

Mind the Gaps: Intersex and (Re-productive) Spaces in Disability Studies and Bioethics

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Abstract With a few notable exceptions disability studies has not taken account of intersexuality, and it is principally through the lenses of feminist and queer-theory oriented ethical discussions but not through ‘straight’ bioethics that modes valuing intersex *difference* have been proposed. Meanwhile, the medical presupposition that intersex characteristics are inherently disabling to social viability remains the taken-for-granted truth from which clinical practice proceeds. In this paper I argue against bioethical perspectives that justify extensive and invasive pre- and post-natal medical interference to eradicate intersex. I argue instead that to constitute the necessary conditions for the recognition of the intersexed child as a person, a life valid in its own right, clinicians must refrain from aggressive interference. Clinical specialists presuppose that intersexed children will be socially disabled and unrecognizable as persons; frustrated by the general failure of traditional interventions to assign a sex, clinicians are now pursuing prenatal technologies, including selective termination, to erase intersex.

Keywords Intersex · Disability studies · Critical ethics · Critical gender studies

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Introduction

With a few notable exceptions disability studies have not taken account of intersexuality [1–2]. Moreover, it is principally through the lenses of feminist and queer-theory oriented ethical discussions but not through ‘straight’ bioethics that modes valuing intersex *difference* have been proposed [3–4]. Meanwhile, the medical presupposition that intersex characteristics are inherently disabling to social viability remains the taken-for-granted truth from which clinical practice proceeds. On this point, the bioethicist, and philosopher Carl Elliott has argued that to ask clinical practice to change its view of intersex is to fail to understand that:

...we treat these children the way we do because this is how we see the world. And it isn’t just the way doctors see the world; it is the way the parents see the world, and most importantly, it is the way that the children themselves are taught to see the world. It is the fact that they do not fit into this way of seeing the world that causes the problems [5: 39].

Because Elliott is generally thought to be a “radical” bioethicist, his comments on intersex are surprising; however, as I will argue in this paper, his assertion is congruent with his attitude toward other forms of difference in children, and with his belief in the fundamental correctness of the clinical perspective.

Elliott's assertion contradicts Suzanne Kessler's findings on the clinical encounter between the parents of an intersexed child and those in charge of its medical assessment and treatment [6]. Kessler showed that clinicians had *to teach* the parents how to understand intersexuality in clinical terms, and *to learn* its meaning according to medical priorities: that is, to see the children's appearance as problematic and to apprehend intersex as appropriately serious but absolutely repairable with medical intervention. If we can understand that this process of teaching and learning is rendered possible and enforced through the clinical encounter, then we can understand that the social crisis and inability to view the child as a person begins not with the child's appearance, but with the medical discourse that frames and shapes the viewing angle that parents are to take. Elliott is correct that this may be how "we" do and see things, but it is important to understand that some cultures do not, and that without the clinical encounter we would likely still see intersex in terms of difference but not necessarily of monstrosity that forecloses on the child's species membership as a human, and subsequent status as a person.

Clinicians assume that unhappiness in the form of isolation *will result* if the intersexed child's body is not altered through techno-medical intervention. Arthur Frank reminds us, however, that any technology that promises to put an end to human unhappiness takes place in a larger social context of mutually sustaining market forces at play between the consumers, suppliers and builders of medical technologies [7: 46]. In cases of intersex, it is the parents who demand or consume treatment; however, it is the children who have to live not only with medicine's technical shortcomings, but also with the awareness of the message conveyed through intervention, namely, that in their intersexed bodies they were unacceptable, perhaps unlovable, and certainly unrecognizable as persons. The literature demonstrating the harm done to self-perception is growing rapidly [8–14]. Crucially, Frank observes that when a medical technology is known to have a high failure rate it can nonetheless continue as the dominant mode of management because clinicians have successfully "blamed failure on the patient" (ibid). As we shall see, blaming the patient remains a powerful means of saving face for those who have specialized in the diagnosis and treatment of intersex.

There is a need to wrest intersex management away from the medical domain. And there is good reason to address intersex principally through a critical disability studies apparatus that may hold in abeyance the commonsense attitudes that not only fail to provide well-being, but which are moving in the face of that failure, to eradicate intersex altogether through the use of invasive prenatal technologies, including selective termination. However, I also maintain a critical stance toward tendencies in disability studies that make a 'straw woman' out of feminist concerns for women's reproductive autonomy, and argue that we need not pit women's reproductive autonomy against those whose lives are described as "lives of difference" [15]. I address these concerns in the paper's final section.

