opinion suggests the creeping acknowledgment that it was a failed neologism, and we assume that gender and sexuality scholars, like the participants in Lundberg et al. (2018), would quickly see that it is a pathologizing term that serves as a poor point of entry into this field. Hegarty et al.’s (under review) survey also suggested a more general note of caution on neologisms as ways of managing terms’ unwanted associations. Survey participants commonly listed the more familiar terms ‘intersex’ and ‘hermaphrodite’, both as associates of each other and of ‘disorders of sex development’. However, they *never* listed ‘disorders of sex development’ as an associate of ‘intersex’ or ‘hermaphrodite’. In other words, whilst neologisms, such as ‘DSD’, often aim at new, fresh understandings that are free of past associations, people construct the meaning of unfamiliar terms by analogizing them to older, more familiar ones. This common strategy limits the effects of those methods that attempt to escape history and to create conceptual change via linguistic inventiveness.

6 Conclusions

We hope this chapter leaves scholars in Gender and Sexuality Studies new to this topic reflecting critically on the ways in which intersex has been made an object of curiosity and fascination from ancient times (Groves, 2016) to postmodern Gender and Sexuality Studies (Koyama, Weasel, 2001). These emotions show only a part-way learning and awareness that a norm has been troubled. However, this should not satisfy scholars who understand that Gender and Sexuality Studies require sustained engagement with the concerns of people with lived experiences of what academics are interested in representing – as well as a willingness to open up our concepts to their experiences.

We close this chapter with thoughts about openness and linguistic plurality in the current era of the history of our own field, psychology. Historians of psychology are interested in the question of whether psychological terms emerge first in the culture or in the writings of psychologists themselves. William James and Sigmund Freud loom large in discussions of the field's most effective inventors of neologisms (e.g. Benjafield, 2012). John Money deserves greater attention in gender and sexuality literature, both for successfully getting us all to think about gender in his original papers on the case management of intersex and for his many less popular neologisms. These neologisms nonetheless allowed him to *avoid* engagement with existing literatures, to keep his texts opaque to critics, and to keep control of what language terms mean (Downing et al., 2015, 69–100). For much of this chapter, we have been describing how experts talk about the performative aspects of speech acts, and, by so doing, create unequal access to flexible, open-ended language and concepts.

In a sustained reading of Money's misreading of the psychology of his time, Morland (2015) points out that Money analogized gender to language and believed that both were akin to self-organizing cybernetic systems. But Money misread the cybernetics of his time and particularly misunderstood the *openness* of cybernetic systems to feedback. Consequently, Money believed that human gender was open to feedback until about eighteen months of age, but closed thereafter, without a clear grounding for his beliefs. This underestimation of the openness of cybernetic systems to feedback was also reflected in

Money's belief that humans could never really truly be bilingual, any more than we could be bi-gendered.

With Roen (2019) and others, we continue to ask the question of what, if anything, is changing in medical treatment of intersex in our own time, and what kinds of diverse languages are needed for its critical engagement. We would suggest that gender and sexuality scholars who wish to contribute to this important endeavour would do better to push past debates about which language is used here and to interrogate contradictory assumptions about how diverse experts presume that language functions. Critical engagement might include interrogating the unequal consequences for access to self-determining language created by *linguistic futurism*; the fantasy that – at some point in the future – language will resolve easily into a solid form of essentialism whilst moral, ethical, and political questions evaporate into thin air. In contrast, we advise a kind of strategic anti-essentialism that recognizes the ordinary creativity that all humans need to use language and concepts flexibly to develop common ground and socially shared realities.

