The power in a name: diagnostic terminology and diverse experiences

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Soon after the disorders of sex development (DSD) terminology was introduced in the 2006 medical consensus statement on the management of intersex traits, intersexuality became an outdated term within medical discourse. Because of the way the DSD terminology was officially introduced by an international medical consortium, it appears individuals with intersex traits are left to engage with it. Interviews with thirty-seven research participants with intersex traits show that DSD terminology is engaged in different ways by those the terminology is meant to describe, with some arguing against it, others supporting it and a few being indifferent to it. Participants also tended to describe self-understandings that might conflict with the intersex identity that was observed in the 1990s. Patterns across participants' preferred terminology and their relationships with family members and medical providers are also observed.

Keywords: intersex; DSD; qualitative naming; identity formation; family and medical relationships

Introduction

In the 1990s, an intersex[1] identity was born as many individuals with intersex traits bonded with one another over their shared medical histories in order to challenge the medicalised (surgical and hormonal) treatment of intersexuality (e.g. Preves, 2003; Turner, 1999). Intersexuality is defined here as traits where one is born with 'ambiguous genitalia, sexual organs, or sex chromosomes' that deviate from the 'norm' (Preves, 2003, p. 2). Historically, medical professionals treated intersexuality by surgically modifying the 'abnormality' at birth, or sometime during adolescence, despite the fact that such surgery left many intersexuals emotionally and physically scarred (Preves, 2003). This medical treatment, and the publication of provocative feminist critiques of such practices (e.g. Fausto-Sterling, 1993; Kessler, 1990), paved the way for the formation of intersex support groups and the development of the intersex rights movement (Karkazis, 2008; Preves, 2003). Turner (1999) even concluded that through the mobilisation efforts of the Intersex Society of North America (ISNA), intersexuals managed to move beyond the sex binary and create a 'third sex'. She stated:

> Embodying what they feel is a failure of medicine to make them what they cannot be in the first place, [intersexuals] envision a wholly new intersection of sex and gender, a kind of 'third sex' that evades gender determination yet also somehow solidifies into a category of identity. (Turner, 1999, p. 458)

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The medical profession also acknowledged that the birth of a baby with an intersex trait constitutes a 'social emergency' (Committee on Genetics [COG], 2000, p. 138).

In 2006, the *American Academy of Pediatrics* revised their policy regarding the treatment of intersex infants due to technological advancements and intersex activism, among other factors (Lee, Houk, Ahmed, & Hughes, 2006). They offered several recommendations including revising 'intersex' to the new diagnostic terminology 'disorders of sex development' (DSD). Research has already indicated that this recommended terminology was widely accepted throughout the US medical profession as a way for medical professionals to reclaim jurisdiction over intersexuality, which intersex activists were successfully defining as a social, rather than medical, problem (Davis, 2011). The introduction of DSD terminology, and its acceptance throughout the global medical community in a relatively short amount of time (Davis, 2011; Pasterski, Prentice, & Hughes, 2010a, 2010b), left me wondering about the fate of intersex identity.

Although there have been a handful of non-clinician academics who are openly critical of the new DSD nomenclature (e.g. Davidson, 2009; Holmes, 2009; Karkazis, 2008; Reis, 2007), it has received scholarly support. Academics Alice Dreger and April Herndon (2009), for instance, acknowledge that '[r]eception of the new terminology has been mixed among people with intersex' (p. 212), yet they embrace the possibility for positive change that DSD terminology could bring to those whose lives are personally affected by intersexuality. They conclude 'that [DSD] terminology accords with the experience of many intersex adults and patients, it gives them a term that feels right in that it seems simultaneously to name, scientise, and isolate what it is that has happened' (Dreger & Herndon, 2009, p. 212). In 2008, Ellen Feder and Katrina Karkazis, academics and allies to intersex activists, collaborated together in a paper where they openly struggled with the new DSD language, but were willing to embrace it if it '[would] help to refocus medical care on lifelong health; [and] not only contribute to improving medical care but also to promoting attention to affected individuals' quality of life' (p. 33). Feder (2009) has since advocated for 'progressive' DSD language (p. 226). Karkazis, on the other hand, remains sceptical of DSD and has since moved away from it in her work (Karkazis, Jordan-Young, Davis, & Camporesi, 2012).

