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# DISTRACTED ATTENTIONS: INTERSEXUALITY AND HUMAN RIGHTS PROTECTIONS

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The recent release of the report by the San Francisco Human Rights Commission (SFHRC Report) marks only the second identifiable official document that recognizes and questions medical interference with intersexed persons as a *human rights* issue.<sup>1</sup> The first was a Colombia Constitutional Court decision,<sup>2</sup> in which the international U.N. treaty, Convention on the Rights of the Child,<sup>3</sup> served as a model for consideration of matters concerning surgical interference with the developing autonomy of minors.

However, the Columbia court also posed a question that interfered with the integrity of the consideration of the rights of intersexed persons—how to balance the rights of families against the rights of children.<sup>4</sup> This question ultimately

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\* Morgan Holmes has been involved personally and professionally in research and rights lobbying in intersex since 1993. Morgan wishes to thank Betsy Driver of *Bodies Like Ours* and Julie Zando-Dennis from the *Cardozo Women's Law Journal* for their efforts in making the Intersex Symposium happen. Thank you also to anonymous readers and editors at *CWLJ* for patience and support; it is much appreciated.

I wrote the concluding paragraphs a few hours following my first complete physical exam in over three years. Although all women are supposed to have a pelvic exam every year, I cannot muster the courage to go that often. My primary care provider has no time to listen to the reasons why I cry when she begins the exam. She brushes me off when I try to explain that it feels like being raped. But with a blood-pressure measurement of 160/100 it is clear to me that every pelvic exam repeats for me the experiences of my childhood. My primary care provider thinks I find the exams distasteful in the same way that “all women hate them,” but I don’t. My situation is very different. I suspect, though I have not investigated the issue, that many adults treated as children for an intersex condition do not see our physicians as often as we should to ensure good preventive health care. That is a serious risk for morbidity and mortality rates in the intersex population; clinicians should consider this when assessing the greater good of their practices.

<sup>1</sup> MARCUS DE MARÍA ARANA, SAN FRANCISCO HUMAN RIGHTS COMMISSION, A HUMAN RIGHTS INVESTIGATION INTO THE MEDICAL “NORMALIZATION” OF INTERSEX PEOPLE: A REPORT OF A PUBLIC HEARING BY THE HUMAN RIGHTS COMMISSION OF THE CITY & COUNTY OF SAN FRANCISCO (2005), available at [http://www.sfgov.org/site/uploadedfiles/sfhumanrights/Committee\\_Meetings/Lesbian\\_Gay\\_Bisexual\\_Transgender/SFHRC%20Intersex%20Report\(1\).pdf](http://www.sfgov.org/site/uploadedfiles/sfhumanrights/Committee_Meetings/Lesbian_Gay_Bisexual_Transgender/SFHRC%20Intersex%20Report(1).pdf) [hereinafter SFHRC REPORT].

<sup>2</sup> Principio de Publicidad del Proceso – Armonización con la intimidad del menor y su familia / Sentencia de Revisión de Tutela – Publicidad parcial para el caso, Sentencia Su-337/99, Cons. Ct. (Colombia) T-131547 (1999), available at <http://www.isna.org/node/166>.

<sup>3</sup> Convention on the Rights of the Child, G.A. Res. 44/25, U.N. OHCHR (Nov. 20, 1989), available at <http://www.ohchr.org/english/law/crc.htm>.

<sup>4</sup> See Morgan Holmes, *The Doctor Will Fix Everything: Intersexuality in Contemporary Culture* (2000) (unpublished Ph.D. dissertation, Concordia University) (on file with author and available in Canada holdings library and archives). Holmes demonstrated that framing the issue as one of family integrity protections is wrong-headed and leads to severe impairment of the scope of the decision to protect the developing autonomy of actual intersex persons. *Id.*

limited the ability of the decision to properly and fully explore the ethical problems that arise when medical standards dominate sensibilities by presupposing about the place of anatomy in the development of a self concept.<sup>5</sup> As Alice Dreger and Cheryl Chase observed in the SFHRC Report, there is a need to reconsider the notion that intersex is “a matter of charity” beyond questions of justice and as such, a purely medical problem that is best solved through surgical intervention.<sup>6</sup>

With only two major documents addressing the treatment of intersex as an issue of human rights rather than one of medical necessity, this article considers reasons for the lack of focus on intersex as, principally and fundamentally, a human rights concern. Furthermore, the discussion advances that intersex should not only be understood broadly as a human rights issue, but more specifically, as a *children’s rights* issue.

