

Somatechnics of Consensus: Situating the Biomedicalisation of Intersex

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Introduction

Iain Morland describes his vision of an ethics of intersex as that of an opening up of a discussion that has come to a stalemate: 'The ethics of intersex, in this historical postmodern moment, begin when we no longer rush to pronounce the single right way to manage intersex, but admit uncertainty, replace dogma with discussion' (Morland 2006: 331). Morland's vision stands in stark contrast to an inclination towards consensus that has coloured both clinical and activist discussions on intersex in recent years. One might go so far as to talk about an orientation towards consensus in the phenomenological sense: as organising certain types of relations, procedures, and intra-actions as agreeable, understandable, and necessary, and ignoring, marginalising, and delegitimising others (Ahmed 2006, 2007).¹

In this article I will investigate this orientation towards consensus as it frames the somatechnics of intersex². With the introduction of the idea of a somatechnics of intersex Nikki Sullivan set the grounds for a different approach to feminist interventions in issues of intersex (Sullivan 2009a, 2009b). The term *somatechnics* captures the notion that our bodies and beings are shaped by technology and narratives alike, in intra-action. Sullivan deploys it to

think through the varied and complex ways in which bodily-being is shaped not only by the surgeon's knife but also by the discourses that justify and contest the use of such instruments. In arguing that the conceptions of, debates around, and questions about specific modificatory practices are themselves technologies that shape corporeality at the most profound level, I aim to make a critical

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intervention into, and open up new spaces for reflection in, existing debates about the somatechnics of intersexuality. (Sullivan 2009a: 314)

In other words, the somatechnics of intersex encompasses individual life narratives, clinical procedures, medical standards of care, advocacy work, the biological concept of dimorphism, gender appearance and behaviour norms, and feminist critique; this list could go on for the length of this article. For example, the terminological debate that culminated in abandonment of the term *intersex* in favour of *DSD* (disorder of sex development) in the medical community and parts of the activist community ought to be analysed as a vital part of the somatechnics of intersex. The term is especially interesting for the inquiry of this article, since it can be understood as a way of orienting clinicians, activists, and intersex people towards consensus, however, not altogether successfully, which in itself indicates that the somatechnics of consensus needs to be scrutinised for leakages, rips, and cuts. These are no less part of the somatechnics of consensus, and when the term is used henceforth it refers to both the orientation towards consensus and the processes, relations and organisations that challenge it.

While a large portion of the studies done on intersex by feminist scholars focus on the ideological underpinnings of the clinical management of intersex tend towards textual materials such as descriptions of diagnostic criteria in research articles, and put emphasis on the materialisation of human bodies, I will turn the attention to a different type of bodies; organisational ones. I propose that further investigation into the organisational and material aspects of these practices would help to nuance and deepen our understanding of the somatechnics of intersex, letting us see not only the normative and regulatory processes but also the processes of resistance and negotiation. So, in setting out to investigate the orientation towards consensus that colours the somatechnics of intersex, my main question will be: How does the orientation towards consensus furnish certain types of relations, intra-actions, and procedures, and delegitimise and marginalise others? What kinds of effects does the orientation towards consensus have on the material and organisational aspects of the somatechnics of intersex? In other words, how does it create a somatechnics of consensus in relation to intersex?

In this article I will argue that the theoretical framework of biomedicalisation will help in understanding the complexity of the somatechnics of consensus. As introduced by medical sociologists such

as Adele Clarke et al. (2003), the term *biomedicalisation* describes the transformation of biomedicine as a knowledge- and technology-producing domain, and the effects these transformations have on clinical practices (Clarke et al. 2003: 165). As a theoretical framework, biomedicalisation investigates the complex interconnectedness of material, social, and cultural conditions framing illness and health, and gives special attention to changes on organisational and institutional levels and their intra-actions with individual narratives and experiences. In this article I will follow the model of theorisation offered by Clarke et al., insisting that discursive forms and practices and material forms and practices need to be analysed as co-constitutive (Clarke et al. 2003: 176), by focusing on how technoscientific changes, terminological debates, and the orientation towards consensus have had effects on the organisation of intersex, in terms of both medical management and advocacy work.

To investigate the biomedicalisation processes beyond the theoretical level, I have chosen to take a comparative perspective and look at local somatechnics of intersex in order to explore the complexity of a network of relations, structures, communications channels, alliances, narratives, and so on. The differences and similarities in the US and Swedish somatechnics of intersex – organisational, institutional, material, ideological, normative, critical – will be used as a case study. I argue that, while the intellectual, discursive conditions that have formed the somatechnics of intersex³ – especially as articulated in treatment protocols and standards of care – to a large extent are common goods and therefore shared, there are material and organisational conditions specific to Sweden. Sweden differs from the US, the context in which most literature on intersex takes its departure, in significant ways. For example the Swedish health system is largely state funded; hence, the commercial aspects that colour the US medical system are far less prominent in Sweden. The number of people directly affected by intersex (medically or professionally) is substantially smaller in Sweden compared to the US. The so-called *folkhem*, the socio-political system of the Swedish welfare state, characterised by a strong belief in the power of social engineering, and a paternalistic approach to its citizens, functions as the institutional and organisational backdrop for the somatechnics of intersex in Sweden. I will also investigate the connection between the somatechnics of consensus described above and the fact that Sweden often is described as a country that is oriented towards consensus, politically and culturally (Sontag 1969; Martinsson 2006; Habel 2012). Keeping an eye on the organisational and material aspects

is vital in pursuing this line of inquiry. In a small country like Sweden there is a continuum between reconstructive, aesthetic, and normalising surgery in the sense that the same surgeons perform the different kinds of surgery, sharing the institutional and organisational framework. Perhaps we can understand the consequences of this as a somatisation of technology in line with Sullivan and Murray (2009), and the organisations themselves as affective bodies in line with Sara Ahmed (Ahmed 2006, 2007)?