However, while many medical experts support DSD nomenclature and several influential scholars of intersex studies remain hopeful in it, little empirical research explores how intersexed individuals themselves feel about this terminology. This current empirical research is intended to fill this gap. I begin with a brief overview of the medicalisation of intersexuality, focusing specifically on the medical consensus statements intended to guide treatment. I next incorporate sociological theories about naming and medicalised deviance to argue that DSD terminology cannot be ignored by intersexed individuals because it was officially introduced by medical professionals, a powerful and institutionalised professional collective with legitimised control and authority over bodies. While this empirical research shows that intersexed individuals have diverse opinions about the new DSD terminology, I also argue that DSD nomenclature is invested with a degree of power, given the medicalised context in which it was introduced. Finally, I report on the observed connections between participants' preferred terminology, their self-understandings, and their relationships with family members and medical professionals.

The medicalisation of intersexuality

Medical management and feminist critiques

Technological advancements in the twentieth century provided medical practitioners with the tools to surgically and hormonally treat individuals who deviated from binary sex. Intersexuals were defined as having 'abnormal bodies' that needed medical and surgical attention in order to fit into the sex binary and arguably ameliorate the stigma and shame associated with not comfortably fitting into the sex categorisation system. A substantial body of work across the humanities and social sciences provides critical analyses of this process (e.g. Dreger, 1998a, 1998b; Fausto-Sterling, 1993, 1996, 2000a; Holmes, 2008; Karkazis, 2008; Kessler, 1998, 1990; Preves, 2000, 2002, 2003).

Some feminists were critical of the medical management of intersexuality due to their conceptualisation of sex and gender as socially constructed binaries. By arguing for the recognition of five sexes, Fausto-Sterling (1993) attempted to debunk dichotomous notions about sex. Kessler (1998) later critiqued Fausto-Sterling's 'Five Sexes' by maintaining intersexuals should be thought of as evidence of sexual 'variability' rather than sexual 'ambiguity'. According to Kessler (1998), it is neither possible nor logical to maintain the sex system when recognising the existence of multidimensional sexual variability. To categorise intersexuals by attempting to define sex, Kessler maintains, is to perpetuate the validity of the categorisation system. In 2000, Fausto-Sterling accepted Kessler's critique, writing that 'It would be better for intersexuals and their supporters to turn everyone's focus away from genitals' (Fausto-Sterling, 2000b, p. 22).

By providing analytic ground for activists to challenge the medical profession, feminist writers (e.g. Fausto-Sterling, 1993; Kessler, 1990) helped spark an intersex rights movement that seemed to begin to change how physicians treat intersexuality. Fausto-Sterling, for instance, is credited with facilitating the formation of the Intersex Society of North America (Chase, 1997, 1998a; Fausto-Sterling, 2000a, 2000b; Preves, 2003). The publication of her 1993 essay, 'The Five Sexes', inspired Cheryl Chase, despite her open criticism of the piece, to create the Intersex Society of North America, at one time the world's largest intersex advocacy and support group before it closed its doors in the summer of 2008 (Chase, 1997, 1998a, 1998b). In 1997, the American Academy of Pediatrics refused to engage 'zealous' intersex activists (Diamond, 1997; Fausto-Sterling, 2000a, 2000b). However, 3 years later, Chase delivered a plenary address to the Lawson Wilkins Pediatric Endocrine Society, a group she had once protested against (Karkazis, 2008). The American Academy of Pediatrics ultimately acknowledged that the birth of an individual with an intersex trait created a professional 'social emergency' (COG, 2000, p. 138). Shortly thereafter medical professionals instituted guidelines for the treatment of intersexuality, including, but not limited to, taking a more cautious approach to early surgical interventions (COG, 2000).

Medical statements

The 2000 medical guidelines for the treatment of intersexed infants recommended that intersex infants 'should be referred to as "your baby" or "your child" – not "it", "he", or "she"' (COG, 2000, p. 138). Early cosmetic surgery, however, remained a treatment option. The guidelines noted parents should be informed that 'abnormal appearance can be corrected and the child raised as a boy or a girl as appropriate' (COG, 2000, p. 138). The guidelines stated that a number of factors should be considered when determining

which sex category, or in their language 'gender assignment', should be recommended for a given intersex child. Most notably, these factors included 'fertility potential' and 'capacity for normal sexual function' (COG, 2000, p. 141). Both of these factors are deeply rooted within cissexism[2] and heteronormative ideologies about sexuality that presume sex, gender and sexuality are all biologically correlated.