The SFHRC Report found that the dialogue about the protection of rights for intersexed persons has been sidelined, even rendered as a “non-issue” by medical claims of beneficence.<sup>7</sup> The beneficence argument rests mainly on the claim that intersex in infants constitutes an emergency situation that may only be properly rectified through immediate surgical and medical attention. Even frequent criticism of such treatment standards over the last decade has failed to silence such claims; recent articles in medical journals have continued to cast intersex in terms that repeat the notion that an intersexed newborn is very nearly the worst thing that parents can expect to endure in the birth of a child.<sup>8</sup>

E. Eroglu et al. wrote, for example, that “[w]hen a child is born with ambiguous genitalia it can be *catastrophic* for the parents, and management requires the expertise of a team of specialists,”<sup>9</sup> while Y. Low et al. declared that “[n]ext to perinatal death, genital ambiguity is likely the most devastating condition to face any parent of a newborn.”<sup>10</sup> Echoing similar overwhelming concern for the *family* of intersexed persons instead of the intersexed persons themselves, Rink and Adams stated that the intersex diagnosis for newborns is “[o]ne of the most devastating problems that can befall new parents” and thus justifies an expedient move to surgical management of intersex. Rink and Adams further argued that intersex “is truly an emergency necessitating a team approach . . . that should work quickly to identify the genetic sex and biochemical makeup of the child.”<sup>11</sup>

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<sup>5</sup> *Id.*

<sup>6</sup> Alice Dreger & Cheryl Chase, *A Brief History of Intersex for the San Francisco Human Rights Commission Report*, in SFHRC REPORT, *supra* note 1, at 10.

<sup>7</sup> SFHRC REPORT, *supra* note 1.

<sup>8</sup> See E. Eroglu et al., *Feminizing Surgical Management of Intersex Patients*, 20(7) PEDIATRIC SURGERY INT’L 543-47 (July 2004); Y. Low et al., *Rules for Clinical Diagnosis in Babies with Ambiguous Genitalia*, 39(6) J. PEDIATRICS & CHILD HEALTH 406-13 (2003).

<sup>9</sup> Eroglu et al., *supra* note 7, at 543.

<sup>10</sup> Low et al., *supra* note 7, at 406.

<sup>11</sup> Richard Rink & Mark Adams, *Feminizing Genitoplasty: State of the Art*, 16 (3) WORLD J. OF UROLOGY 212.

Clearly, the florid discourse of the earlier generation of clinicians regarding the trauma and emergency of intersexed infants continues to thrive.<sup>12</sup>

One must wonder why the “emergency” rationale remains so persuasive and so accepted in the current medical community as the central model for the proper standards of care of the intersex. The tenacity of the theory is especially surprising against the backdrop in which various intersex support and advocacy groups have successfully challenged the view of bodies and conditions as emergencies worse than death. There must be a reason for such extreme and fundamental conflicts in views.

In *Schloendorff v. Society of New York Hospital*, Justice Cardozo determined that the existence of an emergency negated the requirement of informed consent.<sup>13</sup> It is this determination that may underlie the centrality and persistence of the clinical characterization of intersex as an *emergency*. The process of medicalization is the conventional means by which medical specialists establish and maintain their dominance as conveyors of the meaning of bodily characteristics. Not all medical conditions are considered “emergencies,” however. More than a mere common feature of intersex treatment paradigms, “emergency” plays a central conceptual and discursive role in the ability of practitioners to maintain their ability to be *the* arbiters of sexed subjectivity.

