

# Intersex Rights and Reproductive Justice

## What is Intersex?

The term intersex refers to people born with sexual or reproductive anatomy that does not fit within our typical definitions of male or female, encompassing a variety of conditions.<sup>1</sup>

- Variations of intersex include: people with external reproductive organs of one sex and internal reproductive organs of the other sex, people with genitals that are not clearly male or female, or people with an atypical chromosomal pattern.<sup>2</sup>
- Approximately 1 in every 1,500-2,000 live births is intersex.<sup>3</sup>
- Approximately 1 in every 100 live births, bodies differ from standard male or female genitalia.<sup>4</sup>

## Medical Response to Intersex Infants

In the past, infants who were born visibly intersex were “treated” with genital surgery to “normalize their genitalia.”<sup>5</sup> Most doctors would follow what is known as the concealment method whereby they would assign a gender at birth and conceal the intersex condition from everyone, including the patient.<sup>6</sup> Currently doctors are changing the way they approach intersex infants.<sup>7</sup>

- **New Approaches:** Over time, an increasing number of adult patients who had undergone genital surgery expressed negative outcomes they experienced as a result, including difficulties with sexual function, incorrect gender assignments, and psychological struggles with depression and shame.<sup>8</sup> As some patient activists launched criticisms of the concealment method, the medical community began to reevaluate their procedures.<sup>9</sup> Concerned about the long-term physical and emotional effects of surgery, some doctors decided not to use surgery until the patient is old enough to be part of the decision-making process.<sup>10</sup> Other doctors continue to advocate employing the same standard of care, believing that growing up with atypical genitals will be emotionally harmful for a child.<sup>11</sup> Some doctors seek a middle approach, remaining conservative with the surgical recommendations they make.<sup>12</sup>
- **Decision-making:** In the past, the decision about whether to perform genital surgery was sometimes made solely by the infant’s doctor without even consulting the parents.<sup>13</sup> Now the decision is generally made by the parents in consultation with the doctor.<sup>14</sup> However, the amount and quality of information provided by the doctor can vary greatly in practice.<sup>15</sup>
- **Optimal Clinical Management:** The American Academy of Pediatrics has developed guidelines for managing intersex children<sup>16</sup>:
  - Gender assignment should be avoided prior to an expert evaluation for newborns.
  - Evaluation and long-term management should be performed at a facility with an experienced and qualified multidisciplinary team.
  - All individuals should receive a gender assignment.
  - Open communication with patients and families and participation in decision-making is essential and encouraged.
  - Patient and family concerns should be respected and addressed in strict confidence.
- **Clitoroplasty Controversy:** The clitoroplasty practices of Cornell pediatric urologist Dr. Dix Poppas have recently increased awareness of clitoroplasty, the surgical shortening of the clitoris in young girls with disorders of sexual development. Dr. Poppas performed nerve sparing ventral clitoroplasty on 51 patients with enlarged clitorides.<sup>17</sup> His studies have sparked controversy in part due to his follow-up methods for testing clitoral sensitivity, which include using cotton-tip applicators and, in some cases, a vibrating device, and asking patients to rate the sensations on a scale of 0 (no sensation) to 5 (maximum sensation), with their parents present during the examination.<sup>18</sup> Medical professionals and patient advocates have expressed concern about possible psychological effects and future sexual function, the lack of institutional ethics oversight for this type of sensory testing, and concerns that

## Intersex Rights and Reproductive Justice

parents are not being provided with adequate information about the risks associated with clitoroplasties or possible alternatives to the surgery.<sup>19</sup>

- **Controversial Medication:** Some physicians have recommended that pregnant women with history of congenital adrenal hyperplasia (CAH) births or genetic predisposition to the condition take dexamethasone, or dex, during the early stages of the pregnancy.<sup>20</sup> Early prenatal exposure to dex has been known to prevent some of the symptoms in girls with CAH.<sup>21</sup> However, the off-label use of dex to treat CAH has not been subject to extensive clinical research.<sup>22</sup> There is concern that doctors may not be adhering to guidelines requiring the patient's written informed consent; furthermore, amassing knowledge about the use of prenatal dex through off-label treatment leaves patients without the ethics-committee oversight guaranteed to participants in clinic research studies.<sup>23</sup> Doctors and researchers have also criticized the practice for the way it normalizes gender behavior, exceeding the scope of clinical care.<sup>24</sup>

### Alternatives

Many intersex activists advocate for postponing surgery and enabling infants to grow up and express their gender naturally, only then allowing the child to determine if she wants or needs any genital operations.<sup>25</sup> Although some disagree about whether a gender should be assigned to the child before she expresses a preference, virtually all agree that any genital surgeries should be performed only with the consent of the affected person and that a child is assigned a gender should be allowed to change if she wishes.