In 2006, the American Academy of Pediatrics revised their policy regarding the treatment of intersexed individuals. They maintained their protocol needed revision due to 'progress in diagnosis, surgical techniques, understanding psychosocial issues, and recognising and accepting the place of patient advocacy' (Lee et al., 2006, p. 488). The timing and extent of this revision could be read as one way in which power operates through the institution of medicine. This particular revision illustrates the power invested in medicine to not only treat but also to define and (re)name intersexuality as DSD.

Naming and medicalised deviance

A medical condition does not officially exist until after the 'abnormality' in question is defined (Conrad, 2007; Scott, 1990). The process by which an 'abnormality' is defined has shifted throughout history. In ancient Greece, medicine was practiced without diagnostic names (Veith, 1981). Instead, descriptions of disease were used until eighteenth century medical professionals turned to a botanical model of classification that linguistically identified, labelled, classified and named a wide range of medical conditions. This move to naming diseases was not widely accepted by all medical professionals, yet this 'classificatory project' prevailed (Jutel, 2009, p. 280).

It has only been several years since the 2006 consensus statement reclassified intersexuality as DSD, yet evidence suggests that intersexuality has already become an outdated term within medical discourse (Davis, 2011; Pasterski et al., 2010a, 2010b). The process of naming ought to concern us because history has shown that there are implications to defining conditions as disorders (e.g. Brown, 1990, 1995, 2007; Conrad, 2007; Cooksey & Brown, 1998; Jutel, 2011). Consider, for example, attention deficit hyperactivity disorder (ADHD). Conrad (2007) argued that ADHD diagnosis expanded in the 1990s to include adults who were not previously diagnosed in ways that had a lasting impact on how individuals, after diagnosis, understood and explained their behaviours.

The trajectory of intersex medicalisation, and shifts in its naming, is evidence of Conrad and Schneider's (1980) five-stage model of medicalised deviance. Intersexuality was initially viewed as an unfavourable deviation from the sex binary (stage one). Then, with medical advancements, doctors had the tools to identify and describe intersexuality chromosomally (stage two). Soon after, medical professionals started claiming intersex expertise (stage three). What marks the fourth stage in Conrad and Schneider's (1980) model is a battle over diagnoses. The medical profession faced a substantial amount of resistance in this stage from some feminist scholars and intersex activists determined to stop, albeit unsuccessfully, the fifth and final stage, where the condition in question becomes a legally recognised 'abnormality', as evident in the shift to DSD. This raises several important questions. How widespread is DSD terminology among intersex individuals? How do intersex individuals feel about DSD nomenclature? How does this nomenclature relate to identity formation?

Methods

My analysis relies on thirty-seven in-depth interviews conducted throughout the US with individuals who have intersex traits. As part of my doctoral research, I collected data from

October of 2008 to April of 2011 through the now defunct Intersex Society of North America, the Androgen Insensitivity Syndrome Support Group-USA,[3] Accord Alliance and Organisation Intersex International. I collected over forty hours of interview data, with each interview ranging from 45 minutes to well over 3 hours. All interviews were audio-recorded and transcribed, and all participants were asked to choose their own pseudonym. In some instances, participants requested that I not use a pseudonym, in which case, I honoured their request. I conducted all of the interviews face-to-face in order to gain informants' trust and establish a level of comfort only possible in person. Before the start of data collection, ethics approval was obtained from the University of Illinois at Chicago.

As a feminist with an intersex condition, my lived familiarity with intersexuality has shaped this project from conceptualisation to data collection and analysis. However, throughout each stage, I have stayed true to standpoint epistemology, an epistemology that takes into account a variety of experiences – including the experiences of the researcher – when asking, addressing and evaluating a particular research question and its findings (Sprague, 2005). Standpoint epistemology allows us to frame research questions from our own standpoint or the standpoint of others. It grounds interpretation in experience, and through this process allows for research that challenges dominant standpoints. As Koyama and Weasel (2002) document, most of what we know about intersexuality has been presented by non-intersexed academics and clinicians, and while unquestionably valuable as pieces of the conversation, their scholarship does not make up the entire puzzle. Intersexuality needs to be analysed from more diverse standpoints, especially those personally impacted.

