

# Contextualising Intersex: Ethical discourses on intersex in Sweden and the US

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*As of the beginning of the 1990s the medical management of intersex has been up for debate, and the US has been the epicentre of debate. Scholars like Iain Morland and Anne Fausto-Sterling have identified three key actors in the U.S. context: clinicians, patient oriented support groups and intersex advocacy organisations, and feminist scholars with a critical perspective on the medical discourse surrounding sex and gender identity (Fausto-Sterling 2000; Morland 2004). There has been fairly little discussion about intersex rights in Sweden until the last couple of years. The budding Swedish discussions are all framed by international discourses, especially the U.S. discussions among clinicians on the pros and cons of the traditional treatment model, and the discussions between intersex people, intersex advocates, clinicians and politicians on intersex rights. However, while the U.S. discourses on intersex have been greatly affected by the participation of feminist scholars such influences have been scarce in Sweden. This article explores differences and similarities between the Swedish and the U.S. context, arguing that the relative lack of feminist scholarly attention to intersex has had consequences for the Swedish discussion.*

*Keywords: intersex, Sweden, U.S., feminist theory, DSD, ISNA, INIS, medical management of intersex*

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In the spring of 2008 an article titled 'Boy or Girl—Never Guess!' appeared in the Swedish medical journal *Läkartidningen*. The authors, some of Sweden's most prominent physicians working with the targeted group, called for changes in the management of children born with atypical sex characteristics (what is commonly called intersex or disorder of sex development).<sup>1</sup> They stressed the necessity to keep up with international discussions on

intersex, and referred to the latest developments in the negotiations between clinicians and intersex advocates in the US as groundbreaking (Nordenström, et al. 2008, 629). However, a major actor in the US discussions was unnoticed by the Swedish physicians: feminist scholars working in alliance with intersex advocacy organisations. While the US discourses on intersex have been greatly affected by the participation of feminist scholars, such

influences have been scarce in Sweden. This article explores the cultural specificity of intersex discourses and discussions, through a reading of the Swedish context in relation to the US one. The aim of this article is to give an outline of the discursive field in Sweden on questions of intersex rights, and to initiate a discussion on the necessity for feminist studies in Swedish material relating to intersex. I have used both texts – feminist studies carried out on the Swedish discourses of intersex, and articles written by Swedish clinicians and intersex advocacy organisations that discuss the situation in Sweden – and interviews for this study. The interviews with the key actors in the Swedish context will be presented in a forthcoming article.<sup>2</sup>

There has been fairly little discussion about intersex rights in Sweden until the last couple of years. It is not until recent years that the experiences of intersex people have reached the attention of the public via documentaries and interviews in the press, television and radio.<sup>3</sup> The budding Swedish discussions on intersex are all framed by international discourses, and especially the US discussions among clinicians on the pros and cons of the traditional treatment model, and the discussions between intersex people, intersex advocates, clinicians and politicians on intersex rights.

In light of the fact that the Swedish discourses on intersex

have been so influenced by the US ones, I will start by providing an introduction to the US context, to set the background. Then I will focus on the specificity of the Swedish context, posing tentative questions like: is there something culturally specific about the Swedish medical and juridical management of intersex? Does the lack of Swedish feminist scholars discussing intersex limit the possibilities of an open and productive discussion about the medical, social and cultural management and representation of individuals not fitting the sexual dimorphic model?

### **Introduction – the US context**

With the dissolution of ISNA (Intersex Society of North America) – the largest and most influential of the non-governmental organisations working for intersex rights in the US – and the simultaneous creation of Accord Alliance, ISNA's successor, in March 2008, a new discursive landscape on intersex is now forming. ISNA has, since its formation in 1993, had a key role in the development of an intersex movement internationally, and hence the US has been the country above all others where discussions on the medical management of intersex, and intersex rights, have flourished.

