Intersex conditions and differences of sex development: Theology, ethics, and care

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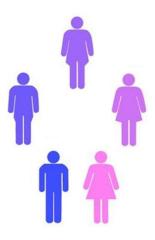
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Intersex Conditions and Differences of Sex Development:

Theology, Ethics, and Care



A Thesis

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by

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Abstract

Intersex conditions (ICs) or disorders of sex development (DSDs) are biological variations that cause difficulties in determining whether a person is male or female at birth. In the 1950s, cosmetic surgery aimed to "normalize" the infant's body became the standard of care when a child is born with an IC/DSD. Many adults who were operated on as infants, however, have begun to voice their dissatisfaction with the surgeries, which have caused tremendous long-term physical and emotional pain.

While new standards of care have been proposed in the medical community, the practice of normalizing surgeries has continued, in part because of the demands of the parents. The birth of a child with an IC/DSD is a source of great distress and anxiety for parents and doctors. The surgical option is viewed as quick-fix that offers immediate relief to this anxiety. There is no data, however, that supports normalizing surgeries as a proven therapy for the long-term satisfaction for the child. These irreversible operations result in heavy scarring, loss of sensitivity, and are a great source of shame. Further, the initial surgery usually requires several other surgeries throughout the person's life.

The mechanisms that drive these surgeries are the anxiety of the parents and social intolerance for ambiguity. ICs/DSDs are unanticipated by Catholic theology and expose a lacuna within Catholic theological anthropology. The Catholic tradition, however, has a number of tools (*Imago Dei*, Incarnation, dignity, vocation) that theologians have utilized to undergird a Catholic response to the suffering and mistreatment of people with ICs/DSDs for improved medical, pastoral, and spiritual care for people with ICs/DSDs and their families.

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Preface: Blessed Nicolas Steno

In 1988, St. John Paul II beatified a 17th century bishop from Denmark named Nicolas Steno. Steno was a geologist, who studied the existence of the salt-water seashells on mountaintops. The placement of the seashells thousands of feet above sealevel seemed impossible and perplexed Steno. The main scientific theory of Steno's day supposed that the Great Flood during the time of Noah washed some seashells to the tops of the mountains where they remained for centuries. Steno was dissatisfied with this explanation, because a forty-day rainwater flood would not be able to displace salt-water shells to mountaintops. Steno was eventually able to prove that the seashells were fossilized from when the earth was covered in water thousands of years ago. Steno's writings furthered both Biblical interpretation and geological understanding. Steno's breakthrough resulted from his critical analysis of both theology and science. Through use of reason and available tools, Steno was able to reconcile the truths of both theology and science.

Bl. Nicolas Steno presents a challenge and an inspiration for the 21st century

Christian. When faced with realities that contradicted contemporary assumptions, Steno
utilized both faith and reason to discern truth and advance human knowledge. The
exhortation to blend physical sciences and metaphysical theology is the one of main
features of the Vatican II document *Gaudium et Spes*. *Gaudium et Spes* proposes a
conversation between science and religion, which was a robust and fruitful enterprise in
Medieval times. The Scholastics viewed both nature and Scripture as the two books

¹Alan Cutler, *The Seashell on the Mountaintop: A Story of Science, Sainthood, and the Humble Genius Who Discovered a New History of the Earth* (New York, NY: Dutton, 2003), passim 7.

² "Let them blend modern science and its theories and the most recent understandings with Christian morality and doctrine. Thus their religious practice and morality can keep pace with their science and an ever advancing technology." (*Gaudium et Spes*, 62).

authored by God that reveal who God is. In the 21st century, however, the relationship between science and religion has become tenuous because of misconceptions on both sides and a lack of meaningful dialog at the highest level. Yet, science and religion continue to be mutually enriching. As John Paul II wrote to George V. Coyne SJ, Director of the Vatican Observatory, "Science can purify religion from error and superstition. Religion can purify science from idolatry and false absolutes." In this reconciliation, Albert Einstein and John Paul II are in accord. Einstein writing to philosopher Eric Gutkind, "Science without religion is lame, religion without science is blind."

My intention for my thesis is to take a small part in the conversation between biology and theology to improve medical and pastoral care for people with certain types of biological variations. While Steno was examining fossilized sea-shells, and I am reflecting on human beings; the common thread that connects both is that seashells on mountaintop did not seem to fit for Steno, and people with intersex conditions do not seem to fit into our social norms for what a body should look like.

Steno took seriously the given-ness of nature, which inspires us to search for knowledge and understanding of the human body. This thesis will examine the biology of the body followed by an analysis of how culture and society have shaped the body historically through surgeries with their own pre-conceptions, which has made it difficult for people to choose and accept the given-ness of the body. Following the historical review, we will look at theological possibilities to support improved care.

³ Letter to Father George V. Coyne, Director of the Vatican Observatory (June 1, 1988) available at http://w2.vatican.va/content/john-paul-ii/en/letters/1988/documents/hf_jp-ii_let_19880601_padrecoyne.html.

⁴ Alice Calaprice, *The Ultimate Quotable Einstein* (Princeton, NJ: Princeton University Press, 2011), 342.

Foreword: A Word on Words

Words communicate and allow us to share our thoughts. Words express past history and future dreams. Within Scripture words are especially important. Words can reveal who God is and who God is inviting us to become. In the book of Genesis, we see that "Words create Worlds." In the Gospel of John, "the Word became flesh and dwelt among us." The Word still echoes in the Church to communicate God's message of covenantal love and mercy.

Words are not always harmless though. As Cher reminds us, "Words are like weapons, they wound sometimes." Words can be destructive, and the language we use has consequences. Horrific accounts of bullying and psychological abuse illustrate that words can do tremendous harm. Often the words that do the most harm are the words that go unchallenged, assumed words of exclusion that we learn from our parents, media, and culture, which we unconsciously pass on to our children. In our ministry and care for people, we should be attentive to the language we use, especially unchallenged terms that have a history or harm.

The words used to describe members of the intersex community have been laden with judgment and shaped by socio-cultural values. One such word is "disorder." In the last ten years, the medical view of intersexuality as "disorders of sexual development" has become increasingly controversial. People with intersex conditions and their advocates have not favored the medical term "Disorder of sexual development," because of the connotations of "disorder." While both terms "intersex condition" and "disorder of

⁵ "The Spiritual Audacity of Abraham Joshua Heschel (Dec 6, 2012)." *On Being*. December 6, 2012. Accessed March 20, 2015. http://www.onbeing.org/program/spiritual-audacity-abraham-joshua-heschel/transcript/4951.

⁶ Cher's 1989 hit, "If I Could Turn Back Time" on Cher's album, *Heart of Stone* was written by Diane Warren.

sex development" show a movement away from "hermaphrodite," which connotes freakish deformity, advocate groups are not totally sanguine with these alternatives, and each term has been met with some resistance. In her book, *Bodies in Doubt: An American History of Intersex*, Elizabeth Reis addresses some of the controversy surrounding how to name these conditions. Reis highlights the weaknesses of historical and current terms, which give us a clue to how people with these conditions were regarded historically (and currently):⁷

Hermaphrodite (or pseudo-hermaphrodite) – This term is derogatory and inaccurate with connotations of "monster and freak" and has seldom been used after 1960. The term "hermaphrodite" still has some utility in the biological sciences especially in describing some invertebrate organisms.

Intersex Condition (IC) – While this term is preferred by many advocate groups, it is controversial because "intersex" can feel like something other than male or female.

The majority of people with these conditions identify as either male or female and do not feel "in-between" or in a "3rd sex." Additionally, parents do not like using the term for their children, because parents complain that the term sexualizes their children.