Biopower and the Clinical Setting

In the world of the clinic into which they are born, intersexed infants and children face a prevailing perception that they are so seriously damaged it is impossible even to conceive of admitting them to the category of personhood without performing extensive and immediate medical and surgical intervention on them. The birth of an intersexed child has until very recently been described with near unanimity in the medical literature as a crisis, with these alarmist tones calming only very recently in favour of other, more subtle means of promoting immediate surgical intervention [16], and continues to be unequivocally described as a "medical and social emergency" [17: 388] in some of the literature that still uncritically cites and accepts the received wisdom of publications that are now 15 to over 20 years old. Most important here, however, is to point out that it is a function of power, rather than a statement of fact, to attribute the source of crisis to the birth of the intersexed child. The crisis in the clinic ought instead to be understood as a failure of the discourses of personhood in which expectant parents and their attendants invest.

Long before the birth of a child, those awaiting its arrival are encouraged to imagine its future as either male or female, and to map out the various, usually opposing, gendered divisions of aspirations, fantasies, labour, and so forth. Much of the internal structure of these expectations hinges on heteronormative assumptions about genital appearance as a 'natural'

signifier of desires and sexual identity, and thus reifies and naturalizes gender as an effect of anatomy and biology. On the point of such expectation and the horror that parents must face when a newborn does not meet it, D.F.M. Thomas offers the following:

Ambiguous genitalia and intersex states are serious disorders with profound and potentially lifelong implications for the affected individual. Gender assignment is often an imperfect exercise and where the long-term outcomes of genital reconstruction in infancy have been documented they have proved disappointing. There is widespread recognition of the need for long-term functional and psychosexual outcomes studies to formulate a more evidence-based approach. Aggressive and unnecessary early surgery is unjustifiable. However, the approach advocated by some patient groups, which envisages leaving some girls with an obviously uncorrected male genital phenotype, *is likely to prove unacceptable to most parents* [16: 50].

Thomas' statement appears in an article that acts as an apologia for the still dominant clinical practice of rapid surgical intervention. While Thomas admits that surgical outcomes have been less than optimal, he charges that patient groups have been "unjustified" and "strident" in their "misinformed" criticism of the motivations of doctors who treat intersexuality who, he asserts, "have always been motivated by the wish to do what they genuinely believe to be in the best interests of their young patients and their families" [16: 47]. That is, in spite of his acknowledgment that early surgery is 'unjustifiable' when it is both aggressive and unnecessary, Thomas allows for any surgical intervention not deemed to be either. We should, then, pose the question to Thomas, "Aggressive and unnecessary according to whose measure?" After all, Thomas places the blame for failure squarely on the shoulders of activist malcontents, and is clear that former patients who have spoken out are quite misguided in their assessment of their own experiences, and ought to leave such narrative descriptions to the appropriate domain. Disability scholar Thomas Couser [18] explains that the difference between the medical and patient assessments is a struggle over who gets to tell the story that will make sense of one's ill self or body, of one's self or body in treatment, and of one's self or body after treatment:

...even when medical treatment may be objectively successful, patients may feel they have been poorly treated. They often express anger at depersonalizing treatment and sometimes advocate alternative modalities. ... just as patients wish to vanquish the illness that alters their lives, they may also wish to regain control of their life narratives which they have yielded up to 'objective' medical authority [18: 10].

Couser's observations speak to the experiences of persons who at least agree with their practitioners that they were sick, and had experienced themselves as *ill* and for whom the struggle to re-personalise the meaning of that experience persists. With intersex, there is an extra layer of struggle as most of us who were treated as children did not experience ourselves as *ill*, and there is little agreement in the intersex population with the medical assessment of our bodies as diseased, rather than merely different. However, in common with those who have experienced illness, intersexed persons inhabit what Couser describes as "colonized bodies" [18: 11], granted little opportunity to speak authoritatively and granted little credence by medical audiences. Thomas' concept of discounting is exemplary of the manner in which our narratives are discredited as overly personal, as a form of public self-pity, and as an inappropriately politicized response to ostensibly apolitical medical management. Thus, we are made by our colonizers not to matter, first as impossible intersexes, and after treatment as the no-longer intersexed.

Instead of addressing questions of epistemic and empirical power to label any intervention as appropriate or not, D.F.M. Thomas' essay directs attention away from concerns about power and toward an image of the clinician as benevolent care-giver. Moreover, the continued focus on the taken-as-obvious right course of using surgery to assign the child both a sex and gender ought to, and yet does not, signal to all concerned that sex and gender both arise as manifestations of cultural, not biological, imperative.

In focusing on an asserted benevolence grounded in the concern of the clinician for the 'best interests' of intersexed children and their families, Thomas denies any negative bias—such as sexism and heteronormative prejudice—in the motivation to treat quickly and aggressively. Summing up the enormous body of medical literature on intersex, Myra Hird

concludes that “[t]here is consistent concern in the medical literature that an unstable gender identity will precipitate homosexual desire,” [19: 1069]. The claim for medical benevolence ‘works’ only if one agrees with Thomas (and the practices he defends) that gender instability is the only possible outcome for a male with an ‘inadequate phallus’, or for a girl with ‘an obviously uncorrected male genital phenotype’ [16: 50]. Indeed, Thomas’ language asserts that a child cannot have a ‘clear’ gender in the absence of a ‘clear’ anatomy that more-or-less meets the ideal for one sex or the other. However, Thomas’ account fails to acknowledge that the anatomical model for sex *is* an ideal, and thus, by definition, something impossible for any individual body to possess or perform.

