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DSD Debates: Social Movement Organizations' Framing Disputes Surrounding the Term 'Disorders of Sex Development'

Robert J. Davidson

Introduction

In the last 15 years discussions around 'intersex' have increasingly moved beyond the medical/biological realm and taken growing prominence in gender studies, within social movements, and in the socio-cultural realm. This shift was highly promoted by social movement organizations (SMOs) that have arisen to address various issues related to intersex and was also encouraged by some academics in the social sciences and the humanities. Social movement research is only beginning to address intersex advocacy in social movement terms (Turner, 1999; Preves, 2005; Greenberg, 2006). Research regarding social movements in the last two decades has paid increasing attention, however, to discourse (Steinberg, 1998) and how social movements engage with cultural institutions and use frames (Snow & Benford, 2000) to reshape cultural codes (Melucci, 1985, 1996). This article traces the framing processes executed in a debate over the reshaping of a code among three groups of the intersex social movement in order to understand how the groups engage with the medical discourse on intersex. A medical discourse on intersex is traced based on a Foucauldian perspective. A textual framing analysis of the websites of three intersex SMOs is then presented to examine the internal frame disputes between them over the proposed terminology 'Disorders of Sex Development,' or 'DSD'. The SMOs included are the Intersex Society of North America/Accord Alliance (ISNA/Accord)[1], Organization Intersex International (OII), and Androgen Insensitivity Support Group UK (AISSGUK). A schema of how each SMO

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[1] The combination 'ISNA/Accord' is used throughout the article to refer to the activities of both of these groups. ISNA was closed in 2008 and replaced by Accord Alliance. Many materials now available on the Accord Alliance site were originally developed when the group was still ISNA. The combined 'ISNA/Accord' term acknowledges that the groups are separate and yet related.

engages with the discourse surrounding intersex is presented and related to the frame disputes over 'DSD'.

Background of 'DSD'

Cheryl Chase, representing ISNA/Accord, attended a conference in Chicago (hereafter termed the Chicago Conference) on October 27-31, 2005 at which numerous medical practitioners working on intersex issues also participated. One other activist, Barbara Thomas of the German intersex group XY-Frauen, also participated. The German group member was also an informal representative of AISSGUK. The participants were mostly from North America, particularly the U.S. At this conference participants unanimously agreed to change nomenclature from 'intersex' and 'hermaphrodite' to 'DSD.' Their statement regarding the decision was called the 'Consensus Statement' (Lee & Houk 2006). ISNA/Accord then hosted the 'First DSD Symposium' on October 13-14, 2006 as a mini-conference within the (U.S.A.) Gay and Lesbian Medical Association's (GLMA) annual conference. After these conferences took place the DSD terminology became a point of contention between the SMOs. Previous academic literature concerning debates over the adoption of the new terminology has been rather opinionated and has failed to integrate information from SMOs themselves (Reis, 2007; Feder & Karkazis, 2008).

Discourse

Stemming from the semiotic turn, which proposed that language constructs reality, the concept of discourse analysis has become increasingly central to cultural analyses. Michel Foucault's concepts of discourse and power/knowledge concerning the medicalization of the 'hermaphrodite' will be used to trace a medical discourse of intersex that is based on pathology.

Foucault's work presented a re-conceptualization of power from repressive to productive power. Power, for Foucault, was not only the physical strength of the state to repress

through violence but also included the power of ideas about individuals, such as the division between health/sickness, produced through various institutions. For Foucault (1980) this productive power is inextricably tied to the production of knowledge and truth claims, such that Foucault uses the term power/knowledge. Knowledge is shaped through discourse, which is a rationalizing system based upon the qualification of certain knowledge and the disqualification of other knowledge in the process of 'truth' production. Knowledge production is intertwined with particular social institutions which have gained the authority to make certain claims to truth. The knowledge and 'truth' which is produced by these institutions result in the disciplining of bodies and the regulation of individuals.