As of the beginning of the 1990s the medical management of intersex has been up for debate, mainly due to the media coverage on the life of David Reimer and the subsequent questioning of the man behind the

Reimer case, psychologist and sexologist John Money (Kessler 1998; Colapinto 2000; Fausto-Sterling 2000).<sup>4</sup> Money and his colleagues had dominated research on intersex since the late 1950s. The basis for the treatment model was an assemblage of heuristic assumptions: the primary one being that humans are born psychosexually neutral, which means that we are not born with a biologically determinate inclination for a specific gender identity, rather the gender identity develops as an effect of gender rearing and body image. This hypothesis led Money to conclude that children born with atypical sexual characters can develop a stable gender identity in the chosen sex, if the social rearing is consistent, and if their bodies are brought into alignment with the chosen sex, by means of surgical and/or hormonal treatment. Money's theories were well received by academics in the natural sciences as well as in human and social sciences. In *Lessons from the Intersexed* (1998) psychologist Suzanne J. Kessler testifies that she and other feminist researchers used Money's theories as heuristic tools to show that femininity and masculinity are socially constructed categories.<sup>5</sup> During the early 1990s a reassessment of the theory of psychosexual neutrality gained ground, most notably through the work of biologist and sex researcher Milton Diamond and the founders of ISNA. Diamond argued that there is no substantial evidence

supporting the so-called Optimum Gender of Rearing model (OGR model), on the contrary there are many indications that the guidelines Money and his colleagues formulated are counterproductive. Diamond and ISNA stressed the same points: that early genital surgery often has serious medical consequences (severe scar tissue, loss of sensation etc), and that the secrecy surrounding intersex creates life long trauma and shame.<sup>6</sup> Cheryl Chase (now known as Bo Laurent) founded ISNA in 1993 as a direct reaction to the maltreatment of intersex people. Feminist researchers began to examine the culture-specific and deeply problematic assumptions about gender and identity that characterise Money's theories. Despite this critique, Money's legacy persists in US guidelines for the medical management of intersex (Dreger 1998; Kessler 1998; Fausto-Sterling 2000).

### **A trio: clinicians, intersex advocates, and scholars**

David Reimer's story highlighted the ethical problems surrounding the management of intersex, and, as his story was told and retold by journalists, physicians, scholars and intersex advocates and activists, a general discussion about the pros and cons of the current standards of medical care developed. Three key actors can be identified in this discussion: practising physicians and other caretakers, patient ori-

ented support groups and intersex advocate organisations, and scholars interested in and critical of the medical discourses on sex and gender identity (Fausto-Sterling 2000; Morland 2004). When the *Human Rights Commission of the City and County of San Francisco* held an open hearing about intersex in May 2004, physicians, scholars, intersex people, parents of intersex children and intersex advocates and activists gave testimonies (Arana 2005). The explicit aim of the open hearing in San Francisco was to create a polyphonic discussion on intersex, leaving the endeavour for consensus behind. However, in other contexts the search for consensus is prevailing, and there are different opinions on who ought to be included in the formulation of consensus statements and clinical guidelines.

Two recent examples from the US reveal the discord. On the one hand we have a consensus statement on the management of intersex formulated during the International Conference in Paediatrics, in Chicago 2005. Despite the fact that the conference was attended not only by medical specialists but also by representatives of ISNA, the consensus statement stresses the importance of consensus *within* the medical practice and only mentions the necessity of a dialogue between parents, intersex individuals, and clinicians in passing (Lee, et al. 2006). On the other hand we have the *Clinical Guidelines*

*for the Management of Disorders of Sex Development in Childhood* put forth by the Consortium on the Management of Disorders of Sex Development, in 2006. The Consortium is a project initiated by ISNA to give voice to the experiences of the so-called 'the DSD clinical triad': clinicians, intersex patients, and parents of intersex people. These guidelines echo the ones put forth by Milton Diamond and his psychiatrist colleague Keith Sigmundson in 1997. Diamond and Sigmundson formulated provisional guidelines challenging those implied by the OGR model for management for intersex. The new guidelines, which are in accordance with the demands for change put forth by ISNA, are described as a turn towards a patient oriented model of management (Diamond and Sigmundson 1997). Diamond and Sigmundson emphasise openness, honesty, peer support and professional counselling, and avoidance of early surgery.