In short, this article will attempt to sketch the somatechnics of intersex by combining the attention to affective orientation with an exploration of the material-discursive processes of biomedicalisation. Like Sullivan, I am interested in what an approach that ‘foregrounds rather than forecloses the “trans-ing” of somatechnologies and the bodies (of flesh, knowledge, politic) to which they are constitutively bound’ (Sullivan 2009b: 282) might look like. I will also take cue from Iain Morland’s discussion on the conditions for critique that follows from the stalemate between advocacy narratives and clinical narratives (Morland 2009c).

Since the concept of a somatechnics of intersex encompasses feminist interventions as well as medical procedures, and the backdrop for the theoretical argument of this article is feminist approaches to intersex, I will begin with an outline of the most commonly taken positions of feminist intervention. Then, I will make the case that biomedicalisation theories help us to understand the somatechnics of consensus and the effects this orientation has on the somatechnics of intersex, by discussing three examples of the organisational and material aspects of the somatechnics of intersex in the US and Sweden. The first example concerns the orientation towards consensus within the medical community and the effects this might have on the biomedicalisation processes making up the medical community and the engagements with patients and their families. The second example discusses the orientation towards consensus as a way of establishing alliances between different groups, and how adopting a certain terminology might exhibit a willingness to collaborate and compromise. The third example focuses on how technoscientific innovations put stress on the orientation toward consensus within the medical community, and how they also pose challenges to which activist work need to rise. Finally, I will return to the question of affective organisations, arguing that we can understand clinical treatment of intersex in terms of touching, and that critique in the transgressive sense is dependent on living with uncertainty when it comes to the ethical outcomes of the somatechnics of intersex.

Feminist somatechnics of intersex: Foucauldian readings

Feminists have, as scholars and activists (often as both), contributed to the development of an intersex movement in fundamental ways, by participating in everyday lobbying activity, but also by providing theoretical underpinnings for intersex rights (Dreger and Herndon 2009).

The main focus of feminist attention in relation to intersex has thus far been that of early genital surgery. Feminists have worked hard, alongside intersex activists and clinicians, to reform the medical management of intersex, challenging not only the medical framing of intersex and the concept of sexual dimorphism, but also the psychological theories underpinning intersex management, in particular, the assumption that an intersex child might develop a problematic (read: not stable) gender identity if corrective surgery is delayed. Nikki Sullivan has identified two different approaches often taken by feminists critiquing intersex surgery: the analogical approach and the isolationist approach (Sullivan 2009b).⁴ While the isolationist approach claims that no medical intervention can be compared to intersex management, the analogical approach investigates ideological links between intersex management and other interventions, for example, female genital mutilation. The two approaches might seem incommensurable at first sight, but they both foster logics that hinder more complex understandings of the somatechnics of intersex; the isolationist approach focuses on the uniqueness, and specificity, of intersex management and tends to become solipsistic, and the analogical approach often ends up being universalistic and ignorant of contextual, ethical differences (Sullivan 2009b). Might this have to do with the theoretical framework used?

The main frame of analysis in feminist inquiries into intersex has been discursive analysis, and there has been a distinct tendency to focus on intersex as an example of a larger theoretical project: that of exposing the problems inherent in the contemporary, heteronormative, and sexist gender discourses. Intersex people are often represented either as victims of discursive violence or as gender warriors compared to the *hijras* of India.

Feminist scholars have often deployed Michel Foucault's understanding of biopower and normalisation processes as theoretical framework, when arguing that the very core of intersex management is the normalisation of intersex genitalia to fit the sexual dimorphic model (Morland 2009b; 2009c; Feder 2009). While the critique is well deserved and necessary, and the Foucauldian theories useful,

occasionally feminist critics attribute intentionality to individuals, especially to clinicians and politicians, but also to parents, despite using Foucault (Feder 2009: 233–4). In other words, some feminist scholars describe certain individuals as representatives of an absolute power to which others are victims. In doing this they neglect a specific aspect of the Foucauldian take on power, the part about ‘where there is power, there is resistance, and yet, or rather consequently, this resistance is never in a position of exteriority in relation to the power’ (Foucault, 1976/1990: 95). Feminist theorists using Foucault often focus on discourse as punishing and disciplining, but not on discourse as subjectivating – subjecting the individual to power through social disciplining and internalisation processes, and at the same time making an intelligible political subject possible.