In the *Birth of the Clinic* (1963) Foucault traced the development of modern medical practice, emphasizing how medicine increasingly gained the authority to make truth claims about the 'sick' or 'healthy' body and how the base for determining the 'sick' or 'healthy' changed through time. Foucault found that while it was not the case in the eighteenth century, by the nineteenth century 'health' was increasingly tied to the concept of normality. In *Abnormal* (2004) Foucault traced the development of psychiatry, emphasizing how psychiatry also gained authority and began to make truth claims about the 'sick' or 'healthy' mind. The concept of psychiatric sickness was based heavily, as referenced by the book's title, on the abnormal. Thus, the normal/abnormal dichotomy, which had not been previously related to health or morality, became highly tied to the diagnosis of illness and to 'curing', or regulating, individuals to fall in line with a particular norm. Through this logic sexual 'abnormality,' either in the body or in behavior, became a central site for medicalization.

Medicalization of Intersex

The figure of the 'hermaphrodite' is a central example in Foucault's exposition of the disciplining mechanisms of rationalizing apparatuses, and Foucault traces the productive element of power/knowledge in relation to 'hermaphrodites'. Foucault documents how

individuals identified as hermaphrodites were at certain points in history socially excluded or potentially put to death, and how a shift occurred in the late 17th and early 18th centuries tied to changes in knowledge. 'Hermaphrodites' ceased to be seen as embodying a mixture of the two sexes, and were rather labeled as 'pseudo-hermaphrodites.' This labeling indicated that they were not 'true hermaphrodites' but had a 'true sex' (either male or female) that could be medically discerned within a binary system of sex categorization. Dreger (1998) has documented the historical medicalization of intersex beginning in the mid-1800s. In this period medical practitioners searched for a criterion by which a 'true' male or female sex could be determined in manifestations of so-called 'pseudo-hermaphrodites'. Dreger also traces how the criteria for determining 'true sex' shifted through time (Dreger 1998), as each criterion proved to be inadequate. Instead of re-evaluating the two-sex paradigm, new criteria continued to be sought in attempts to 'prove' a 'true sex'.

The disciplining effects of this approach can most clearly be seen in how medical practice regarding intersex has, since the late 1950s throughout the global North, followed the so-called 'Money Protocol' based on the work of John Money at Johns Hopkins Hospital in Baltimore, U.S.A. This protocol involved the use of surgery and hormones to create the appearance of 'normal' male or female genitalia within the first eighteen months of life. Largely through the critical work of Diamond and Sigmundson (1997) the Money Protocol is under critical re-evaluation.[2] Fausto-Sterling (2000) documented, however, that intersex conditions, particularly those involving the appearance of the genitals, continue to be approached as medical emergencies, even though genital appearance is not life-threatening.

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[2] The Money Protocol was based on a publication series from 1955 to 1957 and the 'John/Joan' case. Money claimed that the 'patient' in the 'John/Joan' case had been lost to follow-up. Diamond and Sigmundson found the 'patient' and discovered that 'John', who Money had attempted to make into 'Joan' rejected a female assignment and returned to living as male-identified. This discovery led to the critical re-evaluation of the Money Protocol but has had other problematic side effects, as Diamond and Sigmundson have used this case to re-institute a binary view of sexuality based on prenatal influences of androgens on the brain.

Intersex Advocacy in Relation to Medical Discourse

Several advocacy groups have arisen to challenge medical approaches to intersex. These primarily began as support groups for individuals diagnosed as having intersex 'conditions' and transitioned to focus on political action for changes in medical practice. Each of the three SMOs involved in this study is attempting to influence the medical discourse on intersex, but each of them pursues this in different ways. A schema introduced to interpret this engagement with the medical discourse is a distinction between evolutionary and revolutionary approaches. An evolutionary approach involves altering *how* intersex is medicalized. This approach is characterized by working within the medical paradigm and through medical logic and language to bring about eventual changes for individuals with intersex 'conditions'. A revolutionary approach involves opposing the medical discourse on intersex and the logic through which it operates, for example by challenging the very language of 'intersex condition(s)'. The strategy for engaging with the discourse can be seen in how each of the SMOs produces frames to conceptualize problems and solutions and to motivate potential constituents.

ISNA/Accord is attempting to decrease the shame surrounding intersex as well as decreasing "'normalizing' surgery on children" (ISNAa). ISNA/Accord attempts to alter these medical practices by working closely with medical practitioners. Preves' study of ISNA/Accord's activism has documented their shift from protest activity (outside) to collaboration with medical professionals (inside), writing that ISNA/Accord is "now working on building bridges and on making changes from within the medical arena" (Preves 2005; 284). ISNA/Accord is thus working from the inside to change medical policy, and while the group that would benefit would be intersexualized individuals themselves, the targets of ISNA/Accord's activities are medical practitioners and to some degree the parents of children with so-called 'intersex conditions'. ISNA/Accord thus engages with the discourse surrounding intersex from an evolutionary perspective of altering medicalization through working within the medical realm.