Disability, Intersex, and the Problem of the Ideal Body

From birth forward, recognition of the personhood of the child requires inclusion of all the narrative components that instantiate recognition, and which begin at the very least with the performative pronouncement of a sex upon which to hang a subject/identity. The pronouncement of a sex, Judith Butler explains, sets into play the recognition of a subject who is also recognizable to itself as such [20: 231–232]. But more than requiring just the pronouncement of sex, the very *concept* of personhood requires an entire and productive discourse around its being in order for its existence to become articulate, and from which the status ‘person’ must articulate.¹ Butler explains:

Where there is an “I” who utters and speaks and thereby produces an effect in discourse, there is first a discourse which precedes and enables that “I” and forms in language the constraining trajectory of its will. Thus there is no “I” who stands *behind* discourse and executes its volitional will *through* discourse. On the contrary the “I” comes into being through being called, named, interpellated... and this discursive constitution takes place prior to the “I”; it is the

transitive invocation of the “I” [21: 225].
(Emphasis in the original)

Butler’s point does not apply uniquely to the manner in which intersexed children are apprehended and managed in the clinical setting, but to the manner that persons *in general* are instantiated as subjects. I draw attention to the point here only to help locate the imperative motivating clinical practice as the extra step required for all those already formed subjects to recognize and treat the intersexed child *as a person*. I reject the clinical characterization of intersex as a form of calamity, but must acknowledge that *something* about the child has interrupted the discursive trajectory that the expectant family and their attendants had been following.

Current clinical practice is instantiated and assumed as an obvious requirement to return the child to the discursive trajectory; moreover, it assumes that through fairly simple surgical practice clinicians will be able effect the bodily type that would otherwise—if left alone in its confounding state—render impossible the conditions of/for the child’s status as a person to be recognized. Critically, in the stance that Butler explains so well, personhood does not emanate from the individual/body, but from those around the individual/body who have the privilege and power to recognize or to deny the personhood of the individual/body they confront.

Tom Koch points out that bioethicists tend to focus on ‘extreme’ cases that raise questions about beginning-of-life and end-of-life concerns, especially where the two are temporally proximal, and tend also to assume that the terms of their focus are already fixed [22: 252]. Carl Elliott’s discussion of the disagreement between parents and clinicians over questions of whether to withdraw or continue treatments to sustain the lives of “severely brain damaged”² children is exemplary of Koch’s point [23]. The disagreement tends to be over what are loosely termed “quality of life” or “best interests” issues, with families often able to see their children as persons in a relational manner that clinicians, who hold to requirements regarding self-awareness and reciprocity, simply do not. For my purposes here, the crucial point is not to settle what it means to be a person, but to question the taken-for-

¹ For a much longer discussion of how concepts of personhood and their implications for care provision and citizenship are structured, see Martha Nussbaum (2006) [38] especially chapters two and three, and Eva Feder Kittay (2005).

² Through out his essay Elliott refers to these children as “brain damaged”, “seriously damaged” and “neurologically damaged”.

granted position that without a clear sex a child cannot become a person.

When an intersexed child is born, the level of concordance between parents and clinicians tends to be far higher than over questions of how to treat a child living what James Overboe, parsing Agamben, refers to as a “bare life” [24]. With intersex the issue is *not* whether to pursue or withhold life-sustaining treatments, as it *is* for those whose lives are discounted in the clinical view as ‘not worth living’. With intersex the problem is not a lack of will to provide treatment, but rather an excessive commitment to invasive treatment. The clinical standards of care for intersex assert that only through treatment to erase their ambiguous traits can the intersexed become fully human with the capacity for development as persons. With intersex the “best interests” and “quality of life” questions articulate at/from the point of acquiring human subjectivity: ‘it’ may obviously have a life, but ‘it’ will not become a person unless, as Iain Morland observes, some narratives can be held in abeyance while others are effected through surgical alteration of the children’s bodies [25]. At the very least, when intersexed children are identified, the unintelligibility of a subject position from which a clear sense of self (a requirement for self-reflection) may develop is presupposed and their potential to develop into persons is assumed to be thus threatened. It may even be that the intersexed infant is thought to lack the criteria for inclusion in species membership as a *human being*, insofar as the development of the intersexed body is thought to be arrested at some ambiguous embryological stage. Intersexed infants clearly have the capacity—if brought out of their embryonic status—to meet the criteria of species membership, and eventually to achieve full status as persons, but that achievement is structured as possible only if surgical technologies and prenatal interventions vault them past their ambiguous embryonic stage into human species membership. My line of reasoning here is indebted to the arguments in Eva Feder Kittay’s 2005 essay, “At the Margins of Moral Personhood”, in which she discusses at length and ultimately rejects the typical psychological and developmental criteria for both species membership as human beings, and for personhood status. Given this set of cultural assumptions there is little reason for clinicians and parents to be in conflict over how to proceed or what to withhold; it is obvious to the adult

stakeholders that to withhold surgical “correction” is to forestall unnecessarily the development of the child’s identity.

