

# Applying Social Work Values to the Care and Treatment of Intersex People

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## Understanding the Problem

The "problem" of intersex conditions is not due to intersex variations themselves, rather contemporary society's binary understanding of sex.

The term "intersex" refers to individuals born with "anatomies that are considered 'atypical' for either male or female bodies."<sup>12</sup> There are over 40 variations of sex development that can be referred to as "intersex", which makes conforming to the binary (i.e. male/female) system of gender problematic.<sup>4</sup>

The United Nations Human Rights Office of the High Commissioner affirms that, "**being intersex relates to biological sex characteristics, and is distinct from a person's sexual orientation or gender identity.**"<sup>29</sup>

Dominant medical procedure throughout the past 60 years has been to perform genital "normalization" surgery on infants to make them conform to a strict male/female binary.<sup>19</sup>

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Due to a lack of policy regarding the treatment of intersex infants, many hospitals continue to perform early surgical intervention on infants, which fails to consider the future quality of life and well being of intersex people.<sup>29</sup>

The practice of early surgical interventions ignores the agency of individuals. It is a blatant disregard of one's capacity to be free to make a choice,<sup>12</sup> which contradicts social work values.

Intersex is an **UMBRELLA TERM** used to describe a wide range of *natural bodily variations*. In some cases, **INTERSEX TRAITS** are visible at **BIRTH** while in others, they are not **APPARENT UNTIL PUBERTY**. SOME **CHROMOSOMAL** intersex variations may not be **PHYSICALLY APPARENT at all**.

Source: Intersex Fact Sheet from Free and Equal United Nations for LGBT Equality of United Nations Human Rights Office of the High Commissioner



# Impacts of Medically Unnecessary Intersex Surgeries

Medically unnecessary intersex surgeries are “all surgical procedures that seek to alter the gonads, genitals, or internal sex organs of children with atypical sex characteristics **too young to participate in the decision**, when those procedures both carry a **meaningful risk of harm** and can be **safely deferred**.”<sup>12</sup>

Parents and physicians may feel pressure to perform “normalizing” genital surgery on infants due to fear of future psychosocial struggles stemming from ambiguous genitalia.<sup>8</sup> However, intersex persons who undergo early genital surgery may face greater harm, including physical and psychosocial repercussions:

## Physical Repercussions

- Loss of sexual sensation or inability to achieve orgasm<sup>8, 18</sup>
- Genital scarring<sup>8, 18</sup>
- Need for repeated surgeries<sup>8, 18</sup>
- Loss of reproductive abilities<sup>8, 18</sup>



“My entire life I was lied to, and made to lie. At 19, I discovered I was born intersex. Intersex kids don't need to be 'fixed', we need to fix society in order to make it more accepting of the natural variance present in all of nature.”<sup>21</sup>

**-Pidgeon Pagonis**

Intersex artist and activist

Underwent non-consensual gonadectomy at 9 months, clitoridectomy at age 4, and vaginoplasty at age 11

Up to 1.7 percent of babies are born with sex characteristics that don't fit typical definitions of male and female.



That makes being intersex as common as being a **redhead**

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visit [www.unfe.org/intersex-awareness](http://www.unfe.org/intersex-awareness) for more information



## Psychosocial Repercussions

- Gender misassignment<sup>15</sup>
- Feeling abused by or mistrust of medical system<sup>13</sup>
- Feelings of shame from unexplained and/or repetitious medical examinations and genital photography<sup>17, 25</sup>
- Dissatisfaction with the DSD (differences/disorders of sex development) terminology<sup>17, 14</sup>
- Fear of devaluation<sup>17</sup>
- Negative body image<sup>17, 25</sup>
- Social isolation<sup>17</sup>
- Barriers to communication with significant others<sup>17</sup>

Many intersex children and their caregivers *do not* experience diminished psychosocial functioning resulting from an absence of surgical intervention.<sup>23</sup>

In order to preserve the autonomy, dignity, and worth of human beings, *informed consent to medically unnecessary intersex surgery is vital*. Delaying medically unnecessary intersex surgery until a person can make an informed choice can reduce the risk of physical and psychological harm.<sup>8</sup>