Findings

All of my participants were familiar with DSD terminology. However, it was not similarly received by all, as some were opposed to it, others supported it and a few were indifferent to it. Still, everyone seemed to have to acknowledge and engage with this terminology. This potentially forceful situation might explain why I observed some polarisation between participants who were dissatisfied with DSD terminology and participants who welcomed it. While there were several who stood on the outside of what appears to be a polarisation, by neither embracing nor rejecting the DSD terminology, they too were familiar with the term. As I describe below, this terminology preference, or lack thereof, was frequently related to how participants understood themselves and how they described their relationships with family and medical professionals.

'Who wants to be a fucking disorder? . . . I don't'

In the late 1990s, individuals with intersex traits reportedly embraced intersexuality and claimed it as an identity (see Turner, 1999). Thus, I was not surprised to hear a substantial number of my participants speak negatively about DSD terminology. Jeanne, for example, explained to me that 'disorders of sex development is such a mouthful . . . and it is kind of a cold word . . . intersex . . . I identify with it'. When I asked Pidgeon[4] what she prefers to call her condition, she enthusiastically replied, 'hermaphrodite or intersex . . . I feel like the language shift to DSD makes no sense to me . . . I don't feel it was necessary'. Millarca expressed similar discontent with DSD language. With passion she stated that 'DSD is not . . . is not something a lot of people want to identify with . . . nobody wants to be a disorder . . . who wants to be a fucking disorder? . . . I don't'.

Participants who tended to be dissatisfied with the new nomenclature also seemed to differently understand and form their identities. For example, Stevie, who embraced intersex language said:

> Ultimately when we look in the mirror . . . and we're like either shocked by oh my god I need some lipstick . . . or oh my god I want to toughen up . . . look more macho or butch . . . we basically are responding to the inner conversation in our mind's eye of what we want to see . . . how we want to appear . . . how we want to be perceived.

Stevie explained gender as a performance that she could alter with lipstick, for example, should she desire. Pidgeon similarly understood gender: '[P]lay with your gender if you want . . . you can do whatever you want! . . . Check out all avenues of sexuality and gender and have fun with it'.

Many of the participants who were dissatisfied with DSD terminology also described fractured familial and medical relationships. For example, Stevie was estranged from her parents throughout her twenties and thirties due to how her parents attempted to police the formation of her non-normative gender identity. Stevie said:

> My mother wanted to get me involved in social philanthropic things that would model . . . what a woman in society does . . . . [For example,] there was a modeling component to [an organization my mother got me involved in] . . . a 'modellette program' . . . basically had beauty and poise training . . . [My parents] knew they had a task to try to bring about a certain result . . . to raise this child as a girl.

Recently, Stevie became reacquainted with her father, a reunion that happened only after her mother's death. When I asked Pidgeon, who claimed an intersex identity, to describe how her parents attempted to influence her identity formation, she replied:

> I think a lot of times, our parents are so scared that the doctors made the wrong decision and we're going to veer off to this other gender world . . . so they kind of police it. My parents didn't technically tell me all the time that 'you're a girl and you're going to be a girl' but I'm sure it was always playing in the background of decision-making.

When I asked Millarca how her parents responded to her activism and comfort claiming an intersex identity in public settings, she replied:

> My family was ashamed. They thought that I shouldn't talk about things in the family outside of the family. So they didn't want to hear or watch the documentary or the show or anything . . . [Today, my relationship with family is] the same. It's still strange. We don't really associate very often . . . it's been like that most of my life. It's not like this just because I'm intersex, it's everything, like intersex, being gay, being into leather and S&M, and just not conforming to their politics.

Participants who expressed dissatisfaction with DSD nomenclature also commonly described troubled relationships with medical professionals. Millarca, for instance, stated, 'I don't trust doctors'. Ann was concerned that her sexuality would be a problem for her endocrinologist. She recalled, 'I remember him asking me if I was . . . after the surgeries were done . . . if I was dating boys . . . in my mind . . . the right thing would be to say "yes, I am" . . . I remember thinking that I should just tell him that I am even though I was not'. Many of the older participants who claimed an intersex identity also refused to defer to the prestige and authority society grants medical professionals. Chris said:

> I just find [genetic experts] . . . dogmatic . . . they have it all figured out . . . and that doesn't sound like science to me . . . Just because they have a doctor in front of their name . . . when I was a younger . . . I was a lot more respectful of that.