It is worth pointing out that parents of non-responsive infants with severe neurological impairments have an easier time attributing the qualities of personhood to their children than do the parents of intersexed children. It may be, as Carl Elliott suggests, that “anencephalics are, after all, living infants who often look very much like ordinary infants” [23: 95]. If the very sick infant *appears* very much like typical infants it is understandable that parents would have difficulty in perceiving the infant as a child who would be better off not to exist. While it disturbs Elliott to witness parents celebrating the birthdays of such children [23: 94], I can only imagine how much worse it would disturb parents of such a child *not to celebrate* his or her birthday. Nonetheless, unable to see in the child what the parents see there, Elliott concludes his article in despair:

We see that the lives of these children may have deep significance for their families. Yet on the other hand, we recognize that these lives fail to meet the criteria by which we count our own lives as meaningful. We try to convince ourselves that we should protect vulnerable lives, but we cannot imagine this as a life we would want to continue living. We say all lives deserve respect, but our measure of the good life does not include a life like this. We say that all lives are equal in the eyes of God, but we wonder why God has allowed such a life to come into being [23: 101].

Elliott is unable to grant that there is a reasonable attachment of the parents to their anencephalic children, and finds no satisfactory answer for how the clinicians ought to decide to proceed. What remains stable in the face of his disquiet is the assumption that it is, in fact, the clinicians’ place to decide how to proceed. Elliott has decided that a “meaningful life is inaccessible to any child with severe neurological impairment” and his consternation, crucially, is over the inability of the parents to take the same view [23: 100]. Unable to do what they think ‘right’, clinicians and ethicists are frustrated by parents who continue to treat their anencephalic children as persons.

As Elliott's remarks cited above show us, clinicians have an easier time following their own sensibilities about the course of treatment because the parents of intersexed children are as unable as medical specialists to perceive the children as viable persons. It seems that where the typical appearance of anencephalic infants makes it easier for their parents to perceive the children as persons—though the parents' perception may have little effect on the treatment decisions of clinicians—the atypical appearance of intersexed children makes it a simpler matter for parents to acquiesce to the clinical view and to accept surgical interference as the obviously right course. In either situation, the clinical view of the atypical child as a defective child prevails.

While the clinical decision to treat or not is very much at odds in the examples Elliott works with (anencephaly and intersex), there is no doubt in his view that in either scenario parents are reasonably acting in concordance with the larger culture when they cede to the expertise of the clinical assessment. While Elliott finds it “hard to blame parents for seeking or consenting to surgery for their intersexed children” and hard to see the reason in parents' demands for continued life-support for their “brain-damaged” children, I disagree [5: 38]. Like Hilde Nelson, I find it difficult to condone wilfully refusing to fulfil our duty to treat with care those children on whom we have conferred the capacity for personhood, and question the medical demand for parents to acquiesce to the view that their children cannot reasonably have a personhood in their anomalous “state of exception” [26].

Sexing the Intersexed

From a clinical perspective, the desire to ‘manage’ (i.e. to treat) the intersexed child's body through surgical and medical means is the volitional discourse that precedes the “I” that the child will become. That is, where in typical births a simple pronouncement of sex is all that is required for the discursive constitution of the subject to be established, when an intersexed infant is born, technical intervention must occur prior to the pronouncement of sex. It is, as we have seen Carl Elliott argue, inconceivable to clinicians that one might legitimately pronounce the child intersexed, or pronounce a culturally imposed sex and then leave the

child's body unaltered. Standard medical and surgical intervention to sex the intersexed has been described metaphorically by Anne Fausto-Sterling as a kind of “shoehorning” in which surgeons alter the child's body to fit the constraints of a binary sex schema [27]. It is actually a little less like shoehorning, and rather more like the version of the Cinderella story in which the step-sisters attempt the removal of their toes and heels in order to fit into the ridiculous slippers that will verify their marriageability.

Indeed, the violent mutilation of heels and toes in the familiar Cinderella story illuminates the second major requirement of clinical intervention: the demand for silence. For just as the reader knows that the *ugly* step-sisters cannot make themselves suitable marriage partners for a prince, so too do the step-sisters know that they cannot really conceal the failure of their bodies to meet the ideal. The problem for the sisters is their *awareness* that they are imposters who know as much as we do that they do not “belong” in the castle. To belong to the order of things, common wisdom says, one must remain ignorant of one's own divergence from the ideal. Cinderella herself is saved/kept ignorant of her own deviation from the ideal and consequent unsuitability for a prince by a narrative conceit that the body mirrors the interior and true quality of the soul; she may be a scullery maid but her beauty reflects an aristocratic soul. Indeed, in some versions of the Cinderella story, when the step-sisters repent for their cruelty, they are transformed into beauties who are married to noblemen in Cinderella and her prince's court. Intersexed children then, must like Cinderella, not be allowed awareness of their unsuitability for entry to the Gender Castle, and like fairy-godmothers who can supply the requirements for entry to the castle, surgeons supply the keys to the magic kingdom in the form of surgically fashioned genitals. David Hester sums up the situation thusly:

Success of the adoption of the gender assignment is premised on the intersexed individual *not knowing they are intersexed*. Truth telling within this protocol is seen as threatening the very success of the protocol, since it would mean informing the parent and the child/young adult that the gender of the child was in question [28: 27].