<u>Disorder of Sexual Development (DSD)</u> – "Disorder" language is considered pejorative by many adults with ICs/DSDs. However, the word "disorder" does give medical people and insurance companies clarity and draws attention to underlying genetic/endocrinological factors as well as indicating some disturbance in the typical process of maturation. Disability rights groups remind us that *atypicality* does not

⁷ Elizabeth Reis, *Bodies in Doubt: An American History of Intersex*, (Baltimore, MD: Johns Hopkins University Press, 2009), 153-162.

⁸ Etymology of hermaphrodite comes from the androgynous offspring (*Hermaphroditus*) of Hermes and Aphrodite.

⁹ Reis, *Bodies in Doubt*, 161.

necessarily mean disorder. One problem with the term "disorder" is that it implies the question, "Don't disorders need to be fixed?" "Disorder" also indicates some dysfunction, which often does accompany ICs/DSDs (e.g., infertility and hormone imbalance).

<u>Divergence of Sexual Development (DSD)</u> – This is the suggestion made by Elizabeth Reis in an attempt to build a bridge between advocate groups and medical professionals. ¹¹ The advantage of this definition of DSD is that doctors and parents can name the condition with clarity, and parents and their children don't have to adopt the "disorder" label. The great strength of this definition is its ability to communicate across social, medical, and theological disciplines.

<u>Difference of Sex Development (DSD)</u> – Similar to Reis' suggestion this definition has no value judgments. One of the largest support groups, the DSD-AIS¹² Support Group uses this term, and I will adopt it in my writing here along with IC.

Since no group is totally felicitous about any one term, I hope that this discussion of language and definitions can continue so that we might provide care and receptivity and avoid using words that perpetuate stigma and exclusion. Far more controversial than the definition debate has been the history of the treatment of people with ICs/DSDs. The past 200 years have been a confusing, contentious, and neuralgic time in the United States for people with ICs/DSDs.

¹⁰ Ibid., 156.

¹¹ The epilogue of Elizabeth Reis' book *Bodies in Doubt* is an examination of the pros and cons of different terminology and names for intersex conditions.

¹² Information on The AIS-DSD Support Group can be found at http://aisdsd.org.

Introduction: The Fiction and the Reality of Intersex

My own interest in intersexuality was sparked some years ago as I was following the international news story of Caster Semenya, the South African runner. In 2009, Semenya won the women's 800m at the 2009 Track & Field World Championships. Her victory made quite a buzz for two main reasons. First, she was 18 years old, the youngest champion in several decades, and secondly after her victory that she was subjected to a gender verification test.

After initially being barred from competitions, Caster Semenya was reinstated and won a silver medal at the 2012 Olympics in London. If Caster Semenya has an IC/DSD, it has never been made public. Many speculated that she may have an IC/DSD called Androgen Insensitivity Syndrome (AIS), because other track & field athletes with AIS have been barred from competition. The case of Caster Semenya shows that the line between male and female can often be biologically blurry and uncertain when dealing with ICs/DSDs.

The same year that I learned about the Caster Semenya story, I also read the Pulitzer-prize winning novel, *Middlesex* by Jeffery Eugenides. *Middlesex* is the story of Cal, who has an IC/DSD called 5-alpha-Reductase-2 Deficiency (5-α-RD-2). Her whole childhood, everyone including Cal assumed she was certainly a girl, but during puberty she developed male secondary sex characteristics. The stories of Cal and Caster Semenya pose fundamental questions about biological sex. Their stories are also tragic because of the shame and misunderstanding they suffered. Their stories reveal a blind spot in the way we view sex as clear, distinct, and never ambiguous. There also exist lacunae in our theological and philosophical responses to people with ICs/DSDs.

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¹³ At the moment, Dutee Chand, a runner from India, is appealing her ban because of her AIS.

Questions emerge: What does their existence reveal about the Creator, who has made every human being in God's image? How do ICs/DSDs square with church teaching? What vocational possibilities would promote flourishing for people with ICs/DSDs? These essential questions are not easily answered by current theology.

The cases of Caster Semenya and Cal are important because they give faces to the conversation of ICs/DSDs. When we talk about ICs/DSDs, we are talking about human beings who suffer because their bodies are misunderstood, and their conditions challenge our current understanding of the body. Further study of ICs/DSDs is important, not as a curiosity about the peculiarities of human biology, but because of the Christian imperative to care and understand those who might be ignored and voiceless.

Chapter 1

I. What are Intersex Conditions and Disorders of Sex Development?

Lack of accurate information adds to the controversy around these conditions. Speaking clearly about these conditions is the first step towards better treatment for people who have these conditions. ICs/DSDs are biological conditions where the maturation of chromosomal, gonadal, or anatomical sex is atypical. ¹⁴ People with ICs/DSDs have features in their genes, hormones, and/or body typically found in both males and females. An IC/DSD can affect a person's external (genital) and/or internal (gonadal) reproductive structures. 15 The role that sex hormones, testosterone and estrogen, play in sex development has begun to be highlighted. A 2015 article states, "The differential action of testosterone and estrogen in males and females throughout the life-span is ultimately responsible for the sexual dimorphism." ¹⁶ In recent years, as ICs/DSDs have begun to emerge into public discourse, a variety of disciplines have proposed both general and specific definitions for intersexuality. To gain the fullest understanding of ICs/DSDs, I would like to offer a survey of the descriptions from different areas of expertise including intersex advocates, medical professionals, historians, and sociologists.

¹⁴ Karen Marcdante and Robert M. Kliegman, *Nelson Essentials of Pediatrics*. 19th ed. (London, UK: Elsevier Health Sciences, 2014), 1958.

¹⁵Amy Wisniewski and Steven D. Chernausek. *Disorders of Sex Development: A Guide for Parents and Physicians*. (Baltimore, MD: Johns Hopkins University Press, 2012), 1.

¹⁶ S. M Weinberg., T. E Parsons, Z. D. Raffensperger, and M.L. Marazita. "Prenatal Sex Hormones, Digit Ratio, and Face Shape in Adult Males." *Orthodontics & Craniofacial Research* 18, no. 1 (2015): 21.

Representing the voices of people with ICs/DSDs and their advocates, the Intersex Society of North America (ISNA)¹⁷ supplied the following definition:

"Intersex: a general term used for a variety of conditions in which a person is born with a reproductive or sexual anatomy that does not seem to fit the typical definition of female or male."18

In 2006, IC/DSD advocacy group, Accord Alliance, worked with health care professionals to create a handbook called Clinical Guidelines for the Management of Disorders of Sexual Development in Childhood (CGMD2006). While the above definition is general, the Accord Alliance handbook provides several definitions for specific ICs/DSDs. In the CGMD2006, Accord Alliance defines specific ICs/DSDs:

- Congenital development of ambiguous genitalia (e.g., 46, XX virilizing congenital adrenal hyperplasia [CAH]; clitoromegaly; micropenis)
- Congenital disjunction of internal and external sex anatomy (e.g., Complete Androgen Insensitivity Syndrome [AIS]; 5- α -reductase deficiency [5- α -RD])
- Incomplete development of sex anatomy (e.g., vaginal agenesis; gonadal agenesis)
- Sex chromosome anomalies (e.g., Turner Syndrome [XO]; Klinefelter Syndrome [XXY]; sex chromosome mosaicism)
- Disorders of gonadal development (e.g., ovotestes). 19

¹⁷ In 2006, ISNA folded and gave its resources to the Accord Alliance (http://www.accordalliance.org/), but the ISNA website is still up and has useful information.