Another problematic aspect of feminist intervention is that while intersex subjectivities are described as negative effects of Foucauldian biopolitics, as victimised and passive, it is not uncommon that feminists describe intersex bodies as subversive in and of themselves, as materialised exceptions to the norm, proofs that the dimorphic sex model is a theoretical abstraction and not a law of nature. The subversive potential of intersex is thus thought to be located in the intersex body, and discussions of intersex as subversive or queer tend to focus on physiology, not on lived experience. Tales of lived experience function at best as illustrations of the harmful effects of discursive violence. This is particularly striking when compared to the subversive potential attributed by many feminists and queer theorists to transgender people, on account of the discrepancy between their sexed bodies and their lived gendered experience. In the case of transgender people the subversiveness is thought to stem from the very lived experience and gender identity of the individual, since it displays this dissonance. However, in recent years feminists have criticised the tendency to separate intersex bodies from intersex subjectivities, taking cues from feminist phenomenology (see, for example, Zeiler 2010; Cadwallader 2011).

The selective reading of Foucault, leaving out the complex relation between power and resistance, and attributing intentionality to discursive agents such as clinicians, fosters a situation in which it is hard to discuss issues of medical treatment with clinicians, and even harder to make alliances and actually contribute to reforming treatment protocols, since the theoretical model assumed often is interpreted by possible allies as pointing the finger and blame at specific groups of people. Iain Morland (2009c) points out that at the heart of some advocacy argumentation (such as

that of ISNA, an organisation I will return to later in this article) is an assumption that there is a self-evident relation between the critique of intersex management, as formulated by advocates and feminists, and the reform of said management. They argue that the reformist narrative, based on intersex life narratives, is trustworthier than the clinical one, and hence more ethical (Morland 2009c: 191). This, in combination with the orientation towards consensus that I have sketched in the introduction, set rigid boundaries for feminist critique as interventional on the organisational level of intersex management. Could a different theoretical understanding help us form our critique more fruitfully in ways that might balance the orientation towards consensus and being trustworthy?

Psychologist and social scientist Katrina Roen envisions a larger focus on relationships, between patients and clinicians; between parents and children; between different clinical disciplines; and between clinicians, social scientists, and feminist scholars, in addition to further investigation of epistemological shifts in relation to intersex and intersex management (Roen 2004: 129). One way of setting relations and epistemological shifts into focus would be to frame the somatechnics of intersex as biomedicalisation processes negotiating health, disease, normality, and pathology, and to understand these processes as co-constitutive of and by their institutional and organisational contexts, as will be the aim of this article. I argue that we can avoid the tendency to relapse into a search for consensus and common ground, if we turn to the biomedicalisation framework, since it will let us focus on how individuals and organisations generate, form, negotiate and react to biomedicalisation processes. Negotiations ought, in this case, to be understood in a Foucauldian manner, as vacillations between power and resistance, in themselves mutually constitutive (Clarke et al. 2003). Biomedicalisation theories will also help us situate somatechnical practices of intersex, so that we avoid isolating them as unique, or strip them of their specificity and describe them as effects of a universal discourse. Sullivan describes her own academic work as

attempts to mobilise this productive tension [of both inhabiting and challenging categorical knowledge], to perform (with varying levels of success) the double-gesture of tracing the specificity of particular modes and practices of bodily (un)becoming thus invoked, and of troubling their alleged essence, their separateness and/or self-sameness. (Sullivan 2009a: 276)

This is an attempt in that same sense.

The biomedicalisation of intersex: Situating the somatechnics of consensus

Biomedicalisation theories take departure in the fact that biomedicine is a fundamental element of mass culture, and that medicine has a privileged role as an exemplifier when the progress and importance of scientific and technological innovations are discussed (Clarke et al. 2003). The theoretical framework combines Foucauldian discourse analysis on medicalisation and normalisation with actor network theory, and science and technology studies on knowledge production and the technoscientific sphere, taking its cue from Donna Haraway and Bruno Latour. In this sense biomedicalisation fits well with the notion of somatechnics in that it allows us to analyse discursive and material formative processes as co-constitutive and entangled, materialising bodies and organisations alike.

Five key interactive processes both engender biomedicalization and are produced through it: (1) the political economic reconstitution of the vast sector of biomedicine; (2) the focus on health itself and the elaboration of risk and surveillance biomedicines; (3) the increasingly technological and scientific nature of biomedicine; (4) transformations in how biomedical knowledges are produced, distributed, and consumed, and in medical information management; and (5) transformations of bodies to include new properties and the production of new individual and collective technoscientific identities. (Clarke et al. 2003: 161)

Biomedicalisation theories are efficient, if we are interested in investigating the complex relations between micro, meso, and meta levels in the structures and discourses of illness and health, showing how changes on organisational and institutional levels affect individual narratives and experiences (Clarke et al. 2003: 165). For the inquiry at hand the analytical framework will be used to analyse the somatechnics of consensus as part of the somatechnics of intersex, and to scrutinise this orientation for leakages, rips, and cuts in order to investigate the effects consensus-seeking might have on the organisation of intersex management.

In the following I have chosen examples to demonstrate the types of questions that might grow out of an engagement with biomedicalisation as a theoretical framework. Some of them are also interesting from the perspective of trying to identify specific (although not stable) somatechnics of intersex, situated in time and space.