Kishka-Kamari Ford observed in her Note:

Justice Cardozo, writing for the majority, reasoned that the requirement of informed consent is necessary “except in cases of emergency where the patient is unconscious, and where it is necessary to operate before consent can be obtained.” Since *Schloendorff*, courts in all jurisdictions have repeatedly returned to Justice Cardozo’s famous words and refused to find a person who responds to a medical emergency in violation of the law.<sup>14</sup>

It is the foremost duty of clinicians to protect the best interests of patients in their care. Cardozo’s statement in *Schloendorff* determined whether the hospital in the case was liable for violating its primary duty to protect the best interests of a patient. Cardozo presumably included the peripheral statement to address his concern of allowing surgeons to perform their duty in cases where patients could not speak for him or herself. The New York Court of Appeals held that the hospital was not liable even though the surgeons had indeed performed an unnecessary operation—an interference to which the patient had never given consent.<sup>15</sup> In fact, the patient may very well have refused the operation.

Cardozo’s emergency intervention rule is similar to Canada’s “Good Samaritan” rule, which states that even if an injury is sustained through the course

<sup>12</sup> See Holmes, *supra* note 3 (tracing early discourse of “emergency”).

<sup>13</sup> *Schloendorff v. Soc’y of N.Y. Hosp.*, 105 N.E. 92 (N.Y. 1914) (overruled on other grounds).

<sup>14</sup> Kishka-Kamari Ford, Note, “*First, Do No Harm*”—*The Fiction of Legal Parental Consent to Genital-Normalizing Surgery on Intersexed Infants*, 19 YALE L. & POL’Y REV. 469, 475 (2001).

<sup>15</sup> *Schloendorff*, 105 N.E. at 92.

of an emergency intervention, the intervener cannot be prosecuted for assault.<sup>16</sup> Yet, these interventionist rules that tout protection of life as its obvious objectives often produce negative outcomes that people may survive to regret. Decisions such as *Schloendorff* and tenets such as the “Good Samaritan” rule demand people to accept outcomes that they would not have chosen for themselves had they the opportunities to make such decisions. However, Cardozo likely did not anticipate that clinicians nearly a century later would distort the intent of his statement to protect their own interests rather than their ability to serve the best interests of their patients. There is a universe of difference between intervening to save the life or to protect the interests of someone who has *lost consciousness* and intervening to prevent the *development* of a particular form of conscious self-awareness.<sup>17</sup>

In fact, there are larger aspects of Cardozo’s ruling, specifically regarding the lack of any apparent pressing need for surgery, which may be called upon to advance an argument for the need to protect the capacity of a patient to decide for him or herself the course of action to be taken *at a future date*. Yet, the development and maintenance of standards in a profession generally oriented toward eliminating biological and anatomical anomalies has chosen to emphasize Cardozo’s peripheral comment and to marginalize the patient’s autonomy.

The combined discourse of emergency and the establishment of accepted standards of care in fact marginalize patients’ autonomy. In their best manifestations, standards of care direct the actions of all clinical practitioners to maximize the potential for the protection of the presumed interest of patients in surviving any form of trauma or organic disease. Standards of care are very useful in demonstrating that practitioners have followed the best course, even if they did not achieve the best possible outcome for the patient. In other words, clinicians cannot guarantee a favorable outcome, and standards of care during emergency situations allow clinicians to act without endlessly second-guessing what the patients would want under the circumstances. *Schoendorff* helps to protect the ability of practitioners to “practice responsible and progressive medicine without fear of frequent litigation.”<sup>18</sup> The idea is that the best interests of *most* patients can be served by protecting medical practitioners’ freedom to make decisions, even if in some cases, it is not what a patient would have decided for him or herself.

The idea of the inherent emergency status of intersex was able to develop through such logic. Surgeons must be aware that their ability to predict outcomes in intersex cases are rough estimates at best, given that surgery for the treatment of intersex is still quite novel, subject to constant revision within the related surgical fields, and publicly contested for over a decade now. Indeed, publications in surgical specializations dealing with intersex regularly note the inability to

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<sup>16</sup> See Good Samaritan Act, 2001, c. 2 (2)(2), available at [http://www.e-laws.gov.on.ca/DBLaws/statutes/English/01g02\\_e.htm](http://www.e-laws.gov.on.ca/DBLaws/statutes/English/01g02_e.htm).