Most of the participants who spoke critically of DSD terminology were heavily involved in 1990s intersex activism, a period characterised by intersex activists protesting against medical professionals. Many were also still involved in activism in the form of appearing on television shows and in documentary films. It was therefore not a surprise to hear many of those involved with intersex activism to voice strong opposition to terminology formally introduced by medical professionals. This historical and contemporary activism might also explain how many participants' positive self-understandings were coupled with criticism of medical professionals. Furthermore, involvement in intersex activism might explain why many shared stories of troubled relationships with their families to whom being an activist may be a shameful and public choice whereas a medical condition may be something one is born with and can be hidden from public view.

'Oh get the fuck over it'

For every two participants who passionately expressed dissatisfaction about DSD terminology, there was one who intensely welcomed it. Jane, for example, did not understand why others so adamantly resisted DSD language. She felt the terminology could be a route for productive conversations with medical professionals. She explained:

> I can be on the outside of the room arguing about terminology and if I embrace [DSD] and the door opens and let's have a real good substantive conversation because we are talking about the same thing . . . you can call me frog. I don't give a crap what you call me as long as we're moving forward advocating for families and advocating for small children that don't have a voice . . . so, when people want to argue till the cows come home that '*disorder is such an ugly word*' and '*we're not disorders . . . we're not disordered*' . . . oh get the fuck over it.

Tara also expressed support for DSD terminology over intersexuality, although without Jane's focus on strategy for change. She said, 'Hermaphroditism and all those kinds of ones . . . I am not a fan of obviously'. Marilyn explained intersex terminology 'bothered [her] a little bit because it was just a little bit too political'. Karen touched on this political tension when I asked her about her terminology preference. She considered intersex as 'bad because it describes a possible third sex or worse . . . a limbo state between them and I don't think humans are in limbo'.

There was also a tendency for participants who embraced the new nomenclature to report less positive sense of self. In Tara's own words:

> After I found out that I technically am a genetic male . . . when I wear a baseball hat or something I kinda look in the mirror and I'm like, do I look like a dude? . . . Some women obviously look like women.

Tara was concerned that gender was biologically correlated to sex rather than something we perform. This understanding of gender leaves individuals feeling 'abnormal', possibly reflecting their sense of self as 'disordered'. Marilyn similarly shared a less positive sense of self:

> When I was growing up, I was having a hard time feeling very feminine because I wasn't developing . . . I didn't feel like a complete woman.

While Marilyn went on to explain that her feelings of not being 'a complete woman' were lessening as she got older, she still concluded, 'I still don't feel like a complete woman'.

   Though it was common for participants who embraced DSD terminology to report a less positive sense of self, I also regularly heard them describe positive relationships with family and medical professionals. For example, Liz, who did not claim an intersex identity, said that her mother, 'was supportive . . . she was just supportive . . . it was very good. She went through all the steps with me . . . took me to doctors and stuff. Very simple'. Vanessa similarly shared that her parents 'always have been supportive of [her] . . . and [tried] to make [her] a happy person'. As with Liz, Vanessa did not particularly care for intersex terminology. She explained, 'intersex rubs me the wrong way . . . I'm comfortable . . . with disorder of sex development. It's the development of your sex in utero . . . I think it explains . . . something that happened versus something that you chose'. Interestingly, Vanessa was also careful to explain that the support she desired from her parents was an ongoing process: 'I would say they're supportive. I think my dad is becoming increasingly so . . . I think my mom is still turning the other way and keeping her distance on this. She'll say, "I'm here for you if you wanna talk", but then if I wanna talk, she's sort of busy . . . That's sort of what goes on with her'.

   Many participants who accepted DSD terminology had similar positive relationships with medical professionals. Liz explained that, '[A doctor] cleared everything up . . . I saw a couple of other doctors [in my city] that also cleared everything up'. Tara similarly had positive experiences with medical professionals. She elaborated:

> [My diagnosis] was straight forward . . . The doctor was . . . really nice about it . . . supportive . . . summed it up like . . . you basically are born like a woman that had a hysterectomy . . . you just have to take estrogen to help with your bones . . . we're gonna remove your gonads.

Karen at one time had less positive relationships with medical professionals, but reported that this has shifted. She explained, 'I've been treated like shit by doctors for a very long period of time [but] not currently'. When I asked her what had changed, she said she started approaching doctors with what she needed without disrespecting them. She explained:

> I said, "This is what I want. This is how I want to be handled. This is what I want you to do. I don't want you to stop being a doctor and not tell me the things I need to know, but I've been lied to in the past and I've been treated terribly and treated like a lab rat, and that's not going to happen here." So he agreed and that's that.