¹⁸ "What is Intersex," Intersex Society of North America, accessed May 2,

^{2014,} http://www.isna.org/faq/what is intersex.

¹⁹ Consortium on the Management of Disorders of Sex Development, Clinical Guidelines for the Management of Disorders of Sexual Development in Childhood (Rohnert Park, CA: Intersex Society of North America, 2006), 2. Available online at http://www.dsdguidelines.org/files/clinical.pdf

The above definitions are accurate and show the genetic nature of these conditions, which can serve to demystify them. However, the technical language can be difficult for non-specialists to understand.

Representing therapists and psychologists who have worked with people with ICs/DSDs, the American Psychological Association (APA) offers a definition for ICs/DSDs that is useful for both clinics and non-specialists:

"External genitals that cannot be easily classified as male or female; incomplete or unusual development of the internal reproductive organs; inconsistency between the external genitals and the internal reproductive organs; abnormalities of the sex chromosomes; abnormal development of the testes or ovaries; over- or underproduction of sex-related hormones; inability of the body to respond normally to sex related hormones."²⁰

The previous definition is a good starting point for explaining ICs/DSDs to a general population.

In the last fifty years, medical professionals in the U.S. have become increasingly involved in the care of people with ICs/DSDs. Articles from medical journals have focused on particular ICs/DSDs. For instance, while "Intersexuality or hermaphroditism is defined as the condition of individuals with physical features of both men and women" $5-\alpha$ -Reductase-2 Deficiency (5α RD-2) is an "inherited condition caused by mutation of the $5-\alpha$ -Reductase gene, resulting in a defect in the conversion of testosterone

²⁰ "Individuals with Intersex Conditions," American Psychological Association, last modified 2006, accessed May 3, 2014, http://www.apa.org/topics/sexuality/intersex.pdf.

²¹ Claudia Lang and Ursula Kuhnle, "Intersexuality and Alternative Gender Categories in Non-Western Cultures," *Hormone Research* 69, no. 4 (2008): 240-250.

to dihydrotestosterone (DHT)."²² Another IC/DSD, "Androgen insensitivity syndrome (AIS) is a condition that is inherited as X-linked recessive. XY-affected individuals have mutation of the androgen receptor gene that is located on the X chromosome. As a consequence of the androgen-receptor mutation, individuals are incapable of responding normally to testosterone or DHT during fetal development."²³

The above definitions for 5αRD-2 and AIS are technical and specific for pediatric endocrinologists, but the implications, effects, and management of these conditions can be a challenge to communicate to the parents of children with ICs/DSDs. The strength of medical terminology, however, is its ability to identify and present conditions and diagnoses with the precision and accuracy that pinpoint the underlying causes, which can provide clarity for treatment. In healthcare, however, sensitivity and pastoral care for the individuals with ICs/DSDs are in need of improvement, especially in relation to education, communication, and management of ICs/DSDs. Because most people have never heard of ICs/DSDs, they can initially seem to be something outside the norm or "unnatural." However, biological variation is normal and natural among sophisticated organisms like human beings. To bridge this educational gap, work in other disciplines can be of assistance.

As defined above, an IC/DSD is a medical diagnosis that makes it difficult to determine a person's biological sex. ICs/DSDs affect hormones, chromosomes, gonads, and anatomical characteristics in such a way that the person's biological sex becomes unclear at birth. For example, a person with Androgen Insensitivity Syndrome (AIS)²⁴

²² Vivian Sobel, Julianne Imperato-McGinley, "Gender identity in XY Intersexuality," *Child and Adolescent Psychiatric Clinics of North America* 13:3 (2004): 609-622.

²⁴ Androgen Insensitivity Syndrome has two varieties: partial (PAIS) and complete (CAIS).

has a genetic karyotype of XY, typical of males. The body of a person with AIS, however, is typical of a female. In the case of AIS, while the genetic type is male (XY), but the person's cells are unresponsive to androgens (literally "man-makers"). In other words, while the person is genetically XY, because of lack of androgen reception, their body developed as a female. As a result, there is either a partial or complete absence of any masculine secondary sex characters. A person with AIS develops female secondary sex characteristics, despite the lack of a uterus and the presence of internal, undescended testes. AIS is one of many ICs/DSDs that illustrate the hidden complexity of human biological sex. The variance of definitions of intersex conditions is expected because they encompass such a large spectrum of conditions which exemplify the complexity of the human body (e.g., AIS, 5α RD-2, CAH, et al.).

II. Distinguishing from Transgender – What Intersex Conditions are not

It is worthwhile to take a moment to describe what intersexuality is not.

Intersexuality is not a sexual-orientation. Neither is intersexuality a 3rd type of gender beyond male or female. Because their presence has been diminished and marginalized, the presence of ICs/DSDs can be confusing for much of the population. Recently, there has been much more scholarly and popular literature written on transgender than intersexuality, and often the two can become conflated compounding the confusion.

People with ICs/DSDs and transgender people are often confused, because both present uncertainties in identity for the individual or for others, which cause social stigma and marginalization, and both populations are seen as something "other" and outside the norm of male or female.

Perhaps the easiest way to distinguish intersexuality from transgender is to look at the sources of ICs/DSDs and transgender: biology vs. psychology.²⁵ A transgender person desires to alter their appearance to represent the sex opposite in which they were born.²⁶ Transgender pertains to matters of psychological identity of male or female interacting with social norms, while intersexuality is fundamentally a matter of biology and anatomy.²⁷

The distinction between gender and sex is often misunderstood or misinformed. Gender is "the behavioral, cultural, or psychological traits typically associated with one sex." Simply put, gender contains social, psychological, and cultural factors, while sex reflects a person's biology, anatomy, and physiology. Of course, while mind and body are not separate realities, a distinction is important because transgender and intersexuality both represent a different of groups of people and conditions that are often conflated and used (incorrectly) interchangeably.

Transgender / Transsexualism / Transvestite²⁹

Also both transgender and intersexuality present ambiguous and uncertain identities in regard to gender and/or sex. Transsexuals are people who often desire to or have had surgery to alter their appearance, while a transvestite is a person who wears the

²⁵ I make this mind/body distinction knowing that the two are not totally discrete. One always impacts on the other. Yet, it is helpful to locate intersexual conditions as stemming from a biological/genetic conditions and transgender within psychology, because there is no readily identified biological characteristic that correlates with the gender with which that person identifies.

²⁶ Transgendered persons have also become more visible in the last decade. While there are some related issues of marginalization between intersexuality (biological conditions) and transgender (psychological conditions), this thesis pertains solely with intersexuality.

²⁷ "What is Intersex?" Organization of Intersex International Australia, last modified January 19, 2012, accessed May 8, 2014. http://oiiinternational.com/intersex-library/intersex-articles/what-is-intersex-oii-australia/.

²⁸ "Gender," *Merriam-Webster Online Dictionary*, accessed May 1, 2014, http://www.merriam-webster.com/dictionary/gender.

²⁹ As with ICs and DSDs, there are also disputes and controversy over the terms transsexual and transgender.

clothing of the opposite sex (*trans* – across, *vestire* – to dress, i.e., cross-dressing). People born with an intersex condition have chromosomes, gonads, hormones, or genitalia atypical of other males or females, while transsexuals have consistency in chromosomes, gonads, and genitalia, but these persons psychologically experience themselves as belonging to the opposite sex other than their biological sex.