AISSGUK aims to encourage more openness, connect people to support services, and promote further research regarding surgery (AISSG 2008a). This is undertaken through

interacting with medical practitioners and maintaining their function as a support group. This is an approach that works from the inside (by working with medical practitioners) and works directly with those affected by medical practice (by maintaining the support aspect). AISSGUK approaches the discourse from the evolutionary perspective to alter medicalization but also maintains a focus on working with and gaining input from individuals who have been intersexualized.

OII proposes the largest shift in thinking surrounding intersex and argues that intersex should be de-medicalized. The SMO argues that by grouping all intersex conditions together under one moniker the focus is on gender and the regulation of non-normative gender. The SMO uses the language of 'discourse' and 'norms' on its site, making such statements as, "Medical, legal, and religious discourse controls our lives in ways that other people with bodies that do not meet norms do not face" (Hinkle 2005). The group also discusses how medical practitioners working on intersex are part of a larger social discourse on gender/sexuality. The group's website includes the statement, "It is only natural that the medical profession would see one of its duties as being to correct what to them appears to be abnormal, because this is part of their professional training" (OIIb). OII rejects the terms 'intersex', 'hermaphrodite', and 'DSD' as catch-all terms for medical conditions that involve sexual ambiguity. They suggest, rather, a shift toward the specific health needs of individuals. OII can thus be conceptualized as engaging with the discourse from a revolutionary perspective, that of the de-medicalization of intersex.

All of the SMOs are concerned with changes in treatment surrounding diagnoses of intersexuality but attempt to affect change through different routes, or different points of engagement with the discourse. These evolutionary or revolutionary different points of engagement can lead to large divergences in relation to specific issues, in this case terminology. The different points of engagement have led to intense debates over the proposed 'DSD' terminology.

Social Movement Theory

The investigation of how linguistic symbols relate to everyday experience and the conceptualization of reality has been a prominent theme in academia since the semiotic turn. Post-structuralist semiotic approaches led to the concept of discourse. In social movement analysis the semiotic turn has led to the increasing importance of the concept of 'frames'. Whereas discourse analysis attempts to uncover a hidden logic, or something which was previously salient, framing is an active process in which SMOs deliberately engage with a discourse in order to re-shape meaning to further their interests.

Within social movement research Melucci has conceptualized linguistic symbols as codes and theorized that, "in complex societies, power consists more and more of operational codes" (Melucci 1985; 806). In a later work Melucci expounded that, "The power of information is essentially the *power of naming*" (Melucci 1996; 228). Codes have thus become resources fought over by SMOs. Melucci has argued that contemporary SMOs, "do not fight merely for material goods"; Rather, they "fight for symbolic and cultural stakes" (Melucci 1985; 797), or codes. Melucci also argues that, "contemporary movements strive to reappropriate the capacity to name through the elaboration of codes and language designed to define reality" (Melucci 1996; 357). Snow and Benford write that, "Movement actors are viewed as signifying agents actively engaged in the production and maintenance of meaning for constituents, antagonists, and bystanders or observers" (Snow & Benford 2000; 613). Framing represents the active engagement with or attempt to reshape a discourse through changing codes, or terminology, in order to garner support and pre-empt the arguments of antagonists.

For example, the use and promotion of the term 'intersex' by SMOs was itself the re-appropriation of a code. The 'intersex' terminology was an attempt to challenge the terminology produced by the medical realm and thus reclaim the power of naming. The medical labels were rejected in favor of self-selected codes. In the medical realm intersex was rarely discussed as 'intersex', and usually permutations of the term

'hermaphrodite,' such as 'male pseudo-hermaphrodite' or 'female pseudo-hermaphrodite' were used (Feder & Karkazis 2008). Whereas the 'hermaphrodite permutations' were clinical terms used to diagnose individuals, the term 'intersex' was used in attempts to change the code into an identity. The term 'intersex' was embraced to shift the power of naming from a medical diagnosis thrust onto the individual to the chosen category 'intersex', which either functioned as an identity, a term of political cohesion and collective action, or a mixture of these.