FIRST EXAMPLE: Clinical medicine is an increasingly internationalised knowledge-producing apparatus constituted by international conferences and international journals. As such, clinical medicine is

largely oriented towards consensus on the level of standards of care and international guidelines. The orientation is motivated by the need to legitimate established treatment models in accordance with science and proven experience. Consensus in the form of standards of care can be understood as a way of reassuring both patients and colleagues that the patients are being given the best care possible. In this sense the orientation towards consensus can be understood as a trust-grounding practice in Naomi Scheman's definition of the term (Scheman 2001). Morland argues that clinicians, contrary to descriptions often given by advocates and feminist scholars, share with their critics the notion that the birth of an intersex child demands 'an ethical response,' but that most clinicians still think of genital surgery as a way of taking responsibility (Morland 2009c: 207). Individual intersex narratives as testimonies of the aftermath of surgery – in forms of scar tissue, psychological trauma, shame, loss of sensation – can be written off as anecdotal within a medical community that is centred on the concept of evidence-based health care. However, there are practices that counter the orientation towards consensus within the medical community, such as the trying out, implementation, and argumentation for innovative treatments that question the established ones. With the effects of commercialisation added to this inherent system of concurrence, how does the orientation towards consensus play out in the relations between clinicians and intersex people and their families?

The Swedish health care system is largely state funded, so the commercial aspects of medical information and management are far less obvious than in the US. Also, the medical management of intersex is regulated in Swedish law (SFS 1972:119). These two factors in combination make the conditions for negotiations amongst clinicians, and between clinicians and intersex people, different from those in the US, since the state has an explicit interest in the registered gender of its citizens.⁵

Swedish clinicians are dependent on the international professional discussions on intersex – carried out at conferences and in journals – since the national group of specialised clinicians is small and the rate of patients with intersex conditions low. The fact that the specialised group of clinicians is modest is an important factor in the implementation of changes in protocol as well, since the formative discussions between clinicians are fairly easy to organise. A physician working with one of the multidisciplinary teams in Sweden commented on this in an interview with me, stating that they put a lot of effort into reaching national consensus; for example, they are planning annual

meetings where they will discuss individual cases and international developments.⁶ It seems that there is at least a potential for a close-knit professional climate furnishing discussions on technoscientific developments and implementation. In addition to this, in a small country the clinical network is so tightly knit that there is a continuum between reconstructive, aesthetic, and normalising surgery in the literal sense that the same surgeons perform the different kinds of surgery, sharing institutional regulations – in terms of centralised, economic, and juridical structures – and organisational framework. All these aspects together make up a different setting for the local somatechnics of intersex management from that of the US. How might the orientation towards consensus within the clinical context influence the relations between people affected by intersex professionally and personally? Do these relations become more personal and informal, and if so, what does that entail? Does it make clinical intervention less likely and enhance the variety of information offered to parents and intersex people? Are the chances of getting a second opinion lessened or heightened by the fact that there are fewer specialists and the economic incentives for referrals are the ones associated with a communal, state-funded system and not a commercial one? These are tentative questions that ought to be posed in studies done in Sweden and the US alike.

SECOND EXAMPLE: Among the key aspects of biomedicalisation, Clarke and her colleagues mention transformations of the notions of and conditions for identities and social forms. The changes in management of medical information and the dislocation of expert knowledge and lay knowledge, in combination with the advent of peer support, patient and advocacy organisations as a specific social form of information distribution, communication, and socialisation, and the self-surveillance and self-disciplining aspects of biomedicalisation to top it off, have created a situation in which what can be described as ‘new forms of social connectivity’ and ‘new forms of embodied subjectivity’ (Sullivan and Murray 2009: xii) have evolved.

The development of peer support groups and intersex advocacy organisations, such as ISNA (Intersex Society of North America), has been imperative for the intersex movement and the reformation of intersex management (Dreger and Herndon 2009). They are essential parts of the somatechnics of intersex. ISNA, founded in 1993 and dissolved in 2008, was during its heyday the largest and most influential advocacy organisation, in the US and in the world. ISNA started out as a regional organisation, situated in California, trying to create awareness on intersex in the local community; eventually, it

embarked on interventions directed at clinicians and politicians, nationally and internationally. Throughout the years ISNA and other peer support groups and advocacy organisations have been affected and reconstituted by technoscientific changes. Most of them are no longer limited to regional networks but have glocalised organisational structures with complex feedback processes of information on micro, meso, and macro levels. Organisations formulate policy documents and information brochures, policies and information that intersex individuals relate to and react to in their everyday lives (Morland 2009c; Sytma 2009). Some of these individuals share their stories on personal blogs and Internet communities, revealing patterns in intersex narratives that affect the lobby work of the peer support groups and advocacy organisations, lobby work that eventually is disseminated back to the micro level as new information about the development of intersex awareness, spread through virtual fora and paper brochures.