### **Scientific controversies, silenced voices**

Diamond and Sigmundson's article created a debate among professionals working with intersex, which focused on questions of expert knowledge and dependable methods, but also on ethical dilemmas. The controversy between the proponents of the OGR model and the ones challenging it is not necessarily one of scientific sustainability but rather of ethics. While the OGR

model is based on Money's studies, initially deemed as scientifically progressive but later questioned for being methodologically unreliable, the early calls for changes were mainly based on ethical grounds, only partly supported by scientific arguments from medical and sociological studies (Ford 2001). More recent critiques point out that there are no scientific studies that can validate the assumptions that atypical genitals are a psychosocial risk factor and that early surgeries are necessary measures (Dreger and Herndon 2009, 204). Despite the lack of scientific studies – especially of follow-up studies on intersex adults – supporting the traditional model of treatment, intersex advocates initially had great difficulty in making the reformist perspective seem credible and justifiable to clinicians (Chase 2003).

The inability of some clinicians to take the perspective of intersex individuals into account seems to hinge on the question of scientific credibility, and representativity as a methodological problem. *A recent example:* faced with the draft of the report from the Human Rights Commission of the City and County of San Francisco, a paediatric urologist questioned the objectivity and political rationale of the Commission, arguing that the report was politicised towards the reformist perspective and not based on enough clinical evidence. He claimed that the intersex patients

he had met and treated were satisfied with the outcome of the treatment (Arana 2005, 205). The critical narratives of intersex people are, in this context, read as individual testimonies, not having any bearing on the opinions and sentiments of the larger group of intersex individuals.

Intersex individuals are rarely heard in the controversy on their own terms, other than as witnesses referred to second hand, as subaltern voices articulated only by others. The texts in the anthology *Intersex in the Age of Ethics* (1999) are somewhat of an exception. Cultural theorist Iain Morland argues that the conversation preferred in the US context is one between experts: professionals that are experts in their field (whether this be endocrinology, psychiatry, history or intersex advocacy) (Morland 2004). Within such a professionalised context intersex narratives are marginalised. However, in recent years the Internet has provided new fora for intersex people to write their own histories, as several scholars and activists have pointed out (Sytsma 2006; Dreger and Herndon 2009).<sup>7</sup> Peer support groups and intersex advocacy organisations are affected and reconstituted by the technoscientific changes. They are no longer limited to regional networks, but are globalised on micro-, meso- and macro-level as intersex individuals share their stories on personal blogs, internet communities, and homepages for intersex advocacy

organisations, revealing patterns in intersex narratives that affect the lobby work of these organisations, lobby work that eventually disseminates back on to the micro-level as information on intersex rights spread through virtual fora.<sup>8</sup>

So far this is all about the US context, but what about Sweden? The article in *Läkartidningen* mentioned earlier was a sign of intersex rights becoming a pressing issue for a larger group than those born with atypical sex characteristics. When RFSU (the Swedish Association for Sexual Education) arranged a seminar on intersex in October 2007 with participants from the medical professions and the intersex support group INIS (Intersexuals in Sweden), it was the first time physicians and intersex advocates met for an open debate. Although a modest arrangement, the seminar served as a platform for a wider discussion. Since then INIS has had a continuous communication with the clinicians, developing a dialogue on the pros and cons of the current model of treatment. This dialogue is influenced by the US discussion between clinicians and intersex people and advocates; the contact with ISNA was a trigger in the founding of INIS, and INIS as an organisation has learned from the experiences of ISNA.<sup>9</sup> The Swedish physicians work within an internationalised milieu, constituted by international conferences and international journals, resulting in international guidelines and con-

sortia. One of the clinicians working in collaboration with INIS, attended the International Conference in Paediatrics in Chicago 2005, and helped to formulate the consensus statement on management of intersex; she is also one of the authors of the article in *Läkartidningen* (Lee, et al. 2005).

If we are interested in studying the specificity of the Swedish context, it is imperative to remember the fact that INIS (currently the only intersex advocacy organisation that takes a comprehensive and critical grip on intersex rights and the management of intersex in Sweden) is a relatively young and by US standards very small organisation. In the US ISNA worked in affiliation with scholars and clinicians to put intersex on the political agenda, and has been a lobby organisation to be reckoned with. Their demands for change, which were initially met with little respect and interest, have resulted in a reform of the standards of care on an international level. ISNA was an established interlocutor in the ethical discourse on intersex. In Sweden, the situation is different; INIS is still in the start-up phase, without financial resources and without political influence in terms of large numbers of members. INIS is dependent on the goodwill of the medical community for its participation in the discussion on intersex. Naturally there are differences in the way these organisations have approached the subject at hand.