Analyses of framing in social movement research examine how codes are produced and situated in the social sphere. Snow and Benford (1992) define a frame as, "an interpretive schema that signifies and condenses the 'world out there' by selectively punctuating and encoding objects, situations, events, experiences, and sequences of action in one's present or past environment" (Snow & Benford 1992; 137). Frames are interpretive in ways that are, "intended to mobilize potential adherents and constituents, to garner bystander support, and to demobilize antagonists" (Snow & Benford 1988; 198). Later research by Snow and Benford focuses on the act of constructing and producing frames, and they conceptualize the process of framing as, "an active, processual phenomenon that implies agency and contention at the level of reality construction" (Snow & Benford 2000; 614). Framing is the active engagement with or attempt to reshape a discourse. Whereas knowledge is produced through pre-existing paradigms in a discourse and is generally salient and unquestioned, framing is an intentional and active attempt to re-shape a discourse.

The production of cultural codes is always in the process of construction, deconstruction, and reproduction. Frames are developed in conflict between movement groups and their antagonists but also between different SMOs within the same social movement. This study will focus on the latter, the internal framing disputes within three SMOs of the same movement. Framing disputes concern active debates over the production of particular codes.

Three different types of internal frame disputes have been identified by Benford (1993): diagnostic frame disputes, prognostic frame disputes, and frame resonance disputes. According to Benford, diagnostic disputes "pertain to problem identification or to attribution of blame or causality" (Benford 1993; 686). Prognostic disputes "concern differences over alternative visions of reality including what is to be done to change extant reality" (Benford 1993; 689). Frame resonance disputes concern, "how reality should be presented so as to maximize mobilization" (Benford 1993; 691). Three questions are essential to analyzing frame resonance disputes: "Will the framing persuade persons to participate in the movement's activities and campaigns? Is it credible? Will the framing resonate with the audience's experiences and orientations?" (Benford 1993; 691). The three types of framing disputes will each be examined in turn through a presentation of how the three intersex SMOs have engaged in framing disputes with each other in relation to the code in question, 'DSD'.

Methodological Issues

This study is not concerned with testing hypotheses but focused on an examination of how intersex SMOs are engaging in framing disputes and discerning what each SMO's position is within these disputes in relation to their engagement with the discourse. Frame disputes regarding the code 'DSD' will be analyzed in the sub-categories of diagnostic, prognostic, and motivational frame disputes. Eckert (2003) and Preves (2005) demonstrated that the internet provided individuals with the ability to coalesce around an intersex identity and exchange information anonymously, which helped to initially overcome the silencing effects of shame and contributed to the development of intersex groups. The internet also facilitated collective action by allowing individuals to overcome geographical, physical distances to share and exchange information electronically. The texts chosen for the analysis are therefore all taken from the SMOs' websites. Texts regarding mission statements and core principles have been used to

identify positions in relation to the discourse, and texts regarding terminology of DSD specifically have been used for the analysis of the framing disputes.

Diagnostic Frame Disputes

Diagnostic frame disputes revolve around the conceptualization each SMO has of the problems that need to be addressed regarding intersex. Interestingly, all three SMOs state similar goals: removing the focus on gender and shifting the focus to health needs. The language, or codes, used in the process of attaining these goals, however, raises points of contention between the SMOs.

ISNA/Accord wants medical practitioners to, "move away from the almost exclusive focus on gender and genitals to the real medical problems" (ISNAb). In attempting to make changes from within the medical realm ISNA/Accord has found the term 'intersex' to be problematic. Excerpts from the materials on ISNA/Accord's website relating to the 2006 GLMA Conference, conceptualize 'intersex' as "a vague term", a term with "a political meaning and history", and a term that "labels a person." (ISNA 2008; 46). Another excerpt includes the statement, "Parents whose children were casually exposed to the term 'intersex' found the word disturbing, damaging, and 'brutal' in one mother's words" (ISNA 2008; 47). The diagnostic frame of ISNA/Accord that has been presented is that the term 'intersex' has problematic connotations for doctors and parents that interfere with its goals of shifting the focus to 'the real medical problems.'