Kathryn Pauly Morgan explains in her own parable, “Gender Dimorph Utopia”, that surgical

and other medical technologies such as those employed in the management of intersexed infants and children are thought to stave off a form of “gender-disability” that clinicians assume to be the obvious outcome of any nonconformity to the usual, oppositional dimorphism imposed on everything from appearance, gendered preferences and individual behaviour to interpersonal relations and general societal membership:

To maximize individual well-being and societal stability, diagnostic and interventionist technologies should be used—prenatally and postnatally—in order to eradicate genetically and/or hormonally gender-disabled fetuses. All gender ambiguous babies (i.e., babies with ambiguous genitalia) are to be labelled ‘temporarily intersexed’ and surgically corrected as soon after birth as possible so that they may fit into the proper gender location [2: 301].

Regardless of how self-evident the current clinical approach to intersex seems, there are other, perhaps better, ways that we can treat intersexed children. That is, we have not to treat the child in the medical sense, but to revise how we think of ‘treatment’ itself, and not to define it solely as a set of clinically grounded options but as a set of behaviours and attitudes that we can take toward a child, or toward a fetus perceived to have a chromosomal, hormonal, or genetic profile likely to express itself in some form of intersexuality. If we understand treatment as an attitude or as a behaviour/stance that we take toward one another, then we can proceed from there to see that any “need for treatment” arises not in the taken-as-obvious “problem” of intersex characteristics in the child; instead, there is a need for a change in attitude emanating from the parents, the wider family, clinicians, social workers, and so forth. The reason that we need to turn away from the standard clinical treatment, and toward a new attitude of acceptance is that the standard treatments undermine the (formerly) intersexed adult’s sense of authenticity as persons, and as gendered subjects.

We must take as obvious the *personhood* of the intersexed child rather than take as obvious that the personhood of the intersexed child is somehow obscured by the state of the genitals. After all, it is worth remembering that any passer-by who sees the child will apprehend a person, not an ‘it’.

Typical Perspectives

Tom Koch argues that bioethics has become a practice and perspective in which “debate is restricted to operational judgments based upon [unquestioned values]” [22: 252]. Bioethics has thus become a mode of thinking and of clinical practice in which only the same questions arise again and again, no longer really as questions but as the accepted ideology, purview and practice of the field. Koch furthermore maintains that questions taking aim at the assumed value-set are rejected from the outset, and those who would dare to ask the questions to challenge the ideology are ejected from the field (*ibid*). For Koch, the two unquestionable principles setting the groundwork of the unquestioned values are ‘the primacy of the discrete individual [and] a more or less utilitarian perspective as an operative principle of ethical decision making and resulting policy’ [22: 253]. The crucial divide between bioethicists and disability studies scholars lies in the refusal of bioethicists to see lives with disability as lives with value.

Koch challenges and reframes such assessments of disability and quality of life by asserting a language of difference rather than of disability. As a person of difference himself, Koch refuses the term ‘disability’, and instead focuses attention on the manner in which the lives of persons of difference (the term he chooses over ‘persons with disability’ or ‘disabled persons’) are devalued. Neither medicine as an institution, nor modern society at large, is able or willing to recognise the inherent value in a life lived with and through difference. Instead, Koch argues, medicine and the larger social world simply take for granted that lives lived with and through difference are to be avoided. For Koch, this matter of how differences in neurological and/or physical function are perceived is crucial because decisions to withhold medical care for those with bodily and/or cognitive difference are rooted in the general failure of both society and medicine to value positively lives of difference [15: 207; 22: 259].

The failure to value difference is a critical target of many rights-oriented movements aimed at the elimination of the social prejudices that prevent specific groups from accessing and exercising full rights as human subjects. The civil rights movement, the various women’s movements, and the contemporary gay, lesbian, bisexual, and transgender/transsexual (GLBT) rights movement all appeal to the broader

social world to extend full inclusion in the social contract to persons who have been marginalised on the basis of race, sex, gender and sexuality, (or a combination of these). As a part of the general civil rights tradition, disability rights advocacy also uses argument, education, and demonstration to demand recognition as full human subjects.