It is also imperative to acknowledge that the Swedish context does not lack critical voices; INIS has played a significant role in putting intersex rights on the agenda, partly through fora presented by two NGOs: RFSU and RFSL (the Swedish Federation for Lesbian, Gay, Bisexual and Transgender Rights). Being non-governmental organisations, dedicated to the education of sexual rights and sexual health, RFSU and RFSL have made intersex rights part of their programme for change, trying to create awareness through encouraging parliamentarians to write motions to the government, formulating policy statements, writing in-house reports on intersex rights, and arranging seminars. Focusing on activism, the annual Stockholm Pride has had seminars and workshops on intersex rights and experiences the last couple of years, in collaboration with INIS. However, as mentioned earlier, feminist scholars, identified as one of three major actors in the US context, have hitherto played a limited part in the Swedish discussions on intersex.

### **Epistemological interventions**

In the spring issue of GLQ 2009, titled *Intersex and After*, some of the leading scholars, clinicians and activists framed the future questions and challenges of the intersex rights movement. Alice Domurat Dreger and April Herndon focused on the role of feminist scholars in the prog-

ress of the movement, both having worked with ISNA for several years. Dreger and Herndon claim that the involvement of feminist scholars has been imperative for the progress of the intersex movement (Dreger and Herndon 2009, 218). While feminist scholars from a range of disciplines have acted on the lack of critical discussion on intersex management in the US – the first generation of critics consisting mainly of biologists, sociologists, and historians (Fausto-Sterling 1993; Dreger 1998; Kessler 1998; Preves 1998), the second including jurists, psychologists, and cultural theorists (Ford 2001; Roen 2004; Greenberg 2006; Morland 2005)<sup>10</sup> – the situation is different in Sweden. It is no coincidence that feminist researchers are not mentioned as possible interlocutors in the article in *Läkartidningen*. Although there are theoretical discussions on intersex in Swedish feminist academia, there are hardly any studies relating to the specificity of the Swedish management of intersex. Two fairly recent doctoral theses examine the management of intersex in Sweden from a norm-critical perspective, informed by feminist theories: Sara Edenheim's *Begärets lagar* (2005) and Erika Alm's '*ett emballage för inälvor och emotioner*' (2006). Both focus first and foremost on juridical issues, analysing the governmental report that formulated the guidelines for the current legislation on sex change and sex assignment in intersex chil-

dren, *Intersexuellas könstillhörighet* (1968). Since then a couple of academic articles have been published (Zeiler and Wickström 2009; Zeiler and Malmqvist 2010), and there are several research projects recently started.

However, since intersex rights and experiences have been on the Swedish feminist academic agenda for less than a decade, the majority of the studies done on Swedish material are written by pioneering students: mainly master's theses and undergraduate term papers written in sociology, gender studies, ethnology and political science. Most of these studies analyse popularised medical texts, such as diagnostic descriptions of intersex conditions, or the governmental report previously mentioned, *Intersexuellas könstillhörighet*. The preferred method is discourse analysis and the theoretical inspirations often come from Michel Foucault's theories on biopower and Judith Butler's theories on gender as performative. Although theoretically well informed, the authors tend to make the assumption that the Swedish medical discourse on intersex and the impact it has had on patients can be equated with the situation in the US. For example, Swedish physicians have described the Swedish standards of care as patient oriented, focusing on individual adaption and functionality rather than aesthetic adjustments (Nordenström, et al. 2008). Such descriptions have been denounced

as false in the socio-cultural studies done on Swedish material, with reference to the life stories of intersex people from the US context.<sup>11</sup> The study most frequently referred to is Suzanne Kessler's *Lessons from the intersex* (1998), which is comprised of case studies from the late 1980s and early 1990s. Many of the Swedish studies seem to assume that the cultural differences between contemporary Sweden and the US Kessler describes are possible to transcend and ignore, despite the fact that the authors of these studies often rely on theoretical work that argues that the pathologisation of intersex people is based on socially constructed and variable standards of normality. In other words, these studies highlight the culture-specific and context-bound aspects of pathologisation of intersex on a theoretical basis, but downplay the potential cultural and social differences between Sweden and the US in the actual analysis. There is a tendency to analyse the Swedish material without taking into account its specific social and cultural contexts, this is true of the doctoral theses mentioned earlier as well. A comparative study on the differences and similarities between Sweden and USA could provide a more nuanced perspective, giving the analysis of the Swedish discourses on intersex a depth it is lacking.