AISSGUK also wishes to de-emphasize gender, explaining on its site, "We are constantly trying to get away from the idea that intersex is necessarily to do with gender identity" (AISSG 2008c). Also on their website the terms 'true hermaphrodite', 'male pseudo-hermaphrodite', and 'female pseudo-hermaphrodite' are said to be 'archaic.' Further on the same page it is written, "The archaic terms have been much criticized by patients as being stigmatizing and out of date" (AISSG 2008c). The term 'intersex' is also found to be problematic, because of "the automatic association of the word 'intersex' with

ambiguous genitalia"[3] (AISSG 2008b). Thus for AISSGUK terms that involve 'hermaphrodite' are out-dated and stigmatizing, while the term 'intersex' can lead to false assumptions.

OII also advocates embracing the "real health needs and not all this focus on which gender identity is best" (Hinkle b). On their site it is written that what OII wants to be treated are, "our actual health problems, not gender or other cosmetic changes to make us meet norms for male and female" (OIIa). OII challenges the idea that "intersex variations need to have a medically accurate name at all" (Hinkle c) and suggests that it makes more sense in the medical sphere to stop using an umbrella term and instead discuss specific health needs. 'Intersex' is an acceptable term for OII for strategic use by the movement group but not in the medical realm.

Diagnoses of the problems surrounding intersex can be seen to revolve heavily around codes which have been produced both by medical practitioners and movement groups themselves. This demonstrates a relationship between how intersex is discussed and conceptualized and the implications for the movement groups to be able to achieve their goals.

Prognostic Frame Disputes

Much explicit conflict between the SMOs is played out in the realm of prognostic framing regarding the 'DSD' terminology, as diagnostic differences are amplified when discussions take place about which codes should be used to address the problems that have been diagnosed.

ISNA/Accord has heavily advocated the adoption of the DSD terminology, and has been the largest player of the three SMOs in promoting the term. ISNA/Accord's website includes the excerpts, "DSD accomplishes describing that the child's development has deviated from the norm without placing a socially stigmatizing label on the child" (ISNA

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[3] Some forms of AIS do not involve ambiguous genital appearance.

2008; 47), and "Disorder of Sex Development explains a child's condition with neutral medical terms" (ISNA 2008; 69). 'DSD' is framed as a term that "labels a medical condition, not an identity" (ISNA 2008; 46). Additionally, it is stated, "'DSD' is a diagnosis, therefore knowledge from all medical fields apply" (ISNA 2008; 46). The terminology was brought into medical practice (to some degree) through the 'Consensus Statement' that resulted from the Chicago Conference organized by ISNA/Accord. ISNA/Accord is now focusing heavily on the promotion of the Consensus Statement's implementation. An excerpt reads, "Since no institution has yet to fully implement the new standard of care it falls short of its aim to positively affect the lives of people with DSD and their families" (Accord Alliance). ISNA/Accord's collaboration with members of the medical community and desire to improve implementation have led

them to abandon the 'intersex' language altogether. ISNA/Accord has used 'DSD' exclusively (instead of the previous 'intersex') in two main texts it has produced for its two target groups: The *Clinical Guidelines for Management of Disorders of Sex Development in Childhood* and the *Handbook for Parents*[4]. These activities pursued by ISNA/Accord indicate that they have gained access and influence in the medical realm and are primarily concerned with reshaping medical approaches to intersex and informing parents. 'DSD' was introduced into the medical sphere through ISNA/Accord's collaboration with medical practitioners in an attempt to focus more explicitly on health concerns. These actions have, however, created conflicts with the other groups.

AISSGUK sees 'DSD' as a step forward but nonetheless problematic. The group proposes the adoption of another term and the use of a patient-centered model of care. An excerpt from the AISSGUK site reads, "The overall *structure* of the scheme [DSD] seems a significant advance on what has hitherto been available" (AISSG 2006). There are, however, also critiques presented. Another excerpt reads, "The choice of the term 'disorder' is bad news" (AISSG 2006), adding that "the term doesn't seem a very good fit

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[4] The *Clinical Guidelines for Management of Disorders of Sex Development in Childhood* and the *Handbook for Parents* can be found at: http://www.dsdguidelines.org/.