ISNA has been the inspiration for several national and international advocacy organisations. In Sweden there is only one advocacy organisation that takes a comprehensive and critical grip on intersex management: INIS (Intersexuals in Sweden), founded in 2006. There are significant differences between the Swedish and US conditions in terms of advocacy organisations. ISNA was a full-scaled, professional lobby organisation with staff, working in affiliation with scholars and clinicians to put intersex on the political agenda – a lobby force to be reckoned with. Their demands for change resulted in a reformation of the standards of care on an international level. INIS is a relatively young and, by US standards, very small organisation, completely dependent on voluntary work. It is still in start-up phase, without financial resources and without political influence in terms of large numbers of members. INIS relies on the goodwill of the medical community for its participation in the reformation of intersex management. While ISNA had close contact with feminist scholars scrutinising heteronormative and sexist notions within scientific knowledge production, INIS has had limited contact with scholars in general. There is a distinct lack of feminist scholars engaging in the Swedish discourses on intersex (Alm 2010). However, INIS has allies in the NGOs RFSU (the Swedish Association for Sexuality Education) and RFSL (the Swedish Federation for Lesbian, Gay, Bisexual and Transgender Rights), two large lobby organisations that have made intersex rights and norm-critical readings of intersex management their business. Using traditional lobby strategies – writing informed referrals during legislation processes, influencing politicians to write motions to the parliament, producing information materials,

arranging seminars, and funding support groups and smaller research projects – RFSU and RFSL are important parts of the local somatechnics of intersex in Sweden (Alm 2010). The chairperson of RFSL describes the organisation's role as that of following INIS's lead in matters of intersex politics, furnishing the smaller organisation with a larger network of contacts, greater economical resources, and a wider scope of members.⁷

The material-discursive differences of the local somatechnics of intersex have implications for the approaches to key issues taken by ISNA and INIS, respectively. One example is the reactions to the introduction of the term DSD, which in recent years has become the preferred term amongst the majority of clinicians working with intersex. The change of terminology from intersex to DSD was proposed during the international paediatric conference in Chicago 2005, and established in a consensus statement formulated afterwards (Lee et al. 2006; Reis 2007). It sparked discussions on the performative nature of terms and naming. Arguments for a term that focuses on the biological conditions underlying intersex diagnoses have been put forth from the medical community; clinicians have claimed that intersex is a term that doesn't say anything substantial about the medical issues at hand, and that it therefore only clouds the interests of the patients affected by it. The proponents of the term DSD often refer to the fact that parents with intersex children have described terms like *intersex* and *hermaphrodite* as offensive and counterproductive, arguing that they frame individuals with atypical sex as being in between sexes, freaks of nature (Reis 2007). Some feminist scholars and activists agree with this line of reasoning, claiming that the term intersex reifies a medical condition as an identity, and fosters the idea that intersex people are a specific type of people in the Foucauldian sense (Dreger and Herndon 2009; Feder 2009). Strategic arguments for adopting the term DSD have also been issued from feminist quarters, stressing the need for intersex allies and activists to appear trustworthy and accountable, not too radical to cooperate with: '[T]he shift to this terminology [DSD] clearly has allowed serious progress toward patient-centered care, in part because it has allowed alliance building across support and advocacy groups, and with clinicians' (Dreger and Herndon 2009: 212). In this sense, the use of the term can be understood as a trust-building device. However the usage also functions as a trust-eroding device since many intersex activists and some feminist scholars have objected to the introduction of a term that pathologises atypical sex in naming it a disorder. Some talk of the need to hang on to the rhetoric of identity politics as a way of framing

intersex advocacy in a time when human rights is the preferred line of political and juridical reasoning (OII online; Reis 2007; Morland 2009a; 2009b).

In light of this debate the term, and the use of it, can be understood as an apparatus to orient the somatechnics of intersex towards consensus – to straighten the relations, alliances, and procedures that are not conformative – what Ahmed has called ‘a straightening device’ (Ahmed 2006). 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. The argument is that intersex is a problematic term, since, in addition to being a generic term for a variety of medical diagnoses, it is thought to refer to an identity category. When ISNA started off, in the early 1990s, identity politics in the name of intersex was one of the key issues on the agenda. However, eventually ISNA changed its approach, claiming that identity politics do more harm than good, since one runs the risk of generalising, if one addresses intersex people as a homogeneous group. The risk of being perceived by clinicians and politicians as too radical to make alliance with was also used as an argument for changing positions (ISNA online; Turner 1999). When ISNA dissolved in 2008 its successor, Accord Alliance, was already in play. Accord Alliance’s aim is to give voice to the experiences of the so-called DSD clinical triad: clinicians, intersex patients, and parents of intersex people. In other words, the search for consensus is written into the very foundations of the organisation. Accord Alliance is not a lobby organisation, but rather a support organisation that has left ISNA’s identity politics and advocacy behind. Swedish INIS embraced the term DSD, and the underlying arguments for a change in terminology, from the start. Consequently, INIS has never had any interest in identity politics. Partly, this has to do with the fact that the contemporary somatechnics of intersex differ from those of the early 1990s. INIS has not met the same resistance that ISNA did; Swedish clinicians have explicitly asked for relations of collaboration and alliance (Alm 2010). One of the founders of INIS said in an interview that INIS has more in common with Accord Alliance than with ISNA, and that the main aim of the organisation is to create conditions that facilitate relations between intersex individuals and clinicians. Ze describes herself as a pragmatist in the name of consensus:

I want to really influence. . . . not just be an opponent and only state my opinion, but rather work with others. . . . I suppose I am the diplomat

then. I want to try to reach a realistic standpoint that we can all agree on, because I think the work will proceed faster then.⁸

The orientation towards consensus seems to work as a way of building trust between different positions and organisations, providing a neutral ground for negotiations. But the orientation towards consensus also works as a way of legitimating individual perspectives, of framing individuals and organisations as trustworthy and invested in the issues at hand, and hence also framing other perspectives and organisations as less trustworthy.