Many of the participants who supported the medical profession's DSD terminology were never involved in intersex activism, nor did they have any interest in constructing an intersex identity. Instead, they welcomed DSD language because it conceptualised intersexuality as a medical, rather than social, condition. This could explain why these participants described having mostly positive relationships with medical professionals. It also might account for why many shared stories of parental support, as they conceptualised their condition as a medical problem that one was born with rather than an identity one has chosen. However, the medical conceptualisation of intersexuality as a disorder might also explain why participants commonly described less positive understandings of the self.

'*Use whatever term suits . . . '*

Although many of my participants held strong views on the medical profession's DSD development terminology, there were a minority of others who were non-committal to either intersex or DSD language and/or felt individuals should have the right to choose whatever terminology they preferred. Even though Cheryl Chase, the founder of the former Intersex Society of North America, advocated for DSD terminology in the medical context – for which she hoped would replace hermaphrodite language – by 'engineer[ing] the entire thing . . . getting the language changed into [the consensus statement] by working through allies', the term belongs to the medical profession who officially introduced it. While Chase encouraged DSD terminology, she also supported the preferences of others:

> I think people should use whatever term suits them. I think in a medical context, 'intersex' is really counterproductive. It isn't a diagnosis . . . It's totalizing, and the way in which it's totalizing causes doctors to be so freaked about it that they're going to lie. If that's the word that they get to use, they're not gonna use it, they're gonna lie about it. And we know that lies create shame.

Maria explained, 'I have mixed feelings . . . for technical reasons, I think DSD is appropriate. But as an activist, intersex really highlights . . . it really is different . . . it's just not some disorder'. Mariela hadn't 'put much thought into' terminology. She went on to say that she preferred, 'Either one, really. It's another label'.

Participants who were non-committal to the terminology seemed to adhere to diverse understandings of the self. On one hand, Mariela expressed concern about her feminine identity. She explained, 'I'm still really self-conscious about my body . . . and I'm worried about falling in love and when to disclose'. Skywalker had similar concerns, although her concerns improved after she became partnered. She explained, 'I'm enough of a woman that he doesn't care and that's enough for us'. On the other hand, Maria had a more positive self-understanding which came from her critique of the sex binary which she concluded was an 'oversimplification'. Emily also had a more positive self-understanding, for she saw the self as something capable of change. She used to think of herself 'as definitely more masculine' but that shifted as people started pointing out the she had 'a lot of feminine qualities'. When I asked her where these qualities came from, she said, ' . . . socialization . . . friends, family, watching the movies'.

While I did not observe a clear pattern of self-understanding among those who were non-committal to terminology, there was a tendency in the interviews for those who were open to both terminologies to describe positive relationships with their parents. For example, Skywalker 'talk[s] to [her] mom a fair amount' about her condition and in return receives lots of supportive internet information from her mom's WebMD searches. Emily described her relationship with parents as 'good', and went on to say that her parents are people she 'get[s] along with'. Jenna had a similarly positive relationship with her parents. She explained, 'My parents were like as long as [I'm] happy, that's all that matters'.

Differences among those who were non-committal to terminology once again appeared when they described their relationships with medical professionals. For instance, Emily explained that she was 'distrusting' of medical professionals. She also went on to say that she takes whatever they say 'with a grain of salt'. While Skywalker had a similar troubled relationship with doctors who encouraged her to 'lose weight' and 'let [her] hair grow out' to adopt a female identity and attract men, others who were indifferent about the terminology had more positive relationships with medical professionals much like those who embraced DSD language. Mariela described doctors as 'very supportive . . . they did

what they could, it was just me that didn't want to deal with it'. Mariela did not claim an intersex identity nor did she exclusively prefer DSD language. Instead, she preferred, 'Either one, really'. Kelly similarly expressed, 'I have a very good relationship with my primary care physician'.

Participants who were indifferent about the medicalised DSD terminology seem to be capable of diminishing at least some of the institutional power embedded within the diagnostic nomenclature. By not strictly adopting one label over another, they could use whichever term they find more effective in any given setting and at any given time. For instance, one could use the power of the intersex label to construct a more posi-tive self-identity if one begins to feel 'abnormal'. When one communicates with medical professionals and/or family members about their struggles with intersexuality, one could perhaps rely on DSD terminology and its construction of intersexuality as a medical prob-lem to fulfil certain relational needs. There should be nothing inherently challenging about floating between intersex and DSD language. However, such flexibility might be challenged by those who are passionate about terminology, which includes some intersex people and some medical professionals alike.