in the world inhabited by patients" (AISSG 2006). Instead of 'DSD' the group advocates changing the medical terminology to 'Variations of Reproductive Development,' or 'VRD' (AISSG 2006). They argue that this terminology avoids the stigmatization of the word 'disorder.' Additionally, AISSGUK finds that 'sex development' could be misunderstood as referring to someone's sex, gender, or identity. Thus AISSGUK proposes 'VRD' to specifically focus on the reproductive tract and includes on its site a quotation from a member which reads, "VRD sounds a lot better [than DSD] because the term gets well away from all that sexuality/gender stuff and just says things as they are" (AISSG 2006). The group also emphasizes that they had previously been engaging with the medical recommendations that resulted from the Chicago Conference with an excerpt that reads, "We have worked since the mid-1990s with selected UK clinicians to promote a patient-centered, multi-disciplinary approach to intersex patient care of the sort recommended in the Consensus statement" (AISSG 2006). AISSGUK is thus closely working with medical practitioners and is invested in a change of terminology to focus on medical issues more than gender issues, but the group also desires to avoid the stigmatization associated with the word 'disorder'.

O.I.I is highly critical of the proposed DSD terminology and questions the need for a medical term that includes all so-called 'conditions' that fall under the diagnosis of 'intersex'. In one excerpt the question is asked "Why do we need to have a name at all?" (Hinkle c). Another excerpt states that with the shift from 'intersex' to 'DSD' "there is no challenge to the assumption that intersex variations need to have a medically accurate name at all" (Hinkle c). OII rejects the terminology, arguing that it increases medical pathologization and continues to focus on issues of sex/gender. One excerpt reads "non-consensual treatments are more justifiable now with the new terminology of 'disorders of sex development' than when intersex activism began in the United States" (Hinkle b). Another excerpt reads, "The term 'disorders of sex development' comprises all the different variations which could result in being intersex and makes our SEX (intersex) itself the disorder" (OIIa). For OII the impact is that "real health issues are often overlooked in intersex people because the emphasis is on the 'sex disorder' aspect"

(OIIa). OII thus advocates a shift from umbrella terms that group so-called 'intersex conditions' together and favors a focus on the particular health needs specific to each condition. OII thus perceived a shift to 'DSD' as a direct attack on their goal of focusing on specific health needs instead of gender.

Frame Resonance Disputes

Frame resonance disputes relate to two areas. The first area is that of the empiricism, or credibility, of the statements made and actions undertaken by the SMOs. The second has to do with resonance, or how the frames are constructed in relation to their target audience.

Debates over Empiricism/Credibility

ISNA/Accord has attempted to enhance its credibility through framing the adoption of 'DSD' as a success in relation to both medical practitioners and parents. ISNA/Accord states that the "new nomenclature is rapidly entering medical usage" (ISNA 2008; 16). Regarding parents, it is claimed that, "The DSD terminology is working for the families who are its intended beneficiaries" (ISNA 2008; 47), and it is stated that, "not one parent objected to 'DSD'" (ISNA 2008; 69).

AISSGUK asserts its own credibility and challenges that of the Chicago Conference, stating, "AISSGUK was the first peer group to be formed to give support, information and fellowship to individuals and families with AIS and other XY-female conditions" (AISSG 2006). It continues, "it is therefore surprising that we were not consulted about the new DSD-based terminology at any stage in its evolution or officially notified about the Chicago Consensus meeting" (AISSG 2006). An excerpt from the group's website charges that, "Patient support/advocacy groups outside the USA were not consulted and had no input" (AISSG 2008c). These statements are meant to undermine the credibility of the 'Consensus Statement' by arguing that the consensus arrived at did not include the voices of AISSGUK and others. AISSGUK also challenged ISNA/Accord's credibility

and previous strategies, writing, "During the mid-1990s to early 2000s, when ISNA were busy staging protests, and managing to alienate clinicians, our UK group were[5] quietly building co-operative relationships with clinicians" (AISSG 2006).

OII raises several issues that relate to the empirical claims surrounding the 'DSD' terminology and the credibility of ISNA/Accord regarding their promotion of 'DSD'. OII claims that the term 'intersex' is not hurtful, writing on their website that, "OII did a survey which indicated that just the opposite is true among intersex adults. The overwhelming majority of those directly affected…felt that 'DSD' was hurtful" (Hinkle a). Additionally, the tactics used by ISNA/Accord are challenged by OII in an excerpt from their site which states: "Instead of functioning as a grass-roots intersex community organization and mostly interacting with intersex people, Chase [former director of ISNA] instead sought attention, respect and recognition by the medical community" (Hinkle 2006a). For OII this statement relates to what they perceive to be the exclusion of intersex individuals in the formation of the 'Consensus Statement'. In relation to 'DSD' an excerpt from the OII site states, "Three intersex activists who were included in the manual of the DSD guidelines have now made it clear that they do not agree with the new terminology" (OIIc). The credibility of the consensus is also challenged through the excerpt: "Was there really any consultation of those directly affected by this new pejorative identity label? It appears there was not" (Hinkle 2006b). The following excerpt also clearly challenges the process through which 'DSD' was adopted, reading, "the decisions were arrived at by people speaking about us but who have not listened to us" (Hinkle d). OII has also charged that the *Handbook for Parents* is "transphobic and homophobic" (Hinkle 2006c).