This psychological condition where a person "experiences persistent, clinically significant distress about their anatomic sex or assigned gender role" has been labeled "gender dysphoria" by the America Psychiatry Association (APA) in the 2013 edition of the *Diagnostic and Statistical Manual of Mental Disorders, 5th Edition* (DSM V). 30 There are sharp disagreements in the medical community about the care of people with gender dysphoria. 31 In most cases, gender dysphoria "in childhood does not persist into adolescence." 32 For the treatment of any person including transsexual persons and people with ICs/DSDs, there exist common standards of care that exhort, "a physician shall continue to study, apply, and advance scientific knowledge, maintain a commitment to medical education, make relevant information available to patients, colleagues, and the public, obtain consultation, and use the talents of other health professional when indicated." 33

³⁰Anne Lawrence, M.D., Ph.D., "Chapter 39. Gender Dysphoria." Gender Dysphoria : Gabbard's Treatments of Psychiatric Disorders. Accessed March 12, 2015.

http://psychiatryonline.org/doi/full/10.1176/appi.books.9781585625048.gg39.

The Diagnostic and Statistical Manual of Mental Disorders (DSM) is the standard classification of mental disorders used by mental health professional in the United States.

American Psychiatric Association: *Diagnostic and Statistical Manual of Mental Disorders*, 5th Edition (Washington, DC: American Psychiatric Association, 2013).

³¹ *Dysphoria*: "a state of feeling unwell or unhappy," from Merriam-Webster online dictionary, accessed March 12, 2015, http://www.merriam-webster.com/dictionary/dysphoria.

³² Jack Drescher and Jack Pula, "Ethical Issues Raised by the Treatment of Gender-Variant Prepubescent Children," *Hastings Report*, (October 2014, 44, No.5), S18.
³³ Ibid., S19.

This principle of care promotes continual reflection on medical practice to promote patients' well-being and to reduce harm. In the last chapter, we will return to the difficulty of applying this principle in the case of children with ICs/DSDs because, "children are not considered autonomous in the eyes of medicine and the law because they are deemed developmentally immature and unable to fully understand the risks and benefits of medical decision making." In the case of infants with ICs/DSDs, their parents also have difficulty fully understanding the risks and benefits of medical decisions, which contribute to the popularity of normalizing surgeries.

Summary of Chapter One

The previous survey of intersex conditions shows that classifying biological sex is not always as cut-and-dried or as clearly male or female as one might think. Many factors compose human sex, some of which can be in discord and cause uncertainty. The next section will review the history of the social attitudes and medical treatment of these uncertainties.

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³⁴ Ibid.

Chapter 2

Classification of Sex and the History of the Medical Management of People with Intersex Conditions/Disorders of Sex Development

Chapter 1 showed the current definitions of intersexuality and described some common ICs/DSDs to demonstrate the complexity of biological sex and the variety of ways to describe it. One reason for the variety has been the changing of criteria for determining sex in the past two centuries.

Since colonial days, medical professionals in the U.S. have grappled with two main reoccurring questions surrounding intersexuality:

- 1) How should a person's "real sex" be determined? Clitoris/penis measurement? Presence of ovaries/testes? Genetic karyotype? Person's self-reported identity?
- 2) Should surgeons intervene when a person manifests an IC/DSD?

 If so when? And to what end?

In the U.S., the classification of biological sex has typically revolved around the binary (male/female) model as seen on birth certificates, information forms, and bathrooms. However, how people have made determination of male and female has undergone revision during the past 200 years, moving from solely external genitalia and secondary sex characteristics in the 19th century to internal gonads (testes, ovaries) in the 20th century, and, in the 21st century, a more holistic view has prevailed including the body (phenotype), gonads, hormones, and genes (karyotype).

Medical journals of the 19th century show that the prevention of homosexuality was consistently stated as the reason for surgery in the case of adults with ICs/DSDs. There was a strong social stigma that identified same-sex intimacy as an evil and "abomination"

to avoid.³⁵ Many of the reports published also had a peiorative view of their patients. especially African-Americans.³⁶ These social biases are significant, because the desires of the patient do not seem to be considered by the doctors who cared for them. Doctors attempted to "fit" the person into social norms, and the goal was heterosexual marriage. The two chief operational theories of sex determination and medical intervention of the 19th century were:

- 1) Gonads determine "true sex," i.e., testes = male; ovaries = female.
- 2) Surgical intervention (only for adults/teens who seek it) would be employed to avoid homosexuality and promote heterosexual marriage.

Despite the abundance of social antipathy towards "hermaphrodites," one exception was Dr. James Parson, who allowed his adult patients with ICs/DSDs to choose the gender that suited them best and choose "their own sexual partners." Parsons' ideas were the minority report at odds with the majority opinion of doctors in the 19th century. The medical data is precious little before the 19th century, but it seems the concern that occupied most surgeons was preventing same-sex attraction, e.g., if a person with an IC/DSD was attracted to males, doctors saw fit "to feminize" that person's body in an effort to promote heterosexual marriage. Influencing doctors' actions was the social understanding that homosexuality was a "perversion" and "depravity." This view held strong force in the medical community until the mid-20th century. This attitude is also represented in many current cultures as discussed in Elizabeth Bucar's 2010 article, "Bodies at the Margins." Bucar describes how Iranian clerics determine a person's true sex by working backwards by inductive reasoning from a person's sexual orientation.

Reis, *Bodies in Doubt*, 15.
 Ibid., 40
 Ibid., 21.

For example, if a person has a sexual attraction to men, that person's true gender is female, and a surgery would be permitted to conform to "the Iranian legal prohibition of homosexuality (a crime punishable by death in the Islamic Republic of Iran)." 38

In the United States, through the 19th century, well-meaning doctors sharing parallel motivations with modern Iranian clerics saw heterosexual marriage as the goal and end of one's biological sex. "In deciding the sex of their patients, doctors sought happy endings, hoping to see their patients embrace at least one element of womanhood or manhood: marriage." Intervention by surgery was intended to make possible "marital requirements," i.e., sexual intercourse. The treatment paradigm towards ambiguous sex had a twofold goal: 1) promote heterosexual marriage, and 2) avoid homosexuality. ⁴¹

There was a major shift in the 20^{th} century that was marked by two theories, the second depending on the first:

- A person's identity as male or female was largely psychological and malleable,
 i.e., if a child was treated and raised as a male, the child would grow into an adult male.
- 2) In the case of ambiguity, it is better to have "corrective/normalizing" surgery immediately after birth to help the parents bond with the child and raise the child as either a male or female.

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³⁸ E. M. Bucar, "Bodies at the Margins: The Case of Transsexuality in Catholic and Shia Ethics," *Journal of Religious Ethics*, 38 (2010): 601–615. Bucar juxtaposes this attitude with the John Paul II's Theology of the Body, which begins with the same Male-Female complementarity, but focuses on biological "true sex" rather than psychological gender. Following John Paul II's theology, surgery on an otherwise physically healthy person would not be permitted because it would damage the person's body, which is in no need of "correction."

³⁹ Ibid., 601-615.

⁴⁰ Reis, *Bodies in Doubt*, 45.

⁴¹ Ibid., 56.

Dominant theories of the 20th century

The most influential person in the treatment of ICs/DSDs in the 20th century was Johns Hopkins psychologist John Money (1921-2006). In the early 20th century, the approach to people with intersex conditions was rather *ad hoc* without any uniform standards of care. Some doctors determined sex by the genitals, others by the gonads. The medical articles from that period showed that while physicians were unsure how to treat patients with ICs/DSDs, "but only a few would admit insecurity." Taking a different approach, Money understood that "true sex" is sometimes uncertain and cannot be determined solely by gonads or genitalia. Money considered the previous criteria of gonads and external genitalia to be doubtful in the presence of an IC/DSD. Money focused primarily on psychological factors for determining sex. Money's numerous articles boasted high satisfaction rates for infant "corrective surgery" to "normalize" the infant's body. The theory held that once the body was normalized, the psyche would follow suit. His theory heavily favored the power of nurture over nature.