Examples 1 and 2 both evoke the idea that certain changes in the processes of knowledge production – such as the increasing numbers of channels for health care consumers to contribute to knowledge production via advocacy and patient organisations, Internet discussion boards, guest books, Internet communities, and so forth – have disrupted the division between expert and lay knowledge. These changes in information and knowledge processes are often described as democratising, giving more people access to medical information and more channels to comment on it. However, Clarke and her colleagues warn that these processes also furnish commercialisation of knowledge production and information management, and may result in a stratification of people based on access to digital health fora (Clarke et al. 2003: 177–8).

While the orientation towards consensus in part is challenged by these processes, in the sense that clinical prerogatives are challenged as the sole source of knowledge on intersex, it cannot be assumed that the disruption of the exclusive domains of expert and lay knowledge will solve the problems with medical information management. Psychologists Lih-Mei Liao and Mary Boyle have pointed out that, although the new clinical regime might furnish situations in which the information management is passed on from clinicians to parents, the problems might linger and take on other forms (Liao and Boyle 2004). The relational and affective bonds between parents and children are in general more intimate than those between clinicians and their patients, and the responsibility to work against secrecy and shame that comes with the position of supplementing information might be even harder to uphold when the questions at hand are personal and not part of one's profession.

In describing ISNA's critique of the management of intersex Iain Morland claims that this reformist narrative suffers from the same paternalism that it accuses the clinical narrative of. He talks about a 'progressive paternalism' in which patients that look to clinicians

for expert decisions and clinicians that resist the patient-centred perspective are positioned as in need of education (Morland 2009c: 202). In this sense some argumentation used by advocacy and activist organisations are just as oriented towards consensus as the medical community is; albeit the preferred narrative is a different one stressing informed consent and patient-centred health care. In line with Liao's and Boyle's reasoning it is also possible to detect a distinct risk that the individual patient and/or parent to intersex child, in the name of informed consent, assumes the responsibility for gathering information needed, and ends up underscoring the self-surveillance and self-disciplining aspects of the biomedicalisation processes.

The Swedish examples discussed above show that the past decades have seen considerable changes in the material conditions for organising intersex advocacy, and in the conditions for negotiating relations between clinicians and intersex people, and intersex people and advocacy organisations of different sorts. Despite these changes, an organisational orientation towards consensus seem to linger, resulting in a way of talking about intersex, and organising intersex advocacy, that makes certain approaches and stances unintelligible, even illegitimate. The somatechnics of consensus fosters a climate that depoliticises large parts of the somatechnics of intersex, in the sense that it sets the boundaries and conditions for critical inquiry. Representatives of the major interlocutors in the Swedish context (clinicians, INIS, and RFSL) express a hesitance towards feminist approaches to intersex. These concerns are articulated in very different ways: some formulate the problem as a lack of investment in the actual practices of advocacy, stating that feminist scholars tend to criticise the management of intersex from a theoretical perspective, but rarely give input into how advocacy work could benefit from these insights (RFSL); others describe feminist scholars as too radical in their criticism of gender norms, more interested in sexual politics than in taking part in the reformation of intersex management (INIS).⁹ What these approaches have in common seems to be a notion of feminist scholars as not oriented towards consensus, and hence not as easy to work with as other interlocutors, and ultimately not trustworthy.

THIRD EXAMPLE: One of the strengths of biomedicalisation theories is that they provide tools to analyse the role of technoscientific innovations in the transformation of the somatechnics of intersex, helping the understanding of how technoscientific innovations affect the organisation of care and the narratives of health and illness, ultimately materialising bodies and organisations alike. The somatechnics of intersex gravitated around the constraints of

technoscientific innovation, materially and discursively. The clinical treatment model now being questioned and reformed by the new standards of care was initiated by psychologist John Money and his colleagues, and puts emphasis on the need for surgical interventions in cases of anatomical atypicality. The technical conditions for surgical interventions has formed information management as well as physical bodies and is an example of what Jessica Cadwallader calls the technoscientific boundaries of social organising and identity (Cadwallader 2009). Vernon Rosario's discussion on microarray gene testing is an excellent example of how biomedicalisation processes change the conditions for the somatechnics of intersex; trans-ing somatechnical processes. Whole human genome testing is not only a reality but also an inexpensive procedure nowadays, which has effects on how often prenatal genetic screening is done, and hence provides clinicians with possibilities of discovering intersex conditions in utero (Rosario 2009: 279).

As an example of how technoscientific innovations transform the somatechnics of intersex, and challenge the somatechnics of consensus, I have chosen the case of fetaldex. For the past couple of years a heated debate has been surging between clinicians, medical ethicists, and feminist scholars on the practice of treating pregnant women with the steroid dexamethasone (often called fetaldex). The women are the ones identified as having an enhanced 'risk' of giving birth to children affected by congenital adrenal hyperplasia (CAH). Alice Dreger, Ellen Feder and Anne Tamar-Mattis (2012) have pointed out that fetaldex has been distributed, by some clinicians, under ethically shady circumstances. The authors show that there are organisational flaws in the US system designed to protect patients from harmful medical experimentation, making possible a praxis in which both physicians and affected families are making decisions based on information that is biased and inconclusive. The somatechnics of fetaldex is coloured by a tradition of medical interventions undertaken in the name of heteronormativity. The main argument for use of the experimental drug is that it reduces the need for further intervention. Consequently, that accords well with aims set up by the consensus statement of 2005, and as such, is in line with the orientation towards consensus. In other words, the normative ideals of dimorphism are constitutive of what is deemed necessary to treat, and the somatechnics of consensus is still oriented towards normalisation as opposed to questioning the idea of biological binarity. Clinicians that are critical of these practices find no support in the organisational system.