# Examination of Current Policy

There is no policy in the United States that addresses the rights of intersex children. However, there are international policies which indicate that progress is being made in intersex children's right to autonomy, self-determination, and independence. Neither the American Medical Association, nor the American Psychological Association, nor the American Academy of Pediatrics have policy guidelines for treatment of intersex children,<sup>4</sup> although the AMA Board of Trustees recommended a policy in 2016 urging the delay of all medically-unnecessary procedures.<sup>3</sup>

## Consensus on Management of Intersex Disorders (2006, updated in 2016)

- In 2006, 50 international experts crafted this document recognizing the need for guidelines in treatment of intersex people, which emphasizes an interdisciplinary team approach to intersex health and addressing the biopsychosocial needs of the patient and family.<sup>16</sup>
- The 2016 update states the primary goal of patient care is the “best possible quality of life” and emphasizes the benefits of peer support groups.<sup>17</sup> However, the statement continues to use the phrase “Differences/ Disorders of Sex Development (DSD)”,<sup>17</sup> despite objection from intersex organizations and activists.<sup>12, 13</sup>

## United States

- **American Counseling Association (ACA), the Gay and Lesbian Medical Association (GLMA), and Physicians for Human Rights**, recommend delaying medically unnecessary intersex surgery until a patient can make an informed decision and support intersex advocacy organizations<sup>2, 10, 22</sup>
- “X” sex marker (along with “M/male” and “F/female”) is an option on legal documents for “non-binary/intersex” identity in four states and Washington, D.C.<sup>27</sup>

## International Law

**Australia:** Implemented the Sex Discrimination Amendment Act in 2013 which contains intersex status as a separate prohibited position of discrimination.<sup>24, 29</sup>

**Malta:** Implemented the Gender Identity, Gender Expression and Sex Characteristics Act in 2015 which, according to the United Nations, is “the first law to prohibit surgery and treatment on the sex characteristics of minors without informed consent” and prohibits discrimination on the basis of sex characteristics.<sup>28, 29</sup>

**The United Nations (UN), Human Rights Watch (HRW), the World Health Organization (WHO), Amnesty International, and the Council of Europe** have condemned the practice of surgical intervention on intersex infants and children without their consent on the basis that it violates their human rights and lacks research supporting its effectiveness.<sup>4, 7, 12, 30, 31</sup>



“For me, I haven’t had a loving relationship. After all, I was a child being told that my body was so horrendous and so not ok it had to have pieces cut off it.”

–**Mani Bruce Mitchell**, an intersex person talking about the long-term psychosocial consequences of surgical interventions and resulting difficulties in finding a loving relationship.<sup>15</sup>

# NASW Policy Recommendation

As an ethics-based profession, the National Association of Social Workers should develop a policy statement guiding best practice in the care and treatment of intersex people. It is essential to provide ethical guidelines for social workers to follow in helping families make decisions regarding intervention. An intersex policy statement by the NASW would provide leadership to other professional organizations by promoting best practice in the care of intersex people.<sup>12</sup>

**This policy statement should include the following recommendations for best practice:**

- Collaborate with intersex organizations and people to develop the policy statement \*<sup>9</sup>
- Endorse withholding medically unnecessary surgery until child is old enough to understand and consent to surgery<sup>29</sup>
- Endorse laws that allow for simplified procedures for modifications of sex markers on legal documents of consenting intersex adults, which can include the gender marker "X"<sup>18</sup>
- Fully disclose all information about intersex condition and treatment options to intersex children and their parents<sup>17</sup>
- Advocate for the maintenance of potential for fertility and sexual function in surgery<sup>18</sup>
- Refer parents and patients to peer support groups<sup>1, 9, 26</sup>
- Use preferred language of individual when referring to their condition and gender<sup>13</sup>
- Utilize a comprehensive support team, including experts from social work/psychology, gynecology, urology, endocrinology, nursing, genetics, and bioethics<sup>17</sup>
- Separate transgender issues from intersex issues<sup>13</sup>
- Include education about intersex in sex education courses<sup>13</sup>

Sign our petition  
to the NASW:



<https://tinyurl.com/NASWpetition>

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