Building on the work of contemporary philosopher and social theorist Michel Foucault (1926-1984), Money viewed sex and the body as malleable constructions of society and culture. The popularity of psychoanalytic ideas of Sigmund Freud (1856-1939) further buttressed the theory that the body is constructed and thus plastic. For Money, a child will adopt the sex assignment in which he or she is raised, provided the body matches. Money considered external genitalia the most important factor on which psychological factors hinged. According to Money's theory, the child's psychological development would take cues from the external body. For the first time in history, cosmetic surgery for infants was promoted by Money to form stronger bonds between

⁴² Ibid., 99.

family and the child and to establish the sex identity as soon as possible. Money preferred infant surgery because it would make it easier for the parents to raise the child as a male or female. Money's theory of early intervention also promised a quick relief from anxiety for both child and family. If the child realizes that he or she is different this was thought to cause anxiety, teasing, and isolation. Therefore, the child should be told the least amount necessary about their condition. Money's school of thought on gender plasticity and "normalizing" surgery was adopted by the majority of medical doctors.

Except in rare cases (such as "salt-wasting" congenital adrenal hyperplasia [CAH]), ICs/DSDs are not harmful to the infant and do not require immediate medical intervention for health. ICs/DSDs are not like infections or diseases that worsen if not treated immediately. Yet from the 1950s until today, immediate surgery has been recommended because of *social* rather than medical motivations.⁴³ The medical opinion was that these people were incomplete, and "doctors would finish what Nature had suspended."⁴⁴

The implicit social belief that allowed doctors to accept so readily infant surgeries was an absolute (yet unproven) certainty that "men could not live without penises or women without penetrable vaginas." While there was no clear criterion distinguishing male from female, there was within the medical community (and wider Western culture) an unexplained and untested intolerance for ambiguity or discord in the body, despite the testimonials (even before 1950) that "surgery has little to offer in aiding such individuals

⁴³ Ibid. Also see American Academy of Pediatrics "Evaluation of Newborn with Developmental Abnormalities of the External Genitalia." 2000 available at http://pediatrics.aappublications.org/content/106/1/138.full

⁴⁴ Reis, Bodies in Doubt, 191.

⁴⁵ Ibid., 94. To illustrate the arbitrary nature of the acceptable size of genitals at birth, the Intersex Society of South Africa has created a satirical tool called a "Phallometer," which is a ruler that labels between .9cm and 2.5cm surgery is said to be required. See

http://www.intersex.org.za/index.php/en/publications/medical-ethics-and-practice/60-the-phallometer

to become adjusted in society."46 Moreover, despite the growing popularity of surgeries. the medical profession had still not been able to clearly set distinguishing criteria for what comprised a male and a female. This lack of uniform criteria coupled with the desire on behalf of doctors and parents to eliminate ambiguity gave rise to Money's model.

Money's 1952 thesis, "Hermaphroditism: An Inquiry into the Nature of Human Paradox," stated that most adults with ICs/DSDs "seemed happy and successful with their gender roles" without surgery. 47 Yet a few years later. Money would champion a treatment program that marked a complete departure from his early conclusion that adults with ICs/DSDs generally have happy lives and healthy relationships without medical intervention.

After earning his doctorate in psychology from Harvard, Money was invited by Lawson Wilkins, the godfather of pediatric endocrinology, to study intersexuality on a large scale. Money and a married couple, Joan and John Hampson, both of whom were psychiatrists studied over one-hundred children and adults with ICs/DSDs. 48 Money and the Hampsons observed that many children with similar conditions and anatomy had received different gender and sex assignments by their parents. Some were raised as boys, others as girls. Despite the similarities in diagnoses, Money determined that because the children successfully took to their sex assignment, infants with ICs/DSDs had a biopotentcy in regards to possible sex assignments, and they could be raised as

⁴⁶ Ibid., 106, 194

⁴⁷ John Money, Hermaphroditism: An Inquiry into the Nature of a Human Paradox. Thesis (Ph.D.), Harvard University, Cambridge, MA 1952, cited in Sharon Preves, Intersex and Identity (Piscataway, NJ: Rutgers University Press 2003), 52. See also Money and Ehrhart, Man and Boy, Woman and Girl.
48 Ibid.

either a male or female.⁴⁹ Because they had a mixed and ambiguous anatomy, they could be raised as either a girl or a boy depending on environmental factors.⁵⁰ Until Money, the focus of intersexuality was strictly medical without input from other disciplines.⁵¹

As a psychologist, observing children with ICs/DSDs, Money theorized that their minds were also bipotent, and the child's psychology would adjust and mature into their given sex-assignment. To avoid social stigma and prevent any public revelation of the IC/DSD, Money advocated for surgery as soon as possible and definitely within the first two years after birth. Beneath the decision to operate on infants with ICs/DSDs is the deep and pervasive, yet irrational fear that anyone (child or adult) who does not clearly have a male or female body cannot be happy or satisfied in their lives. To operate on infants demonstrates the "emergency" that the medical community considers these births to be. The ready acceptance of surgeries illustrates the ubiquity of the false assumption that people cannot live with bodily ambiguity.

Money broke away from the previous models of gonad and genitalia criteria and was the first to synthesize data from biology, endocrinology, surgery, and psychology.⁵⁴ Money understood that "neither anatomy alone, nor genetics, or hormones could indicate the status of psychosexual differentiation and identity."⁵⁵ His theory of plastic sex identity became widely accepted and his theory was hailed as revolutionary and genius.

⁴⁹ Ibid.

⁵⁰ Ibid., 52.

⁵¹ Karkazis, *Fixing Sex*, 47.

⁵² Preves, *Intersex and Identity*, 41.

⁵³ "Evaluation of the Newborn With Developmental Anomalies of the External Genitalia." January 1, 2000. Accessed March 13, 2015. http://pediatrics.aappublications.org/content/106/1/138.full.

⁵⁴ Karkazis, *Fixing Sex*, 48.

⁵⁵ Ibid., 58. Cf. John Money and Anke Ehrhardt, *Man & Woman, Boy & Girl*, (Johns Hopkins University Press, Baltimore, MD: 1972), 6.

In addition to early surgical intervention, Money also recommended keep secrecy about the IC/DSD from anyone who did not need to know, even including the child. Money's goal was for the child to grow up oblivious to ever having had a problem. While this method required secrecy and dishonesty, Money's out-of-sight, out-of-mind and ignorance-is-bliss approach offered a simple and seemingly credible method for the medical field. The prospect of an anxiety-free life was too attractive for both doctors and parents. Medicine and society assume that parents will act as proxy in the best interest of their child. In the case of infants born with an IC/DSD, the parents are also vulnerable because of fear, anxiety, shame, and social stigma. ⁵⁶ Surgeries became the norm in hospitals across the country, but while his work utilizing a multi-disciplinary approach was popular, Money made the error of over-estimating the role of the psyche and underestimated the roles played by hormones and gonads in sex development especially during puberty. Public testimonies decried the results of infant surgery including scarring, loss of sexual sensitivity, and the need for further "corrective" surgeries.

Money's theories became discredited in 1997, when Milton Diamond, an early critic of Money's theories, eventually delivered the deathblow to Money's "outside-in" principle in the famous so-called "Joan/John Case." Money had published a number of articles about David Remier, the unfortunate victim of a botched circumcision, which completely removed his penis.⁵⁷ The distraught parents had seen Money on television and traveled to Johns Hopkins to consult with him about their son. Money recommend that child have a surgery to shape a vagina and be raised a girl, and the couple did so.⁵⁸

Feder, *Making Sense of Intersex*, 38.Karkazis, *Fixing Sex*, 69.