The fetaldex case is an excellent example of how the focus on health surveillance – and on the responsibility of the individual patient for the management of his own health and illness – is affecting intersex people, their families and clinicians alike. At its most formative it is a case of self-disciplining (in the Foucauldian sense) intersex bodies. But it is also an example of the incommensurability of two narratives both claiming to take ethical responsibility in a medical situation. On the one hand the clinical narrative that aims at ‘curing’ or eliminating intersex conditions if possible, on the other hand the reformist narrative that aims at social acceptance as a solution (Morland 2009c: 203).

While fetaldex is an off-label medication in the US, it has been administered within the framework of a clinical study in Sweden since the late 1990s. Swedish clinicians working with CAH patients recently applied the brakes on this prospective study, arguing that there might be serious side effects not accounted for by long-term follow-up studies (Hirvikoski et al. 2012: 1882). The authors conclude the article with a call to arms directed at the international medical community, urging it not only to stop using fetaldex outside of clinical studies but also to take ethical responsibility for the groups of patients already treated and to do damage control by performing retrospective studies (Hirvikoski et al. 2012: 1882). Given that the medical community is an organisational context that is consensus oriented – articulated in consensus statements and international guidelines – the Swedish call might function as a litmus test to determine how wide the gap between guidelines and practice is, putting the searchlight on the fact that there might be national and regional patterns of difference to be dealt with. In this sense the usage of fetaldex can be understood as ‘an ethic canary in the modern medical mine’ (Dreger, Feder, and Tamar-Mattis 2012: 277), and the Swedish clinicians’ call to arms will not only put the gap between guidelines and practice to the test but also the strength of consensus within the medical community and with it the willingness to openly debate the meanings of the Hippocratic consensus on putting the patient’s health first.

Organisational bodies touching and the conditions for critique

I have argued that the somatechnics of consensus has had consequences for the local somatechnics of intersex, and I have tried to situate somatechnical practices in terms of organisational boundaries, defining the possibilities for alliances and relations. In

the following I will elaborate on a different affective somatechnics of organisation, taking cues once again from Morland and Ahmed. In his piece on what queer theory can do for intersex, Morland insists on the need to add an affective register of understanding to the discussions on intersex bodies and intersex management. He describes surgery as ‘an embodied encounter between patients and surgeons’ (Morland 2009b: 300) that leaves lasting physical and psychological marks, not only on intersex bodies but also on clinical ones. Understanding surgery as touching – and the effects of touching as lingering, constituting the conditions for self-understanding, recognition, and relation to the world – opens up an interesting critique of the management of intersex. Morland, taking a cue from Ahmed’s formulation of the body as a surface charged with affect prompted by sensations and touches, adds that ‘the body’s very capacity for sensation is shaped by the impressions of object and others on its surface’ (Morland 2009b: 301). I think that we can understand clinical management of intersex in the same sense, as an apparatus with an affective surface and matter. Understanding the clinical management of intersex as an organisational body will give us insights into how the technicalities of medical management are somatised as it is formed by alliances, relations, dependences, and affects. As I have argued in this article, the somatechnics of intersex can be analysed through the orientation towards consensus. The orientation towards consensus is not only a way of making oneself (as an organisation or an individual) trustworthy in the eyes of others, but also a way of making sense of the different aspects of working with intersex; making them intelligible, legitimate, and ‘in line’ with common sense (Ahmed 2006).

One way of interpreting the orientation towards consensus is to understand it as an orientation towards an emotion – tolerance – that is understood as a common good, as common sense. In other words, the orientation towards consensus is at once an orientation towards a common good and an orientation towards common sense. While consensus as common good might hold a radical, democratic potential in its communal perspective, consensus as common sense doesn’t promote the basis for political discussions or antagonism, since it depoliticises the issue at hand in the attempt to avoid conflict (Brown 2006; Butler 2004). And political, critical discussions are necessary. I want to return to Morland’s vision of an ethics of intersex as a concretisation of the critical and political potential inherent in the trans-ing nature of the somatechnics of intersex, since it formulates the task at hand as that of rethinking uncertainty. Morland echoes Judith Butler’s (2004) insistence on the merits of

uncertainty, the elusiveness of a radical, critical position, and the need to live our lives as political, in the sense of assuming a responsibility for a collective future:

It may be that what is “right” and what is “good” consist in staying open to the tensions that beset the most fundamental categories we require, to know unknowingness at the core of what we know, and what we need, and to recognize the sign of life—and its prospects (Butler 2004: 227).