<sup>17</sup> See *supra* note 2 for a more detailed discussion of the particular manner in which this distinction plays out in the Colombia decision.

<sup>18</sup> Ford, *supra* note 14, at 475.

determine outcomes or current practice standards used to treat a mature person. Initiating intersex as an emergency sets up a paradigmatic relationship that aligns diagnostic practice with existing principles for standards of care.

In the case of intersex diagnosis and management, the paradigm allows surgeons to follow procedures that continue to be experimental, even though as expected, they do not directly acknowledge the experimental quality of the interventions. The experimental character of the procedures becomes evident only as published reports describe the ongoing pursuit for better results with the latest “state of the art” approach.<sup>19</sup> Furthermore, labeling intersex cases as “emergencies” disguises the issue of experimentation. Such obfuscation is crucial to sustaining the interests and ability of practitioners to follow standard procedures and to maintain their “expert status.”

Bold acknowledgement of the experimental character of the procedures would contravene informed consent law. Procedures widely known to deliver imperfect results that may impair function cannot possibly serve the best interests of the child, particularly where intersex anatomy is altered for the sake of a more “normal” appearance to *external observers*. As Ford notes, citing Wilson and Reiner’s contention that parents cannot cope with such mundane tasks as changing the diaper of an intersexed baby:

[I]t is the parents and doctors of intersexed infants who are experiencing a medical emergency, not the intersexed infant. Intersexed genitalia make almost everyone—doctors, parents, and society as a whole—uncomfortable . . . Doctors act quickly not because the infant is in any medical danger, but ‘to spare parents the trauma of seeing their child as intersexed each time they change the infant’s diaper.’<sup>20</sup>

Ford finds three compelling reasons to argue “the required elements of legal informed consent are likely to have not been met.”<sup>21</sup> First, there is no emergency to the child; second, the experimental procedures have no demonstrable benefit to the child; and third, consent on behalf of the child, or consent-by-proxy, undermines the very autonomy the informed consent is supposed to protect.<sup>22</sup>

The clear conclusion here, as Ford bluntly advises, is that practitioners who operate on intersexed children are legally vulnerable to subsequent cases when former patients can speak for themselves. Hence, the focus on *emergency* rather than *experimentation*, and the willful neglect to openly discuss potential negative

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<sup>19</sup> For a sense of the ongoing discourse of simultaneous experimentation and perfection see S.J. Kogan et al., *Subtincal Total Reduction Clitoroplasty: A Safe Method of Existing Techniques*, 130(4) J. UROLOGY 746-48 (Oct. 1983); S. Krege et al., *Long-Term Follow-up of Female Patients with Congenital Adrenal Hyperplasia from 21-Hydroxylase Deficiency, with Special Emphasis on the Results of Vaginoplasty*, 86(3) BRIT. J. UROLOGY INT’L 253-59 (Aug. 2000); T.E. Lobe et al., *The Complications of Surgery for Intersex: Changing Patterns over Two Decades*, 22(7) J. PEDIATRIC SURGERY 651-52 (July 1987); C.A. Sheldon et al., *Vaginal Reconstruction: Critical Technical Principles*, 152(1) J. UROLOGY 190-95 (1994).

<sup>20</sup> Ford, *supra* note 14, at 477.

<sup>21</sup> *Id.* at 488.

<sup>22</sup> *Id.*

outcomes, allows surgeons and practitioners to evade accountability for complications that may arise from intervention. Ford's conclusion may serve as an effective warning against behaviors and orientations toward the implementation of standards of care but he leaves unaddressed a separate concern that is not antithetical to his concern—the human rights of children. Similarly, the SFHRC Report has no effective judicial power although it strengthens the level of argument and bears witness to the negative outcomes of standard treatment of intersexed persons. Furthermore, the Colombian Constitutional Court's decision fell short of delivering on its declaration to protect the right of children's developing autonomy.