⁵⁸ Ibid., 69. For more on this story, see the documentary: Dr. Money and the Boy with no penis: http://documentarystorm.com/dr-money-and-the-boy-with-no-penis/

Ultimately the infant-surgery solution proved too good to be true. The Joan/John case revealed that there was little follow-up and a growing body of evidence against Money's mind/body plastic-bipotency theory. "The Joan/John case" was a tragic story of the suicides of twin brothers, Bruce and Brian Reimer. Both had a condition called phimosis, which involves a tightness of the foreskin. The surgeons performing Bruce's circumcision severely damaged his penis, and his parents sought guidance from John Money. Money recommended that Bruce have another surgery to create a vagina so he could be raised as a girl named "Brenda." Bruce never accepted a female sex assignment despite numerous surgeries and hormone treatments, and as a teenager, "Brenda" (birth name Bruce) desired to be called David because of his overcoming of Goliath obstacles in life. According to the documentary, "The Boy with No Penis,

In 1997, in a move which would cause Dr. Money's studies to come under intense criticism from the scientific community, he decided to go public with his story. In 2002, David's twin brother, Brian, died from an overdose on drugs used to treat his schizophrenia- apparently Dr. Money's therapy sessions with both boys had left him psychologically scarred as well. Two years later, David Reimer himself committed suicide.⁵⁹

As the public learned about the Joan/John case, Money's theories became discredited, yet no model of care emerged immediately to replace Money's model. Despite a lack of evidence of success and Diamond's articles discrediting infant surgeries, Money's "outside-in" theory still holds sway in much of the medical

⁵⁹ "Dr. Money And The Boy With No Penis." Documentary Storm Dr Money And The Boy With No Penis Comments. March 10, 2010. Accessed March 1, 2015. http://documentarystorm.com/dr-money-and-the-boy-with-no-penis/.

community, but there is a trend of rising voices against infant surgeries.⁶⁰ To address this great gulf between the intended goal of surgery for infants with ICs/DSDs and the real outcomes, the World Health Organization released a 2006 consensus document that acknowledged the poor care that infants with ICs/DSDs had received.⁶¹ There is still much work to be done to improve the care and treatment of people with ICs/DSDs and their families.

Analysis from other disciplines can help us to clarify the motivations, circumstances, and outcomes to propose best practices for the medical management of ICs/DSDs. Only in the last fifty years has surgery on infants been the medical response to ICs/DSDs. The histories written by Elizabeth Reis and Alice Dreger describe a time period, before the second half of the 20th century, when people with ICs/DSDs could mature and develop with little or no medical intervention. From the records, they seemed to be happy people who often married and were sometimes able to have children. Their conditions were usually hidden, sometimes often even to the people with ICs/DSDs themselves.

Summary of Chapter Two

Medicine and society have historically struggled to understand ICs/DSDs. A lack of information and knowledge in what causes ICs/DSDs has led to poor classification and treatment of these people. While they are no longer called by the freakish term "hermaphrodites," cosmetic "normalizing" surgeries on infants represent a lack of

⁶⁰ Karkazis, Fixing Sex, 216-235.

⁶¹ The 2006 WHO document was entitled *Eliminating forced, coercive and otherwise involuntary Sterilization is a*vailable at

http://apps.who.int/iris/bitstream/10665/112848/1/9789241507325 eng.pdf?ua=1

acceptance of ambiguity and the body that has an IC/DSD. The surgeries to reduce the size of the infants' clitoris (in the case of CAH) or mold a micropenis into a vagina have resulted in stigma, shame, and outrage for violation of their dignity and autonomy in the decisions that affect their lives. The desired outcomes of infant "normalizing" surgeries do not serve the patients well enough to warrant continued use as medical therapy.

Chapter 3

Current Models of Care and Efforts for Reform

Ellen Feder's 2014 book, *Making Sense of Intersex*, is a great source of hope for people with ICs/DSDs, their families, and medical professionals unhappy with the current treatment model of infant surgery. Despite a tremendous amount of evidence that adults who had surgery as infants resent the surgeries and lament the irreversible effects, medical practice has been slow to change. Feder suggests three central reasons for the continued use of "normalizing surgeries" on infants with ICs/DSDs.

- 1) The parents desire to "do something" rather than wait and "do nothing." 1
- 2) Pediatricians, surgeons, and nurses generally are not trained and unprepared to counsel parents in these decisions.⁶⁴
- 3) A child's ambiguous appearance causes anxiety for the family and doctors, and surgeries offer a relief from the anxiety caused by the ambiguity. ⁶⁵

While an infant's IC/DSD may make their biological sex uncertain, the principles of care and motivations beneath the practice should be clear and sturdy. Feder offers a close look at the underlying attitudes in medical management of ICs/DSDs and offers philosophical proposals for better decision making and outcomes. At the moment, the state of the question has moved to respect for the child's autonomy rather than the parents' autonomy as the principal value. Feder critiques the current medical practice

⁶² Ellen Feder, *Making Sense of Intersex: Changing Ethical Perspectives in Biomedicine,* (Bloomington, IN: Indiana University Press, 2014), 145.

⁶³ Ibid., 149.

⁶⁴ Ibid., 146.

⁶⁵ Ibid., passim 145-150.

that prioritizes the parents' autonomy over the autonomy, dignity, and integrity of the child, especially if their decision is not in the child's best interest.

Technological innovation and advances in surgical techniques give doctors and patients with ICs/DSDs options that were unavailable decades ago. Because patients (especially infants) are in a vulnerable position, their families place a great amount of trust and faith in their doctors. In recent decades, many adults with ICs/DSDs have complained that doctors have violated the infant's vulnerability and trust by frequent and unnecessary examinations, photography, and surgery. Even if the parents and/or older children are asked for their consent, their position and fear of confrontation make it difficult to challenge or refuse the doctors' recommendations of surgery. As a result, these adults report being humiliated and made to feel like a freak. While the medical practice of surgery on infants with ICs/DSDs continues, there are a handful of surgeons who can be raised up as examples for their ability to read the signs of the times and respond to the voices of those who have been irreparably harmed by the surgeries they received as children. Feder records the interviews of several doctors, who have performed surgeries on infants with ICs/DSDs. One such doctor, "Dr. Spruce" was involved in many decisions to operate on infants early in his career. Years later, one of those infants grew to be a teenager unhappy with his female sex assignment and was seeking to be a male in a clinic where Dr. Spruce worked. "He didn't know that I had been involved in his care as an infant. And I wound up telling him that."66 Spruce looked back and realized that, "[surgeons] don't put a lot of energy into exploring the errors in judgment that they made."67 Dr. Spruce is among the few who have admitted

⁶⁶ Ibid., 194. ⁶⁷ Ibid.

error in past operations on infants. Reasons for this might include both widespread medical arrogance and financial reasons. In 2014, a lawsuit in Germany resulted in a €100,000 settlement for a person with AIS, who had surgery as an infant. In the U.S., there is a similar lawsuit pending.⁶⁸ Analysis of current practice and admission of past wrong-doing are among the first steps to improving patient care for persons with ICs/DSDs.