References

- Alderson, J., Madill, A., Balen, A. (2004): Fear of Devaluation: Understanding the Experience of Intersex Women with Androgen Insensitivity Syndrome. *British Journal of Health Psychology*, 9, 81–100.
- Austin, J. (1962): *How to Do Things with Words*. Oxford: Oxford University Press.
- Barsalou, L. W. (1983): Ad Hoc Categories. *Memory & Cognition*, 11, 211–227.
- Benjafield, J. G. (2012): The Long Past and Short History of the Vocabulary of Anglophone Psychology. *History of Psychology*, 15, 50–71.
- Bennecke, E., De Vries, A. (2016): European Research Project 'DSD-LIFE': Paper Presented at the Conference *After the Recognition of Intersex Human Rights*. University of Surrey, Guildford.
- Bowker, G. C., Star, S. L. (1999): *Sorting Things Out: Classification and Its Consequences*. Cambridge/MA: MIT Press.
- Carpenter, M. (2016): The Human Rights of Intersex People: Addressing Harmful Practices and Rhetoric of Change. *Reproductive Health Matters*, 24, 74–84.
- Carpenter, M. (2018): The 'Normalisation' of Intersex Bodies and 'Othering' of Intersex Identities. In: Scherpe, J. M., Dutta, A., Helms, T. (Eds.),

- The Legal Status of Intersex Persons*. Cambridge: Intersentia, 445–514.
- Chase, C. (1998): Hermaphrodites with Attitude: Mapping the Emergence of Intersex Political Activism. *GLQ*, 4, 189–211.
- Colapinto, J. (2001): *As Nature Made Him: The Boy Who Was Raised as a Girl*. New York: Harper Perennial.
- Cools, M., Simmonds, M., Elford, S., Gorter, J., Ahmed, S. F., D'Alborton, F., et al. (2016): Response to the Council of Europe Human Rights Commissioner's Issue Paper on Human Rights and Intersex People. *European Urology*, 70, 407–409.
- Cornwall, S. (2016): *Sex and Uncertainty in the Body of Christ: Intersex Conditions and Christian Theology*. London: Equinox.
- Crawford, M. E., Unger, R. K. (2004): *Women and Gender: A Feminist Psychology*. New York: McGraw-Hill.
- Creighton, S. M., Michala, L., Mushtaq, I., Yaron, M. (2014): Childhood Surgery for Ambiguous Genitalia: Glimpses of Practice Changes or More of the Same? *Psychology & Sexuality*, 5, 34–43.
- Davis, G. (2015): *Contesting Intersex: The Dubious Diagnosis*. New York: New York University Press.
- Delimata, N. (2017): *Articulating Intersex: A Crisis at the Intersection of Scientific Knowledge and Social Ideals*. Doctoral Thesis. Institute of Technology, Sligo.
- Delimata, N., Simmonds, M., O'Brien, M., Davis, G., Auchus, R., Lin-Su, K. L.-S. (2018): Evaluating the Term 'Disorders of Sex Development': A Multidisciplinary Debate. *Social Medicine*, 11, 98–107.
- Diamond, M., Sigmundson, K. (1997): Management of Intersexuality: Guidelines for Dealing with Persons with Ambiguous Genitalia. *Archives of Pediatric and Adolescent Medicine*, 151, 1046–1050.
- Downing, L., Morland, I., Sullivan, M. (2015): *Fuckology: Critical Essays on John Money's Diagnostic Concepts*. Chicago: University of Chicago Press.
- Dreger, A. D. (Ed.). (1999): *Intersex in the Age of Ethics*. Hagerstown/MD: University Publishing Group.
- Dreger, A. D., Chase, C., Sousa, A., Gruppuso, P. A., Frader, J. (2005): Changing the Nomenclature/Taxonomy for Intersex: A Scientific and Clinical Rationale. *Journal of Pediatric Endocrinology and Metabolism*, 18, 729–733.
- DuBois, J. M., Iltis, A. S. (Eds.). (2016): *Normalizing Intersex: Voices: Personal Stories From the Pages of NIB*. Baltimore/MD: Johns Hopkins University Press.
- Fausto-Sterling, A. (1993): The Five Sexes. *The Sciences*, 33, 20–25.
- Griffiths, D. A. (2018): Shifting Syndromes: Chromosome Variations and Intersex Classifications. *Social Studies of Science*, 48, 125–148.