Discussion

DSD terminology is not uniformly accepted by those whose bodies the terminology describes. Yet, all of my participants were familiar with it lending to the medical pro-fession's power to name and introduce new terminology in ways that could not be avoided. While research participants held diverse views about this new terminology, they were all familiar with it, indicating how prevalent and unavoidable DSD has become. What also emerged from the interviews were patterns between how participants felt about DSD terminology and understandings of the self. Additionally, the terminology prefer-ence participants expressed was regularly aligned with how they described their family and medical relationships. Participants who were inclined to oppose DSD terminology commonly described more positive conceptualisations of the self, yet they also spoke of troubled relationships with family members and medical professionals. Participants who tended to embrace DSD terminology generally described positive relationships with their families and medical professionals, yet it was not uncommon for them to also express feel-ings of 'abnormality'. Although in the minority, there were a few participants who were indifferent to the new terminology, and/or felt people should have the ability to choose their own terminology without their choice being politicised.

What my analysis suggests is that medicalised power-to-define operates through DSD terminology. No matter how opposed one is to this terminology, it must be engaged with. The same is not true with intersex terminology that 1990s intersex activists success-fully reclaimed and defined as a social, rather than medical, problem. Very few medical professionals continue to use intersex terminology (Davis, 2011; Pasterski et al., 2010a, 2010b). While DSD terminology might allow collaboration with medical professionals, it might also heighten the struggles and difficulties around self-understanding that some participants in my study expressed. Participants who were inclined to hold on to intersex terminology, expressing strong opposition to DSD language, regularly shared stories of struggles, but their struggles did not seem oriented towards the self. Rather, their struggles were commonly described in terms of fractured family and medical relationships, likely heightened by their history with intersex activism. Although it might be beneficial to hold on to intersex language, which is consistent with claiming intersex as an identity, per-haps the best approach is to straddle the terminological options and not be exclusively tied

to either label. This approach could allow individuals to strategically employ whichever terminology they assume to be most productive in any given situation. It also suggests that there does not need to be a permanent preference in terminology. However, to float between labels for strategic purposes, one needs to acknowledge that a medical condition is only as real as its definition (Conrad, 2007; Scott, 1990). Perhaps, the medicalised institutional power expressed through diagnostic naming can be diminished when diagnostic labels are approached as socially constructed phenomena employed or withheld for strategic purposes.

The participants who passionately prefer one term over another seem to be in a verbal battle with one another rather than with the medical profession who officially introduced the terminology. Those who are indifferent about the terminology may have escaped the war for now, but unless more people meet them in the middle, I imagine they are going to have to pick a side sooner or later. Regardless of where one falls on this naming issue, there is evidence here that diagnostic terminology is powerful because it originates in the medical profession, and in the case of DSD, is not uniformly accepted by those it describes. Given the five stage model of medicalised deviance (Conrad & Schneider, 1980), the naming situation described here is particular because it seems to be evidence of a sixth stage where there is a battle happening among intersexuals themselves and not exclusively between those with intersex traits and those who have the institutional power to officially define nomenclature. As long as there are sides for intersexed people to fall on, this turf war over naming will likely continue in ways that constrains progress towards ending the shame and stigma wrapped up in the intersex diagnosis.

Notes

1. I use the language of 'intersex' and 'intersexuality' throughout this paper as opposed to 'disorders of sex development' for three reasons. First, due to the greater visibility such words have had in academic publications, across disciplines, over the newer DSD terminology, I found it was necessary to continue to reach a broader audience. Second, recent publications in the medical sciences have, for the most part, abandoned 'intersex' language despite the fact that not all individuals with such conditions prefer DSD terminology (see Pasterski et al., 2010a, 2010b). Third, and the main reason for my choice in terminology, as an individual with an intersex trait, I prefer intersex language over DSD nomenclature.
2. Cissexism is the belief that gender is authentic only when it is neatly aligned with sex and sexuality.
3. AISSG-USA now goes by AIS-DSD Support Group. Available at: http://www.aisdsd.org/
4. Participant has indicated preference for this spelling of the chosen pseudonym. In an earlier publication, the pseudonym was spelled Pigeon (see Davis, 2011).

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