In following my example above, I propose that in addition to criticising the Swedish management of inter-



sex by drawing parallels to studies done on US material, we need to examine critically the culture-specific and time-specific aspects of it. The description of the Swedish standards of care as patient oriented and more focused on achieving a social adjustment in the assigned sex than pushing for surgery on aesthetic grounds, put forth by contemporary clinicians, has a history. It echoes passages in *Intersexuellas köntillhörighet* to the very phrasing. The Swedish Physicians Association writes, in its referral response to the report, that it is more important to take the child's psychosexual development into account than it is to pay heed to morphology and the possibilities of reconstructive surgery, and the commissioners note that one risks making the child's situation worse if major surgery is performed early in life (Referral response from the Swedish Physicians Association 1968; *Intersexuellas könstillhörighet* 1968, 30; Alm 2006). There are other aspects of the governmental report that are also interesting when read in the light of the US context. In the passage describing international standards of care the commissioners express scepticism towards John Money's theories of psychosexual neutrality, a doubt stemming from an interest in the neuropsychological aspects of the development of gender identity. Keeping in mind that the report is written in 1968, when Money's theories were the foundations of the

international standard of care, this is quite remarkable. However, when push comes to shove the commissioners decide to follow the international guidelines. This inconsistency is most likely an effect of what Alice Domurat Dreger has characterised as the conservatism of medical management of intersex: 'the move in the early twentieth century to assigning a 'workable' gender instead of a gender that aligned with a biological 'true sex' was a conservative reaction to the unrelenting messiness of sex' (Dreger and Herndon 2009, 214-215).

### **Political implications, cultural critics**

Does this lack of critical and contextualising studies on Swedish intersex discourses limit the possibilities of an open and productive discussion about the medical, social and cultural management and representation of individuals who do not fit the sexual dimorphic model? Let's take two examples as a point of departure for the discussion on what is missing in the Swedish discussion: the introduction of and reactions to the term *disorder of sex development*, and the hesitance among some intersex people to take part in the critical discourse questioning the norms and regulations that constitute sex and gender dimorphism.

Disorder of sex development is, as of a couple of years, the preferred term among the majority of clini-

cians and some activists working with intersex. In the discussions preceding the change of terminology – established in the consensus statement formulated at the International Conference on Paediatrics in Chicago 2005 – a multitude of arguments have been put forth. Physicians have talked about the need for a terminology that focuses on the biological conditions underlying intersex diagnoses; parents with intersex children have described terms like intersex and hermaphrodite as offensive, leading people to believe that individuals with atypical sex are in between sexes, freaks of nature (Reis 2007; Feder 2009). ISNA took a firm stance in advocating DSD, claiming it is a term that connotes the medical context within which all intersex lives are framed. DSD is thought to be preferable to intersex since intersex in addition to being a generic term for a variety of medical diagnoses, has been used as an identity category. ISNA had previously pursued identity politics in the name of intersex, arguing that all intersex individuals share certain experiences based on the sole fact that they deviate from the socially constructed norms of sex and gender dimorphism. ISNA later toned down the identity politics, arguing that identity politics do more harm than good (ISNA, on line; Turner 1999). In a US context the drawbacks of pursuing recognition for intersex identity – the most obvious obstacles being that one runs the

risk of portraying the group represented as homogeneous in a generalising manner, and that one might be perceived as too radical to make alliance with by clinicians and politicians – might outweigh the advantages. In the words of Dreger and Herndon: ‘the shift to this terminology [DSD] clearly has allowed serious progress toward patient-centred care, in part because it has allowed alliance building across support and advocacy groups, and with clinicians.’ (Dreger and Herndon 2009, 212).