To pursue human flourishing, specialists from a variety of disciplines engage in public discourse on several fronts to help doctors and patients make moral decisions in medical situations. The controversial practice of surgery for infants with ICs/DSDs has recently come under scrutiny by ISNA, which represents both the families and adults with ICs/DSDs who experienced these types of operations as children. Since its founding in 1993, ISNA has objected to normalizing surgeries (for nonlife-threatening conditions⁶⁹) and advocated for greater honesty between doctors and patients.⁷⁰ In 2006, ISNA teamed with over thirty health-care professionals including surgeons, pediatricians, social workers, psychologists, psychiatrists, nurses, and geneticists to compose the landmark document mentioned earlier, *Clinical Guidelines for the Management of Disorders of Sexual Development in Childhood* (CGMD2006). The stated purpose of the document was, "to assist health care professionals in the provision of diagnosis, treatment, education, and support to children born with disorders of sexual development

⁶⁸ The open letter to 53rd Annual Meeting of the European Society for Paediatric Endocrinology can be found at http://zwischengeschlecht.org/pages/Open-Letter-of-Concern-to-53rd-ESPE-2014-Irish-DSD-Universities-and-Childrens-Clinics

⁶⁹ A type of CAH called "salt-losing" or "salt-wasting" CAH is life-threatening, and the 2006 document recommends immediate surgery for the infant. "Salt-wasting" CAH, however, is among the rare exceptions where infant surgery is necessary and the outcome has been desirable. This type of surgery is to prevent the child's death is not cosmetic or "normalizing."

⁷⁰ http://www.isna.org/faq/surgery

(DSDs) and to their families."⁷¹ CGMD2006 is the most comprehensive document on care for infants with ICs/DSDs, and should be lauded for its inclusion of the experiences and the expertise of clinicians, patients, and parents to provide for the psychological and physical health of the child.

Currently, advocates are focusing their efforts towards "minimizing potential harm" and caring for the well-being of the child and family. CGMD2006 states that, "care-providers should not seek to force the patient into a social norm (e.g., for phallic size or gender-typical behaviors) that harm the patient." To these ends, the CGMD2006 recommends some new care and treatment directions for infants with IC/DSD including:

1) Honesty between patients, parents, and doctors, which was previously absent for fear of shocking parents and children.

- 2) Listening to the voices of persons with ICs/DSDs who have been wounded by the well-intentioned surgeries, which "exacerbate the physical and emotional suffering."⁷⁴
- 3) Recognizing that biological factors (gonads and hormones) prevail over the child's upbringing in the determination of sex.⁷⁵
- 4) Decreasing the advocacy for infant surgery unless necessary (e.g., salt-wasting CAH) and presenting other less harmful options for care and management.

A boon to this effort has been the work of both medical professionals and social scientists to understand the biological complexity of sex-indicators for the criteria of sexual taxonomy of biological sex. At the moment, the firm binarism of male or female has become muddy. Australia, New Zealand, Nepal, India, Bangladesh, and Germany

⁷¹ Clinical Guidelines for the Management of Disorders of Sexual Development in Childhood, 1.

¹² Ibid., 2.

⁷³ Ibid. Specifically, these harmful behaviors refer to the clitorectomies for CAH, PAIS, or micropenis.

⁷⁴ Reis, *Bodies in Doubt*, 151.

⁷⁵ Ibid., See the case of Drs. Childers and Dicks on p.127-128.

have begun to acknowledge the reality of ICs/DSDs on birth certificates, passports, and censuses where "indeterminate" is an option alongside "male" and "female."

As early as the 1970s, medical textbooks have advised the highest caution in assigning sex when sex is uncertain. A popular pediatrics textbook from 1975 closes its section on intersexuality by stating that, "the most serious mistakes in human medicine concern incorrect sex assignment in the presence of ambiguous external genitalia." The voices of adults with ICs/DSD have taught us that indeed this is a most grievous mistake, which causes tremendous physical and emotional suffering, which is extremely easy to prevent by not performing a surgery. Despite the evidence and the warnings in textbooks—current pediatric textbooks have adopted the advice of CGMD2006⁷⁷—there has been no evidence that the surgeries for infants with ICs/DSDs have decreased in the U.S. or in Europe. While more and more testimonies from adults with ICs/DSDs witness to the suffering caused by surgery, one consistent strength of medicine has been its precision in seeking to understand the complications and causes of ICs/DSDs.

CGMD2006 advises that ICs/DSDs, like many other congenital conditions, require a long-term commitment to the "physical, psychological, and sexual well-being of the patient." Medicine is an institution where change can be slow. Despite a lack of evidence validating continued surgeries on infants with ICs/DSDs, "there appears to be only a minor diminution of "normalizing surgeries."

⁷⁶ Charles A. Janeway and Robert E. Cooke, *Pediatrics*. Ed. Mohsen Ziai. (Boston, MA: Little Brown, 1975), 882-883.

⁷⁷ Marcdante and Kliegman, *Nelson Essentials of Pediatrics*. 19th ed. (Saunders Philadelphia, PA: 2014), 1959

⁷⁸ Feder, *Making Sense of Intersex*, 134.

⁷⁹ Clinical Guidelines for the Management of Disorders of Sexual Development in Childhood, 1.

⁸⁰ Feder, Making Sense of Intersex, 145.

Ellen Feder analyzes the ethical dimensions surrounding the decision for infant surgery by reflecting on a fascinating study conducted by psychologist Suzanne Kessler. 81 In her study. Kessler separated men and women into two groups. "The women were asked to imagine that they had been born with 'clitoromegaly' a condition defined as having a clitoris larger than one centimeter at birth" while the men were asked to imagine themselves born with a 'micropenis,' "a penis smaller than the putative 2.5 centimeters stretched at birth." Kessler then asked them if they would have wanted their parents to agree to an operation (clitoral-reduction surgery for the women, and reassignment as a female for the men). 93% of women said "they would not want their parents to agree to surgery," and "almost all" men rejected the prospect of gender reassignment if "pleasure sensitivity or orgasmic capacity" were negatively affected. 82 Feder concluded, as Kessler did, that an overwhelming majority (93% to "almost all") preferred not to have surgical re-assignment for atypical genitalia. Not a surprising conclusion given all the testimonials of adults with ICs/DSDs calling for an end to unnecessary surgeries for infants with similar conditions.

The findings from Kessler's second study presented surprising contrast to the first. In her second study, she asked different groups of men and women to imagine that they had a child with ambiguous genitalia. In this study, the participants indicated that they would "consent to 'corrective' or cosmetic surgery." They gave a similar rationale as the doctors and parents in real cases: "They didn't want their child to feel different, and earlier surgery would be less traumatizing than later surgery." Taken together the two studies present a remarkable and worrisome finding: parents want for their children,

⁸¹ Ibid., 40. ⁸² Ibid., 44. ⁸³ Ibid.

what they would not want for themselves. Throughout her book, Feder approaches the different angles of the question, "Why would parents consent to procedures on behalf of their children that they would refuse for themselves?"84 Feder builds upon sociologist Anne Fausto-Sterling's social analysis by articulating of the vulnerability within the relationship between parents and doctors in the discernment regarding the advisability of surgery.

Because the other option (not operating or delaying surgery) is seen as "doing nothing," parents and doctors usually opt to do something rather than nothing to relieve their distress despite a lack of evidence for doing so. 85 Feder raises up the vulnerability of both parents and children in need of special care. To ask a mother who is bewildered, confused, and scared after just having given birth about a major decision that will affect the rest of her child's life is imprudent, inappropriate, and unethical. Similar to the CGMD2006, Feder calls for improvement in several areas of medical care.

- 1) Give more attention to the whole person, rather than fixating on shape of genitals.
- 2) Dishonesty and concealment between doctors and parents, and between parents and children, does not reduce anxiety, but intensifies "psychological trauma."
 - 3) The testimonies of adults and patient follow-up are needed for ongoing care.