- Groves, R. (2016): From Statue to Story: Ovid's Metamorphosis of Hermaphroditus. *Classical World*, 109, 321–356.
- Hampson, J. A. (2010): Concepts in Human Adults. In: Mareschal, D., Quinn, P., Lea, S. E. G. (Eds.), *The Making of Human Concepts*. Oxford: Oxford University Press, 293–311.
- Hegarty, P., Donnelly, L., Dutton, P., Gillingham, S., Williams, K., Vecchietti, V. (2019): Public Understanding of Intersex Controversies and the Umbrella Terms That Frame Them in the USA and the UK. Manuscript under review.
- Jones, T. (2017): Intersex and Families: Supporting Family Members with Intersex Variations. *Journal of Family Strengths*, 17, 1–31. Retrieved from: <http://digitalcommons.library.tmc.edu/jfs/vol17/iss2/8> [accessed 01.01.2019].
- Kelley, H. H. (1992): Common-Sense Psychology and Scientific Psychology. *Annual Review of Psychology*, 43, 1–23.
- Kessler, S. (1990): The Medical Construction of Gender: Case Management of Intersex Infants. *Signs*, 16 (1), 3–26.
- Kon, A. A. (2015): Ethical Issues in Decision-Making for Infants with Disorders of Sex Development. *Hormone and Metabolic Research*, 47, 340–343.
- Koyama, E., Weasel, L. (2001): *Teaching Intersex Issues: A Guide for Teachers in Women's Gender and Queer Studies*. Retrieved from: <http://isna.org/pdf/teaching-intersex-web.pdf> [accessed 01.12.2018].
- Lee, P. A., Houk, C. P., Ahmed, S. F., Hughes, I. A. (2006): Consensus Statement on Management of Intersex Disorders: In Collaboration with the Participants in the International Consensus Conference on Intersex Organized by the Lawson Wilkins Pediatric Endocrine Society the European Society for Paediatric Endocrinology. *Pediatrics*, 118 (2), e488–e500.
- Lee, P. A., Nordenstrom, A., Houk, C. P., Ahmed, S. F., Auchus, R., Baratz, A., et al. (2016): Global Disorders of Sex Development Update Since 2006: Perceptions, Approach and Care. *Hormone Research in Paediatrics*, 85 (3), 158–180.
- Liao, L. M. (2016): Stonewalling Emotion. In: Dubois, J. M., Iltis, A. S. (Eds.), *Normalizing Intersex: Voices: Personal Stories From the Pages of NIB*. Baltimore/MD: Johns Hopkins University Press, 57–64. Retrieved from: https://nibjournal.org/wp-content/uploads/2017/07/Voices_2016_INTERSEX_FINAL.pdf [accessed 01.01.2019].
- Liao, L. M., Boyle, M. (2004): Intersex Special Issue. *The Psychologist*, 17, 446–462.
- Liao, L. M., Roen, K. (2014): Intersex/DSD Post-Chicago: New Developments and Challenges for Psychologists. *Psychology & Sexuality*, 5, 1–4.