- **What can we learn from Colombia:** In 1999, the Constitutional Court of Colombia put a ban on genital surgeries until a child reaches the age of consent.<sup>26</sup> The Court restricted the authority of parents to authorize genital surgeries for intersex children in order to ensure that parents put the best interest of their children ahead of their own discomforts and concerns about sexual ambiguity.<sup>27</sup> The Court held that the surgery could constitute a violation of the child's autonomy and bodily integrity, and that in most cases, the genital surgeries were not medically necessary or effective, nor was urgent action required.<sup>28</sup> The Court's decision created a new category of consent, requiring that parents receive accurate, comprehensive information that includes all risks and information about alternative forms of treatments not requiring early surgery.<sup>29</sup> Additionally, parents must give consent in written form over a period of time on more than one occasion in order to ensure that the parents have had sufficient time to understand the child's condition and give full consideration to the consequences of the decisions made for the child.<sup>30</sup> The decision also indicated that parents would not be able to consent to the surgery after a child has reached five years, given that the child has already developed a gender identity by that age.<sup>31</sup>
- **International Support for Protecting Children's Rights:** Internationally, organizations are working to increase protections for children against medical abuse. In 2006, a group of international human rights experts developed the Yogyakarta Principles to provide a universal guide for human rights regarding sexual orientation and gender identity.<sup>32</sup> Two relevant principles include:
  - States shall "[t]ake all necessary legislative, administrative and other measures to ensure that no child's body is irreversibly altered by medical procedures in an attempt to impose a gender identity without the full, free and informed consent of the child in accordance with the age and maturity of the child and guided by the principle that in all actions concerning children, the best interests of the child shall be a primary consideration."<sup>33</sup>
  - States shall "[e]stablish child protection mechanisms whereby no child is at risk of, or subjected to, medical abuse."<sup>34</sup>



# Intersex Rights and Reproductive Justice

<sup>1</sup>*Frequently Asked Questions: What is Intersex?*, INTERSEX SOCIETY OF NORTH AMERICA, [http://www.isna.org/faq/what\\_is\\_intersex](http://www.isna.org/faq/what_is_intersex) (last visited June 13, 2011).

<sup>2</sup> *Id.*

<sup>3</sup> *Id.*

<sup>4</sup> *Id.*

<sup>5</sup> Anne Tamar-Mattis, *Exceptions to the Rule: Curing the Law's Failure to Protect Intersex Infants*, 21 BERKELEY J. OF GENDER, LAW & JUSTICE 59, 60 (2006).

<sup>6</sup>*Id.* at 59-60 (justifying method with the “John/Joan” case study performed by Dr. John Money).

<sup>7</sup> Anne Tamar-Mattis, *Medical Decision Making and the Child with a DSD*, ENDOCRINE TODAY, Nov. 10, 2008, <http://endocrinetoday.com/view.aspx?rid=32542>.

<sup>8</sup> *Id.*

<sup>9</sup> *Id.*

<sup>10</sup> *Id.*

<sup>11</sup> *Id.*

<sup>12</sup> *Id.*

<sup>13</sup> *Id.*

<sup>14</sup> *Id.*

<sup>15</sup> *Id.*

<sup>16</sup> See generally Am. Acad. of Pediatrics, *Consensus Statement on Management of Intersex Disorders*, 1 JOURNAL OF AM. ACAD. OF PEDIATRICS (Aug. 1, 2006) available at <http://pediatrics.aappublications.org/cgi/reprint/118/2/e488> (last visited June 13, 2011).

<sup>17</sup> Jennifer Yang et al., *Nerve Sparing Ventral Clitoroplasty: Analysis of Clitoral Sensitivity and Viability*, J OF UROLOGY (Oct. 2007), available at [http://www.jurology.com/article/S0022-5347\(07\)01335-3/abstract](http://www.jurology.com/article/S0022-5347(07)01335-3/abstract).

<sup>18</sup> Alice Dreger & Ellen K. Feder, *Bad Vibrations*, BIOETHICS FORUM (June 16, 2010), <http://www.thehastingscenter.org/Bioethicsforum/Post.aspx?id=4730&blogid=14>.

<sup>19</sup> *Id.*

<sup>20</sup> Catherine Elton, *A Prenatal Treatment Raises Questions of Medical Ethics*, TIME (Jun. 18, 2010), <http://www.time.com/time/health/article/0,8599,1996453,00.html>.

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

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

<sup>23</sup> *Id.*

<sup>24</sup> *Id.*

<sup>25</sup> Tamar-Mattis, *supra* note 5, at 76.

<sup>26</sup> Patricia L. Martin, *Moving Towards an Int'l Standard in Informed Consent*, 9 DUKE J. GENDER L. & POL'Y 135, 162 (2002).

<sup>27</sup> Julie A. Greenberg and Cheryl Chase *Background of Colombia Decisions*, ISNA, (1999), <http://www.isna.org/node/21>.

<sup>28</sup> *Id.*

<sup>29</sup> *Id.*

<sup>30</sup> *Id.*

<sup>31</sup> *Id.*

<sup>32</sup> THE YOGYAKARTA PRINCIPLES, THE APPLICATION OF INT'L HUMAN RIGHTS LAW IN RELATION TO SEXUAL ORIENTATION AND GENDER IDENTITY, (Mar. 2007) available at [http://www.yogyakartaprinciples.org/principles\\_en.pdf](http://www.yogyakartaprinciples.org/principles_en.pdf)

<sup>33</sup> *Id.* (princ. 18(B))

<sup>34</sup> *Id.* (princ. 18(C))