OII has by far the most information on its website that is critical of the DSD terminology. ISNA/Accord is highly invested in the terminology, as the terminology has been introduced into the medical sphere through its efforts. AISSGUK is involved in the debate over terminology but seriously questions the credibility of the decisions coming

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[5] Quotations were taken directly from the sources, and grammar was not modified.

out of the Chicago Conference based on the fact that there was little input from groups outside of the U.S.

Resonance

The point or method of engagement with the discourse impacts what will be framed and who the frames will be intended for. The target audiences for the SMOs' respective frames can be inferred through the language that they have used. In order to make statements with more certainty about frame resonance, however, interviews and more research are necessary.

ISNA/Accord seems to be almost exclusively focusing on interactions with medical practitioners, believing that changes in care through collaboration with medical practitioners are the best way to better the lives of affected individuals. This has also been documented in Preves' (2005) article on the movement of ISNA's activism toward collaboration with medical practitioners. One of ISNA/Accord's stated goals is to have "solid partnerships with medical and allied health care professional institutions and with community-based (consumer) organizations that share our objectives" (Accord Alliance). This target group corresponds to engagement with the discourse through evolutionary means in an attempt to influence medical practitioners to change approaches to intersex.

AISSGUK seems to be targeting medical practitioners while maintaining direct engagement with members and serving as a support group. Excerpts from AISSGUK involving their co-operation with medical practitioners have already been quoted above, but this group is not the only target audience. Another excerpt from the group's website reads "We provide information and support to young people, adults and families affected by XY-female conditions" (AISSGa). The group also includes quotations from several of its members regarding their opinions on its site. AISSGUK is thus interacting with the medical community while gaining input in this process from individuals who have experienced being diagnosed with a so-called 'intersex condition'.

The target audience of OII appears to be individuals who identify as intersex and the wider society. Emphasis is placed on grass-roots activism, and their site emphasizes the importance of including the voices of individuals identifying as intersex. Through input from and interaction with the 'intersexualized', the group hopes to raise awareness among concerned individuals and change norms in society at large. Because of their focus on individuals who identify as intersex and their rejection of medical pathologization, OII's approach can be conceptualized as revolutionary, or an approach that attempts to work outside of the medical discourse.

Conclusion

Different points of engagement with the discourse, or different starting points, involve different strategies and logic. In the medical realm the term 'DSD' is relevant, as it is intelligible through the logic of the normal/abnormal, ordered/disorded paradigm outlined by Foucault. 'DSD' is not relevant as an identity or as a base for collective action because of the stigmatizing associations with the word 'disorder'. Differences in the discursive points of engagement of the SMOs have led to major differences over the creation and promotion of the particular code 'DSD'. The same code can thus have very different meanings for each group, since each group approaches the code through different logic, levels of engagement with medical discourse, and strategic framing processes.

Melucci's analysis regarding the importance of codes as resources fought over by contemporary social movements remains relevant. Perhaps an important addition to the production and contestation over codes is the loading of codes, or how codes are loaded with meaning and what those codes mean for each of the SMOs involved and their target audiences. The meaning of 'DSD' is very different for each of the SMOs, and this influences how each group approaches, understands, and frames the code.

More research is necessary in order to understand the concrete impacts of the debate over 'DSD' for the intersex social movement as a whole. The framing disputes over DSD

appear to signal a major point of divergence within the movement, but any resulting impacts are still unknown. Interviews are necessary to further investigate how divergence over DSD impacts cohesion and networking within the movement.

Part of Ongoing Research

This article is part of an ongoing PhD research project that engages in comparative analyses of intersex SMOs. This research will be continued through more textual framing analysis and interviews in order to get a deeper understanding of what is happening and with what impacts.

Acknowledgements

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