- Liao, L. M., Simmonds, M. (2014): A Values-Driven and Evidence-Based Health Care Psychology for Diverse Sex Development. *Psychology & Sexuality*, 5, 83–101.
- Lundberg, T., Hegarty, P., Roen, K. (2018): Making Sense of ‘Intersex’ and ‘DSD’: How Laypeople Understand and Use Terminology. *Psychology & Sexuality*, 9, 161–173.
- Lundberg, T., Lindström, A., Roen, K., Hegarty, P. (2017): From Knowing Nothing to Knowing What, How and Now: Parents’ Experiences of Caring for Their Children with Congenital Adrenal Hyperplasia. *Journal of Pediatric Psychology*, 42, 520–529.
- Lundberg, T., Roen, K., Hirschberg, A. L., Frisé, L. (2016): ‘It’s Part of Me, Not All of Me’: Young Women’s Experiences of Receiving a Diagnosis Related to Diverse Sex Development. *Journal of Pediatric and Adolescent Gynecology*, 29, 338–343.
- Medin, D. L. (1989): Concepts and Conceptual Structure. *American Psychologist*, 44, 1469–1481.
- Monro, S., Crocetti, D., Yeadon-Lee, T., Garland, F., Travis, M. (2017): *Intersex, Variations of Sex Characteristics, and DSD: The Need for Change*. Research Report. University of Huddersfield. Retrieved from: <http://eprints.hud.ac.uk/id/eprint/33535/> [accessed 01.01.2019].
- Morland, I. (2015): Gender, Genitals and the Meaning of Being Human. In: Downing, L., Morland, I., Sullivan, I. and M. (Eds.), *Fuckology: Critical Essays on John Money’s Diagnostic Concepts*. Chicago: University of Chicago Press, 69–98.
- Pasterski, V., Prentice, P., Hughes, I. A. (2010): Consequences of the Chicago Consensus on Disorders of Sex Development (DSD): Current Practices in Europe. *Archives of Childhood Diseases*, 95, 618–623.
- Potter, J., Wetherell, M. (1987): *Discourse and Social Psychology: Beyond Attitudes and Behaviour*. London: SAGE.
- Preves, S. E. (2003): *Intersex and Identity: The Contested Self*. New Brunswick/NJ: Rutgers University Press.
- Reis, E. (2009): *Bodies in Doubt: An American History of Intersex*. Baltimore/MD: Johns Hopkins University Press.
- Roen, K. (2008): ‘But We Have to Do Something’: Surgical ‘Correction’ of Atypical Genitalia. *Body and Society*, 14, 47–66.
- Roen, K. (2019): Intersex or Diverse Sex Development: A Critical Review of Psychosocial Healthcare Literature. *Journal of Sex Research*, 56, 511–528.
- Roen, K., Creighton, S. M., Hegarty, P., Liao, L. M. (2018): Vaginal Construction and Treatment Providers’ Experiences: A Qualitative Analysis. *Journal of Pediatric and Adolescent Gynecology*, 31, 247–251.

- Roen, K., Hegarty, P. (2018): Shaping Parents, Shaping Penises: How Medical Teams Frame Parents' Decisions in Response to Hypospadias. *British Journal of Health Psychology*, 23, 967–981.
- Sanders, C., Carter, B., Goodacre, L. (2012): Parents Need to Protect: Influences, Risks and Tensions for Parents of Prepubertal Children Born with Ambiguous Genitalia. *Journal of Clinical Nursing*, 21, 3315–3323.
- Stout, S. A., Litvak, M., Robbins, N. M., Sandberg, D. E. (2010): Congenital Adrenal Hyperplasia: Classification of Studies Employing Psychological Endpoints. *International Journal of Pediatric Endocrinology*, 191520. Retrieved from: <https://doi.org/10.1155/2010/191520> [accessed 01.01.2019].
- Tajfel, H., Turner, J. C. (1986): The Social Identity Theory of Inter-group behavior. In: Worchel S., Austin W. G. (Eds.), *Psychology of Intergroup Relations*. Chicago: Nelson, 7–24.
- Thorne, S., Hegarty, P. (2019): A Meeting of Minds: Can Cognitive Psychology Meet the Demands of Queer Theory? To Appear in: O'Doherty, K. (Ed.), *Psychological Studies of Science and Technology*. New York: Palgrave Macmillan, 257–278.
- Zajko, V. (2009): 'Listening with' Ovid: Intersexuality, Queer Theory, the Myth of Hermaphroditus and Salmacis. *Helios*, 36, 175–202.