Intersex people have voiced both critique and appreciation of the new term. Some are happy to make use of a word that de-emphasises identity politics and frames the issues at hand in a medical, biological context, others object to the pathologisation of atypical sex inherent in the very term *disorder of sex development* and mourn the political, critical potential of the terms lost, reminding us of the subversive use of *hermaphrodite* in the cocky and empowering newsletter *Hermaphrodites with an attitude*, written by members of ISNA (Reis 2007). The members of international intersex advocacy organisation OII (Organisation Intersex International) argue that the controversy surrounding the introduction of DSD is not only a matter of terminology but also a matter of politics. They have many objections to the new term and the guidelines presented by the Consortium on the Management of Disorders of Sex

Development, among other things pointing out that the guidelines are US centred, and that large groups of intersex people feel that they did not get to have their say in the revisions of the guidelines (OII, online). Feminist scholars have objections as well, Elizabeth Reis, among others, argues that terminology inevitably influences not only the conceptualisation of atypical sex but also the medical, juridical, social, and cultural management and representation of the people affected, and that it is problematic to use a term that includes the stigmatising word 'disorder' (Reis 2007).

What about the Swedish context, where intersex rights have not been on the political or academic agenda until recently? The clinicians argue that the Swedish terminology needs to be in accordance with the international policy, for a comprehensive and ethically informed management of intersex to be possible (Nordenström, et al. 2008). INIS embraced the change in terminology, and the underlying arguments, from the start. INIS has never had identity politics on the agenda. This is probably due to the fact that the contemporary discourses on intersex differ from those of the early 1990s. INIS has not met the same resistance ISNA did, Swedish clinicians have explicitly asked for relations of collaboration and alliance. A member of INIS compares INIS not with ISNA but with Accord Alliance, ISNA's successor.<sup>12</sup> Accord Alliance,

founded by some of the people behind ISNA, focuses on collaboration between the actors in the DSD triad, leaving identity politics and advocacy behind (Accord Alliance, on line; ISNA, on line).

In the Swedish context another question of terminology has sparked a discussion, which provides a different perspective on the problems at hand. RFSL introduced the term trans person as part of their queer sexual politics. The term was an attempt to find a Swedish word to encompass all those individuals whose gender identity or gender expression partly or completely, momentarily or permanently, differ from the sex assigned to them at birth, individuals that challenge the sex and gender norms of our times. The term includes: 'drag queens, drag kings, intersexuals, transgenderists, transsexuals and transvestites' (RFSL, on line). The term was well received in academia and among many queer activists; however, some objected to the broad scope of the term. Benjamin, a national patient organisation for transsexuals, has protested on several occasions, arguing that transsexuals have nothing in common with transvestites and transgenderists; and that their cause – to be accepted as women and men, and to not have to fight for medical and juridical reassignment – is hindered by the association with gender benders (Benjamin, on line). Some Swedish intersex individuals have reacted in

a similar way when confronted with the term, claiming that there are more important issues at hand than taking a discursive, norm-critical perspective on intersex, and that it is essential to pay heed to the differences among the groups lumped together in the term.<sup>13</sup> In other words, at least some intersex individuals have second thoughts on engaging in the larger critical discourse questioning the norms and regulations that constitutes sex and gender dimorphism, and heteronormativity.<sup>14</sup> This hesitation needs to be taken into account and respected.

I believe that the debate on the pros and cons of the 'trans person' term would benefit from the meta-perspective on sex and gender discourses associated with feminist scholars. The specificity of the Swedish context has yet to be systematically studied, and methodological and theoretical approaches influenced by feminist STS-studies and cultural studies – the equivalent of studies done on US and U.K. contexts by Fausto-Sterling, Kessler, Dreger, Preves, Hird, Morland, Roen, etc – would contribute greatly to this task. We need to try to answer basic questions like: who gets to have their voice articulated in the discourses on intersex in Sweden, on what subjects and raising which types of questions, in which fora? These types of questions are seldom posed in the discussions between clinicians and intersex organisations, because there