Notes

1. The following reading of Ahmed focuses on her use of the concept of orientation as put forth in *Queer Orientations* (2007) and ‘The Phenomenology of Whiteness’ (2010), and not her discussions of the orientation towards common sense in *Strange Encounters*.
2. A note on terminology: the term *intersexualism* was used for large parts of the twentieth century, within the medical field and among intersex activists. Intersexualism functioned as an umbrella term for several types of medical diagnoses, and there has been great dispute as to which diagnoses ought to be included (Dreger and Herndon 2009). The term *intersex* has been put forth by intersex people and intersex advocates, as an alternative to intersexualism/intersexual, in an attempt to find words that do not contribute to the misconception that intersex has anything to do with sexual orientation (Dreger and Herndon 2009). Recent discussions between clinicians and intersex activists have resulted in a change in terminology; the preferred term within the medical field is now DSD (disorder of sex development). The pros and cons of this terminological shift will be discussed later in this article. I will use intersex, since it is my firm conviction that the advantages of the term intersex outweigh the disadvantages, in this specific context. Intersex as a term connotes an epistemological standpoint, a position that generates questions about what it means to not fit the sexual dimorphic model of our times, and as such, it fits the interests of this article, since it helps to keep the focus on the performative character of the somatechnical processes surrounding, forming, and defining the phenomenon of atypical sex.
3. Why a case study? Iain Morland argues that we need to move beyond the issues of normativity and ideology. ‘While analyses of the treatment model’s influence in terms of the histories of gender, sex, and sexuality are astute, they ought to be considered in relation to other intellectual and scientific contexts that at first glance seem less relevant to the medical management of intersex’ (Morland 2009a: 195). At the same time, he insists on historical contextualisation. Morland sketches the intellectual and institutional US context in which psychologist John Money and his colleagues (often described as the culprits for the standardisation of intersex management) were active as influenced by a combination of Freudian psychoanalysis, individual psychology, with a hint of Skinnerian behaviourism, and the so-called human sciences, all discourses that revolve around the idea that the human psyche is plastic and socially flexible (Morland 2009a). These are, of course, constitutive discourses for the contexts in which the development of the Swedish praxis of juridical and medical management of intersex emerged as well, but perhaps there are additional discourses to be taken into account, such as the ones mentioned above.

4. In Sullivan (2009) a third approach is described, one that is not as interesting in this specific context as others: the categorical approach. This approach is often taken by physicians arguing for the need for early, normalising interventions, claiming that there is a categorical difference between intersex surgery and the interventions (namely female genital mutilation and cosmetic genital surgery) that the proponents of the analogical approach pinpoint as based on the same foundations as intersex management. One of the main problems with the categorical approach is that it grows out of dichotomies between healthy/pathological and legitimate/illegitimate bodies (Sullivan 2009).
5. There is a plethora of examples of this interest on the part of the state, explicitly articulated in the legislation surrounding the medical and juridical aspects of gender reassignment. The actual decision as to whether a transgender citizen has the right to have hir gender sanctioned by the state or not, a decision issued by the Swedish National Board of Health and Welfare, is a formal ending to a much more complex process of negotiations between the individual and clinical psychiatry. The right to gender reassignment is conditioned by a scrutiny when it comes to individual gender attributes, lifestyle, sexual orientation, anatomical appearance, and desires. Heteronormativity, sexism, racism, ableism, and ageism set the standards to meet: a transwoman who is hesitant about extensive genital reconstruction can still be questioned with reference to the assumption that an authentic transsexual desires the anatomy to match the gender identity. A transman with the same hesitance is less likely to meet resistance, since the technoscientific techniques of constructing an acceptable penis are far less developed than those of constructing an acceptable vagina. The key word here is 'acceptable'; the normative ideals of female and male anatomy, as dimorphic, complementary, and hierarchically ordered – male organs thought of as active, performative, and unique, female organs thought of as passive, receiving, and substitutable/exchangeable – are constitutive in a discursive *and* material sense. The actual legislative text demands that individuals seeking gender reassignment have to be sterilised before their gender reassignment can be sanctioned, and the argument put forth in the governmental report (SOU 1968: 28) that drew the outlines for the legislation is that, otherwise, the possibility of a man becoming a mother or a woman a father cannot be ruled out. Such an event is not, as might be expected from a text from the late 1960s, first and foremost described as a monstrosity, but rather as a bureaucratic problem, messing up the national civic registers. The legislative text also states that applicants for gender reassignment have to be of legal age – 18 years old – since it is assumed the majority of teenagers that express emotions associated with the cardinal symptoms of transsexualism grow out of these inclinations. At the same time the narrative of a childhood coloured by these very emotions is in itself a more or less necessary criteria for diagnosis, and older applicants who are unable to relate such a narrative convincingly (or are uninterested in doing so) are described as secondary transsexuals and are scrutinised by clinicians' insistence on authenticity. In other words, the articulation of gender dysphoria, which is the clinical term for expressing dissonance between genital sex and gender identity, is tightly connected to normative notions of psychic development and maturity. The specifically Swedish somatechnics of transsexualism have been investigated fairly thoroughly over the years (see, for example, Alm 2006, Kroon 2007, Bremer 2011).
6. Interview with a clinician, 24 August 2010.

7. Interview with the president of RFSL, 24 August 2010.
8. Interview with a founding member of INIS, 9 March 2010.
9. Interview with a founding member of INIS, 9 March 2010; interview with the chairperson of RFSL, 24 August 2010.

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