Queer theory, the GLBT movement, and critical disability activism/scholarship have an overlapping interest in “resisting the marginalizing force of the private [and] insist, of course, that gender, sexuality and sex are issues of public concern” explain McRuer and Wilkerson [29: 10]. The point is that once identified as a person with a disability, or an inappropriate (i.e. queer) sexuality we lose the personal privacy that others take for granted, while other aspects of our lives can be commanded to be private in oppressive ways, becoming simultaneously a matter of very public discourse and highly secretive management to facilitate our entry into the ‘normal’ world [29: 8].

Successful entry into the ‘normal world’ generally requires as a condition of entry that we assimilate with it. The terrible consequence of contradictory imperatives to be at once on display as the *demonstrative* case for interested clinicians and medical students and to have to remain ignorant, or, at the very least, *silent* about our embodied difference is that both heteronormative and ableist perceptions of sexuality and embodied difference go unquestioned in the public domain that insists on our silence but cannot itself refrain from speaking about the problem we present to the usual narrative course of human being.

Thus, our entry may raise questions regarding which aspects of our differences we must sacrifice in order to access the rights and privileges of membership in the larger, hegemonic group. For example, claims for retaining the positive value of difference frequently face charges of essentialism. Leaving aside Koch’s antipathy for feminist reproductive rights-claims and what he perceives to be a feminist complicity with a modern eugenic control of reproduction, I wish to take up McRuer and Wilkerson’s appeal for us to ‘desire disability’ and recognize “... that another world can exist in which an incredible variety of bodies and minds are valued and identities are shaped, where crips and queers have effectively (because repeatedly) displaced the able-bodied/dis-

abled binary” [29: 14]. Here, then, I return the focus of the paper to the particular manner in which the value of difference plays out for intersexuals, whose form of “difference” is located in or on bodily terrain hidden from view by virtue of being located in areas deemed “private”, and generally rendered apparent only through invasive inspection. I will return to the question of how women decide to terminate pregnancies or to avail themselves of invasive prenatal therapies in my concluding section, “Prenatal selection, diagnosis and valuing difference”.

Arguments regarding the clinical treatment of intersex turn on its head the value of difference/refusal of care position that Koch advocates and that Overboe demands. The intersex rights movement has said not ‘If you respect difference in life as you should then you will ensure my continued clinical care,’ but rather, ‘If you value difference in life as you should then you must refuse clinical intervention as it is done for your sake and your interests, not mine.’

Thus, intersex activists use arguments grounded in a Difference Perspective, but it is simultaneously to normative ideologies of individual autonomy often rejected by disability scholars that intersex activists often appeal. My own work argues, for example, that we should take more seriously the manner in which surgery on intersexed infants and children interferes with their development as potentially autonomous subjects, and that we ought to take a more ‘hands off’ approach to allow intersexed children time to determine for themselves if and how they wish to ‘deal with’ their differences at some deferred date [30]. By and large, the contemporary intersex movement asks that guardians not bind their wishes for their children to be either male or female so closely to the bodies of their intersexed children as to impose clinical interventions that the child cannot be included in determining, and to recognise that if they are to have reciprocal relationships with their children as adults at a later date then *nothing*, rather than *something*, must be done now.

The argument is not purely a relational one about the value of difference, for it retains aspects of the individualist ideology that Koch describes as objectifying [15]. However, in the combination of both the difference perspective and the individual autonomy perspective a third mode of (e)valuation arises. Bioethicists and Disability scholars alike may then be curious to know how we ought to apply this third way

to the issue of prenatal selection—a classic beginning-of-life issue with which both groups are concerned. Before I introduce the terms through which I think a third approach could be built, it is necessary to examine the prenatal diagnostic tools being developed for intersex, and their relation to selective abortion.

Intersex, Prenatal Selection, Diagnosis and Valuing Difference

The final move of the paper is to discuss the manner in which prenatal technologies, through the use of particular narratives (disease, intervention, cure, inevitable death, future predictions of sex, of quality of life, etc) confer or deny species membership and personhood on a child not-yet born to its expectant parents. The idea of the *expectant* warrants some further scrutiny, for it is specifically against the expected that Tanya Titchkosky explains the *unexpected* becomes problematic [31: 96–128]. If the last half-century has seen the narrativisation of personhood, sex and subjectivity in the post-natal period of an intersexed child's life, prenatal interventions into pregnancies push back the timeframe in which the expected becomes the unexpected, the problematic, the not-quite-human.

Prenatal selection and diagnostic technologies and their eugenic potential are increasingly a concern for the intersexed. At least two forms of intersex— androgen insensitivity syndrome (AIS) and congenital adrenal hyperplasia (CAH)—are detectable in a developing fetus and some clinicians propose that we ought to use prenatal diagnostic tools to prevent intersex births from occurring [32–34] As we shall see, the extremely negative attitudes of genetic counsellors to hypothetical cases of intersex indicate that they strongly concur with the American Academy of Pediatrics (AAP), New, and Donohoe's recommendations.