are more urgent issues. One might think of it as a division of labour: feminist scholars can contribute with perspectives otherwise unmentioned. In addressing these questions it is important to pay heed to the guidelines Dreger and Herndon propose for feminists interested in fighting for intersex rights: 1) listen to intersex people carefully, not assuming that you know what is right or true for them, 2) write about intersex people on their own terms, rather than using them as representations of for example the social construction of gender, 3) do more than theorise, help fundraising or work with advocacy organisations (Dreger and Herndon 2009, 218).<sup>15</sup> Understanding intersex rights as a feminist matter of concern raises questions of trustworthiness and accountability. Perhaps one can approach these issues by regarding trustworthiness as a matter of engagement rather than consent or representativity (Scheman 2001). Scholars interested in putting intersex rights on the feminist agenda in Sweden have reasons to consider the relations between theoretical work and advocacy work since there has been little contact between the two types of discourses in the Swedish context. Sara Edenheim's and Curtis Hinkle's (founder of OII) article in the Swedish feminist journal *Bang*, that stresses the importance of Swedish feminists participating in the fight for intersex rights, is one of the few (Edenheim and

Hinkle 2005).

Regardless of the terminology – whether we use ‘DSD’ in accordance with Accord Alliance, INIS and scholars like Dreger and Herndon, or ‘intersex’ like OII and scholars like Reis – I believe that the possibilities incorporated in the broader and more politicised discussions ISNA and its associates initiated during the 1990s need to be actualised in the Swedish context. From a feminist perspective the question of intersex rights is also a question of what it means to not fit the dominant sexual dimorphic model. One of the reasons why the study of intersex management from a discursive perspective – as an effect of specific cultural restrictions and norms on sex, gender, sexuality, and identity – is needed is the fact that said restrictions and norms affect us all. As gender variant visual artist Del LaGrace Volcano puts it:

I feel that the key issue facing the intersexed is actually a key issue facing humanity in general: *fear of difference* and compulsory heterosexuality as well as gender normativity. For society to function as it does, it is essential that there be clear lines of demarcation between those that have (power) and those that do not... Those who rock the boat, who either cannot or will not conform to expectations, especially of what it means to be a man or a woman, are usually not rewarded except

under extremely limited conditions. (Creighton, et al. 2009, 253)

## Endnotes

<sup>1</sup> *A note on the terminology:* There is no consensus on the terminology in cases of atypical sex development. The term *intersexualism* was used during the larger part of the twentieth century by clinicians and intersex people, advocates, and activists. However intersexualism has never been a diagnostic term, it is an umbrella term for several types of medical diagnoses, and there has been great dispute on which diagnoses ought to be included. The terms *intersex*, *intersex person*, *person with intersex condition* and their likes, have been put forth by intersex people, activists, and advocates as alternatives, in an attempt to find words that do not contribute to the misconception that intersex has something to do with sexual orientation (Dreger and Herndon 2009). Recent discussions between clinicians and intersex advocates have resulted in a change in terminology, with the introduction of the term *disorder of sex development*. The pros and cons of this terminological shift, put forth within the international discussions, will be discussed later in this article. I will use the terms *intersex* and *intersex people* as these are the ones used by some of the intersex people active in intersex advocacy and the leading feminist scholars, and they still have a norm-critical connotation. Alice Domurat Dreger and April Herndon use the following definition of intersex: ‘We define a person as intersex if she or he was born with a body that someone decided isn’t typical for males or females’ (Dreger and Herndon 2009, 200).

<sup>2</sup> The key actors identified are INIS (intersex advocacy organisation), clinicians working with the management of intersex, RFSU, and RFSL (both NGOs dedicated to the ed-



ucation of sexual rights and sexual health, and with intersex rights on the agenda).

<sup>3</sup> In the aftermath of the media storm surrounding the South African 2009 Olympic winner Caster Semenya, Swedish newspapers, television and radio stations featured intersex people, describing their life stories and raising questions of awareness.