There should be a return to serious consideration of laws that permit minors to make their own decisions and that restrict parents and clinicians to impair the future capacity of children to make autonomous decisions. Mounting reams of evidence show that surgical intervention results in a significant risk for physical injury and/or mental trauma. Current standards of care do not treat emergencies, but rather, interfere with the potential for children to make their own decisions regarding treatment at a later date.

Prior to making his observation in *Schloendorff* regarding the emergency exception, Cardozo observed that “[e]very human being of adult years and sound mind has the right to determine what shall be done with his own body; and a surgeon who performs an operation without his patient's consent commits an assault, for which he is liable in damages.”<sup>23</sup> Based on the testimony of the appellant, Cardozo found that the surgeons, but not the hospital, committed an assault on Mrs. Schloendorff. Taking into consideration the arguments of *Schloendorff*, the testimony in the SFHRC Report, and the findings of the Colombian Constitutional Court in favor of the need to protect the developing autonomy, it is difficult to continue to hold in good conscience that the minor status of intersexed patients sufficiently justifies sacrificing their bodily integrity to appease their families and surgeons. It is the duty of all guardians to act in the best interests of the child—to protect the child's future interests instead of the immediate interests of those who cannot see beyond their own prejudices and expectations.

For most people, the line between coercion and autonomous exercise is not at all clear. Decisions relating to the body are generally made in a larger cultural context. Women are, for example, increasingly turning to highly invasive surgical procedures to render a more “standard” appearance, e.g., removing “excessively large” labia, increasing or decreasing breast size, or altering general appearance to rid bodies of unique features of age and ethnicity. Debates rage in feminist circles about these practices<sup>24</sup> and the circumstances that precipitate such extreme dissatisfaction with one's appearance. While one may bemoan the capitulation to

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<sup>23</sup> *Schloendorff*, 105 N.E. at 93.

<sup>24</sup> For basic terms of the debate see KATHY DAVIS, *RESHAPING THE FEMALE BODY* (Routledge 1995), and Kathryn Pauly Morgan, *Women and the Knife: Cosmetic Surgery and the Colonization of Women's Bodies*, 6(3) *HYPATIA* 25 (Sept. 22, 1991).

negative bodily evaluations in submitting oneself to such surgical invasions, a central tenet in a liberal democracy, whatever its ideological and practical limits, includes the right to decide to do things others may not choose to do. Similarly, an adult with an intersex condition might choose to have their appearance surgically altered, and they may or may not be satisfied with the results. Being free to make those choices and to live with one's satisfaction or regret would place intersexed persons on par with everyone else.

Specifically, it is worth considering the difference between mourning a loss and regretting a decision. It is the former feeling that arises most frequently in the testimony of intersexed persons who have stepped forward to address their experiences with medical care. Mourning a loss speaks not only to the loss of a body part and of potential, but also to the loss of autonomy that can never be returned. One is stuck in the experiences of loss, shame, and isolation in the case of mourning. Regretting a decision, on the other hand, is a common phenomenon that everyone experiences at some point. One lives with regrets, and the exercise of autonomy mitigates feelings of isolation and shame.

It is incumbent upon all who have the capacity to do so to sustain the dialogue and to make arguments—be they legal, ethical, academic or activist arguments—so that all people, regardless of appearance, anatomy or biochemical make-up, may make their own decisions and live with the results, whether positive or negative. Maintaining the status quo means accepting the imposition of mourning and loss simply because some clinicians continue to insist, without providing evidence, that *some* intersexed patients are happy with their surgical outcomes.<sup>25</sup> *If* such happy people in fact exist, it stands to reason that they would be no less happy for having the choice to make such a decision. It is unconscionable to sacrifice the bodily and subjective integrity of some in order to secure the contentment of others.

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<sup>25</sup> See the appendices of the SFHRC REPORT for correspondence from Dr. Baskin on this point. Baskin never delivered to the SFHRC any documentation or other form of communication to verify his claim that the majority of silent patients are happy.