In the majority of cases, there are no health considerations associated with intersexuality. In some cases, there are minor health or quality of life considerations; in a small percentage of cases, (in CAH and Turner syndrome, especially) there can be serious considerations regarding metabolism (in CAH) and organ formation (in Turner syndrome).

Current *in utero* treatments can alter the outward manifestations of CAH, but cannot alter the underlying metabolic complications. *In utero* treatment, then,

is effective only for pushing back the point at which parents make decisions about the appearance of their children. Prenatal identification of CAH could be useful for developing ways of treating the metabolic concerns in severe salt-wasting form, but that is not the clinical priority. As the AAP states in its technical report on CAH, “The objective of prenatal diagnosis and treatment of 21-OH deficiency is the prevention of prenatal virilisation in affected female infants...” [32: 1511]. The AAP lists the ability to predict severe salt-wasting only as a secondary concern. Yet, the priority should not be to put mothers on dexamethasone to make sure that female infants will not have enlarged clitorises and fused labia, but to be developing cures for potentially fatal salt-wasting in those infants who will manifest that feature of CAH.

It is possible to identify Turner, Klinefelter and Androgen Insensitivity Syndrome through prenatal testing, but no current there are no therapies available to reverse them. However, health considerations for these syndromes are far from clear and often overstated: many people with these conditions suffer no associated illnesses. The identification of any of these syndromes fails to provide a compelling reason for terminating a pregnancy.

Dorothy Wertz's research shows that 49% of genetic professionals, and 48% of primary care physicians would favour selective abortion of fetuses with Klinefelter Syndrome. Meanwhile, 42% of genetics professionals and 37% of primary care physicians, favour selective abortion of fetuses with Turner Syndrome [35]. To give a sense of how these outcomes compare with the only even remotely close circumstance on the chart of potential identifications, I should point out that only 3% of genetics professionals and 3% of primary care physicians would favour selective abortion of a fetus who was not the sex desired by the parents [Ibid].

In addition, Wertz shows that the number of genetic professionals and primary care physicians who would terminate for Klinefelter or Turner syndrome are significantly higher than the numbers for schizophrenia, alcoholism or Alzheimer's. In a separate test for other measures and with other health care providers, only about 12% would focus on the positive aspects for Klinefelter syndrome and only about 16% would do so with Turner syndrome. Furthermore, the number of genetics professionals

and physicians who would emphasize the positive are only slightly higher than the numbers for Alzheimer's and schizophrenia [36: 279].

The essays in *Prenatal Testing and Disability Rights* show that extremely negative attitudes of genetic counsellors, primary physicians and families prevail in attitudes toward pregnancies and fetuses in which conditions such as AIS, CAH, Klinefelter or Turner Syndrome are identified [36]. In her essay on the importance of attitudes taken by clinical experts, Adrienne Asch argues that a central problem with prenatal testing for congenital anomalies is that it "... is a clear case of first impression, and as with any such impression, it is [incomplete]; when followed by selective abortion or by discarding an otherwise implantable embryo, that first impression includes a decision never to learn about the rest of who that embryo or fetus could become after its birth," [37: 235]. Asch's point applies also to in utero treatments meant to reverse the cosmetic effect of CAH, or to alter genetically the protein behaviours of a fetus with AIS. Yet the 'experts' focus on first appearances is obvious in their very negative attitudes toward intersex. The push of genetics counsellors, and physicians for selective termination of fetuses identified with Turner or Klinefelter syndrome, and of clinicians to use prenatal technologies to alter the appearance of fetuses with CAH, and the hope for genetic manipulation to reverse AIS all suggest that the most important feature of any of these potential children is cosmetic.

My concern here is not to institute laws to impair women's reproductive choice, even in instances in which some form of difference or disability has been identified prenatally. Nor, however, should my position be taken as an exoneration of the medical conflation—as shown in Wertz's study—of difference with disease. As is well-noted in the scholarship on disability, any number of genetic conditions may lead to difference that is not defined by impairment and suffering, and yet clinicians can easily conflate disease and difference, suffering and impairment, and in so-doing steer expectant parents toward termination [38–40]. Moreover, even when clinicians make concerted efforts to provide neutral information, it appears that in many cases the very fact that medicine is able to indicate just the *possibility* of genetic anomalies provokes serious anxiety in expectant parents [41]. As Sharpe and Earle argue, the

problem is not rooted in women's right to abortion and, therefore, the solution to the problem is not to curtail that right, as doing so undermines both the status of the right as such, and the status of women as persons under the law [42]. Rather, the problem begins with clinical attitudes and with social demands and limitations that place exceptional demands specifically on mothers. As Lindemann argues:

It's mothers, not the rest of us, who have to get up in the middle of the night when the baby cries or the ten-year-old has a bad dream; they who have to toilet train and in other ways socialize their children; they who have to spend many thousands of dollars on clothing, feeding, and educating them; they who have to keep them from getting hurt, from running with the wrong crowd in school, from lasting damage or death due to treatable illness and injury. And it's they who, if their child is disabled, have to give care over and above the care all mothers are already duty bound to give their young. ...The trouble with being a mother is that it puts you in a special relationship you can't, morally speaking, exit: here, exiting is called abandonment [43].