<sup>4</sup> David Reimer's story is also known as the Joan/John case. Reimer, born in Canada in 1965, was not intersex, but had his penis completely obliterated at the age of 8 months, as a circumcision went wrong. His parents were advised by John Money to raise Reimer as a girl, and a gender reassignment was implemented when Reimer was 22 months, followed by genital surgery and hormonal therapy. Money used Reimer as a case study in his research on gender identity in intersex children, claiming that the reassignment was a success. It was not until 1980 that Reimer was informed about the circumstances of his childhood, and at that point he, who had never identified as a girl, decided to act out his male gender identity, and lived the rest of his life as a man. In the late 1990s Reimer's story came to the attention of the public with the publication of several academic articles and popular books questioning Money's involvement and judgement. See for example: John Colapinto. *As Nature Made Him: The Boy Who was Raised as a girl* (New York: HarperCollins Publishers, 2000), or Judith Butler. "Doing Justice to Someone: Sex reassign Movement and Allegories of Transsexuality" *Undoing Gender* (New York: Routledge, 2004).

<sup>5</sup> It is primarily in the groundbreaking *Gender: An ethnomethodological approach* (New York: University of Chicago Press, 1978), co-written by Kessler and Wendy McKenna, that Money is used.

<sup>6</sup> In accordance with the OGR model many clinicians have advised parents of intersex

children not to inform their children about the condition at hand, or the reasons behind treatments performed. David Reimer's story of how he discovered the truth about his early years in life echoes the life stories of several generations of intersex people.

<sup>7</sup> The plethora of virtual fora for intersex peer support – personal blogs, internet communities, homepages for intersex advocacy organisations such as ISNA and OII, patient support groups etc – has developed in parallel with the other virtual fora for support and advocacy, such as the virtual transgender communities.

<sup>8</sup> For a discussion on how patient support groups are reconstituted by the technoscientific changes associated with internet, see: Adel Clarke, et al. 'Biomedicalization: Techoscientific Transformations of Health, Illness, and US Biomedicine', *American Sociological Review* 68 (2003). Clark et al discuss the fact the changes in information and knowledge processes disrupt the division between expert and lay knowledge, but also note that some groups are excluded altogether by the digitalisation of medical knowledge; the diversity processes work in stratifying ways (Clarke, et al. 2003, 177-178).

<sup>9</sup> Interview with Jenny Ottosson, chairperson for INIS, 09/03/2010.

<sup>10</sup> Not all of these scholars are US based, but they use US material and examples from the US context. Some of them have done studies on other national contexts as well. The concept of contextualising intersex discourses has nothing to do with the nationality of the scholars conducting the studies, but with the specificity of the cultural and social context discussed.

<sup>11</sup> There are exceptions: in Henrik Hirseland's 'Den lämpligaste könstillhörigheten' (2003) and Cattis Grant's 'Mångsidiga kroppar' (2003) the voices are those of Swed-



ish intersex people. And Lisa Guntham is conducting an interview study on Swedish intersex adolescents.

<sup>12</sup> Interview with Jenny Ottosson, chairperson for INIS, 09/03/2010.

<sup>13</sup> Interview with Jenny Ottosson, chairperson for INIS, 09/03/2010. Dreger and Herndon point out that some transgender people wish to be defined as intersex since there are certain advantages with an intersex diagnosis as opposed to one of transsexualism for example, at least in the US context: 'people in the United States tend to be more accepting of identities that have a definite (or at least implied) biological basis. The current *Diagnostic and Statistical Manual of Mental Disorders* (DSM-IV) provide another reason for transgender people to seek the intersex label. According to the DSM-IV, a person with atypical gender identity can be classed as having gender identity disorder only if the person is not intersex. Thus being labelled with an intersex condition means avoiding the diagnosis of a 'mental disorder' and possibly easier access to legal and medical sex reassignment' (Dreger and Herndon 2009, 213).

<sup>14</sup> *Sex and gender dimorphism*: the assumption that humans are physically and mentally dimorph, either male or female, and that an individual's sex and gender are in accordance within one another, i.e. what is sometimes called *cissexed* and *cisgendered* within transgender studies (Green 2006).

<sup>15</sup> Dreger and Herndon have a fourth point as well: acknowledge that intersex and transgender people often have suffered more by sexism and heterosexism than most biologically typical women (Dreger and Herndon 2009, 218). These guidelines resemble those points articulated by Jacob Hale on the subject of non-transsexuals or non-transgender people writing on transsexualism or transgender (Hale 1997).

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