In this paper, I have discussed the material reasons for my insistence on the right of women to terminate pregnancies, even in cases where I might prefer they decide otherwise. I have also argued that claims such as those Elliott makes, according to which medical care providers have no special obligation to diverge from the values of our society in general when it comes to the perception of lives of difference, form an unconvincing apologia for the support of hegemonic, often oppressive attitudes and behaviours when those who wield bio-power could instead urge us all to do better, to resist oppressive attitudes, and use technology to prepare for greater accommodations.

Approaches to concerns over prenatal technologies and disability rights that suggest the debate revolves exclusively around the question of abortion inevitably pit women's rights claims against disability rights claims. Such approaches assume that women who terminate pregnancies for reasons of disability or difference act in bad faith and "[challenge] the legitimacy of individual choices on the grounds that they emanate from wider beliefs and values. ...On this argument, a case could be made for denying virtually any individual the right to exercise virtually

any preference” [43: 143–144]. In addition, such stances imply that there could never be disabled women who might use prenatal and other reproductive technologies, or at least that no self-respecting women with disabilities would do so.

I propose that we ought not extrapolate from the specifics of intersex to the more general questions of what it means to be human, how to value human life, and what it means to be a person, but ought instead to pursue the specifics of difference and autonomy on a case-by-case basis, being attentive to the positive value of lives lived with difference, and to the need of persons to exercise their own level of qualified autonomy within the networks of social support that enable the qualified autonomy of all persons. I imagine the third mode as one in which we recognize that how we use reproductive technologies is not simply a question of whether we choose to continue a pregnancy or not. In my imagined third mode, neither an apologist stance from bioethicists favouring soft eugenic practices, nor a disability activist stance, which would deny women their own autonomy, would have priority. Rather than assume that women are merely vehicles through which to enact other social objectives, this third mode will be attentive to the value of difference, open to the encouragement of movement away from a quality assurance attitude toward reproduction. A third mode approach and will recognize that women are autonomous persons with the right to exercise that autonomy to protect their own bodies, reproductive labour and mothering. A third mode will also seek to protect the rights of children born with atypical physical, sensory and/or cognitive traits, aiding them to develop the greatest level of autonomy possible at maturity. Autonomy may always be provisional, but to deny some their bodily integrity—as with intersexed children—on the grounds that autonomy is only provisional at best is to continue to divide the world into groups of people who are more and less deserving, with some more able to exercise their provisional autonomy than others. In practice this means adopting a policy of non-interference for any atypical features more troubling to parents than to infants, and while the appearance-based features of intersex are my primary concern here, there are clearly other types of corporeal anomaly to which such a stance could apply. Cochlear implantation for Deaf infants is one example; surgery for various cranio-facial anomalies,

such as cleft-lip, is another. My proposal also requires that we move away from assertions that typically make women out to be adversaries who will always choose to terminate any fetus in which an anomaly is diagnosed. As Chloë Atkins has argued in a paper that discusses with nuance and depth how women think about their pregnancies in relation to medical discourses they encounter, women are increasingly refusing prenatal diagnostics, and increasingly refusing the pathologisation of bodily, sensory and cognitive difference in their fetuses [40: 107].

If we are to develop this third mode, and to encourage more of the kinds of resistance Atkins describes, we need to demand that bioethics discourses not aim to make us complacent about medical knowledge/power. We need to curtail eugenic tendencies in prenatal technologies so that we may value human variability more rather than less. We need to listen seriously to the narratives of adult intersexed persons when they discuss the ways in which medicine, however well intentioned its traditional approach, has failed to meet their needs because it has treated the child as a problem to be fixed, instead of treating the child as an eventual adult who will decide for itself whether its body is problematic. And, even while we demand that medicine rethink its pathologisation of intersex and other forms of difference, we need to be careful not to build a disability stance that vilifies all women whose exercise of their reproductive agency leads to termination. This last stance is important because logically, we cannot grant agency to exercise a right of autonomy if we insist that only one outcome is correct. Ultimately, the rights we recognize for one person inform the terrain on which we recognize rights for others. Because I insist that we must protect the development of autonomy in intersexed children, I also recognize their right to choose surgeries to alter appearance later in life. Were I to insist, as Koch, Asch [44] and Atkins do, that women’s decisions to terminate their pregnancies were based on the devaluation of disabled lives, then I would have to argue that a woman’s right to choose ought to be limited only to “choose life” in cases where some anomaly is discovered in prenatal testing. Such a position sets up an exception in the law that would imperil women’s ability to choose in other cases, and, by extension, would set up the conditions through which to deny the right of other vulnerable groups,

including the intersexed and persons with disabilities to decide for themselves how to appear in the world, how to live, and whether and how to have their own children.

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