To counsel the parents of infants with ICs/DSDs, Feder examines the practice of non-directive counseling, where the care-giver (a social-worker, doctor, nurse, or chaplain) simply offers information and helps the parents reflect on the decision. She

⁸⁴ Ibid., 45. ⁸⁵ Ibid., 89.

cites the uncertainty and misgiving of surgeons in such cases, since they seem to have ultimately just told parents what they want to hear, namely, "that 'normalization' was in their child's best interests, no matter the cost."86 While non-directive neutrality is appealing in principle, in practice it has not been effective, and in the case of purely cosmetic surgery can often be ethically wrong. 87 Perhaps, a better alternative to nondirective counseling is non-coercive counseling, where care-givers dissuade from the use of cosmetic surgery.

Summary of Chapter Three

There is much at stake for the people with ICs/DSDs. The most serious mistakes in medicine concern incorrect sex assignment in the presence of ambiguous external genitalia. The most common and most drastic errors originate from hasty decisions made on the basis of appearance of the external genitalia alone. Despite data confirming the lack of satisfaction with cosmetic surgery for infants, the surgeries continue because of the anxiety of parents and doctors. Education and non-coercive counseling within a team approach provides far better care than surgery. Delaying unnecessary surgery until after puberty or deciding against surgery altogether are desired outcomes. Parents and the care team should discern what sex might prevail and raise the child as a boy or girl rather than having irreversible surgery. If, as the child matures, the other sex emerges, he or she can change. This is a reasonable outcome, but it requires prudence, clear thinking, and comfort with temporary ambiguity and uncertainty in childhood.

⁸⁶ Feder, *Making Sense of Intersex*, 140-141. ⁸⁷ Ibid., 141.

Chapter 4

Foundations of Theological Anthropology and Reflections on ICs/DSDs

The previous chapters outlined the biological conditions and medical treatments for people with ICs/DSDs. The lives of people with ICs/DSDs have been made difficult because of the social expectation of clear unambiguous biological sex. Unfortunately, Christian churches have done little to reach out to people with ICs/DSDs, and adults with ICs/DSDs have felt alienated from Christian churches. Because of the intense controversy within Christianity around issues of sex and sexuality, people with ICs/DSDs have not felt welcome within Christianity. There have been efforts to reconcile Christianity and intersexuality, but these efforts are mostly coming from people with ICs/DSDs and their advocates rather than theologians. This chapter will discuss the alienation of the intersexed and present some theologians trying to offer theological insights relevant to people with ICs/DSDs. These ideas can be starting points for further development within pastoral care for people with ICs/DSDs.

I.Three-Fold Bodily Lenses and the Intersex Body

A theology that orients itself within the body and within the world should consider the three-fold proposal of Colleen Griffith.⁹⁰

1) A body is a vital organism. This way of reflecting on the body pays attention to what is biologically given: the life cycles, height, weight, cells, tissues, and

⁸⁸ Eric M. Rodriguez, and Lourdes D. Follins, "Did God Make Me This Way? Expanding Psychological Research on Queer Religiosity and Spirituality to Include Intersex and Transgender Individuals," *Psychology and Sexuality* 3, no. 3 (2012): 217.

⁸⁹ Brian Still, *Online Intersex Communities*, (Amherst, NY: Cambira Press, 2008), 33; 66.

⁹⁰ Colleen Griffith, "Spirituality and the Body" in *Bodies of Worship: Explorations in Theory and Practice*. Ed. Bruce Morrill (Collegeville, MN: Liturgical Press, 1999), 75-78.

- organs. This dimension of the body is a gift from God that reflects the Creator's wisdom.
- 2) A body is a socio-cultural site. The body exists in time, space, and culture. The conditions of one's life shape that person with language, customs, rituals, education, values, and relationships. In many ways, society forms the body.
- 3) The body is a product of consciousness and will. Much of the body is chosen. In addition to our actions and diet, we also interpret what our bodies mean and what we will become. Our choice may or may not confirm the ways that society and culture have formed the body.

These three lenses are also ways for the spirit to come and dwell in the body.

Moreover, through the body we relate to others and God. In the particular bodies considered in this thesis, we see that while the vital organism may be healthy, the values and patterns of cultures have heavily inscribed these bodies with a meaning not present at their initial moment of created gift nor are these inscripted meanings personally chosen.

The surgeries that shape these children's bodies to conform to social norms have caused a great deal of pain and in many ways limit potential flourishing and ability to choose one's bodily destiny. As the intersex body matures, cultural pressure adds shame and secrecy.

II. John Paul II's Theology of the Body

As a newly ordained priest and doctoral student, Karol Wojtyla explored the "new philosophy of consciousness known as phenomenology as the basis for an exposition of Christian ethics."91 In a way, phenomenology has the opposite starting point than the Medieval Scholastic tradition, which depended upon revealed truths (e.g., the Trinity, the Incarnation, the Ten Commandments) and deduced further truths from these truths. Coupled with Christianity, phenomenology takes seriously the world and the human being which God created and called "Good" and "Very good" and aims at truth by considering the experience of the physical world and our experience within it.

John Paul II sought to apply his philosophy of the person to his interpretation of Genesis. During several years of his papacy (1978-2005), he devoted his Wednesday audiences to teach about sexual morality. All of these talks were collected and came to be called The Theology of the Body (TOB). While the pope grounds his work on personhood, TOB is properly understood as an explanation of the Catholic teaching on sex, sexuality, and marriage.

Founding his work upon Genesis, John Paul II "locates and develops three original experiences of humanity in the Garden of Eden: original solitude, original unity, and original nakedness."92 The original nakedness without shame illustrates a "time of integration with human persons when there was no 'interior rupture and opposition between... male and female." Sin shatters "the original integrity of the person and unity between male and female. [John Paul II] describes the fall as a 'constitutive break within the human person... almost a rupture of man's [sic] original spiritual and somatic unity."94 Following John Paul II, the bodies of males and females have a nuptial (promised) meaning that overcomes this rupture, so men and women can live as was

⁹¹ John Grabowski, "Pope John Paul II on the Theology of the Body," in Marriage: Readings in Moral Theology, ed Charles E. Curran and Julie Hanlon Rubio, Vol. No. 15, (New York: Paulist Press, 2009), 72. ⁹² Ibid., 74. ⁹³ Ibid., 75. ⁹⁴ Ibid.

intended "from the beginning." The unity and fidelity of a married couple fulfills their promised/nuptial nature in marriage as the "primordial sacrament." This bodily unity of woman and man in marriage is called complementarity. John Paul II expresses this model in his "Letter to Women."

Woman complements man, just as man complements woman: men and women are complementary. Womanhood expresses the "human" as much as manhood does, but in a different and complementary way. When the Book of Genesis speaks of "help," it is not referring merely to *acting*, but also to *being*. Womanhood and manhood are complementary *not only from the physical and psychological points of view*, but also from the *ontological*. It is only through the duality of the "masculine" and the "feminine" that the "human" finds full realization.⁹⁷

Drawing from both the Wednesday audiences from 1979-1984 and his 1988 apostolic letter *Mulieris Dignitatem* there are five essential features to John Paul II's complementarity:

1) The Book of Genesis reveals God's design for humanity to include both male and female. 98

⁹⁵ Ibid., 76.

⁹⁶ Ibid.

⁹⁷ John Paul II, "Letter to Women." June 29th 1995 accessible from www.vatican.va/holy_father//john_paul_ii/letters/documents/hf_jp-ii_let_29061995_women_en.html.
⁹⁸ John Paull II states, "The meaning of the original unity of man, whom God created "male and female," is obtained (especially in the light of Genesis 2:23) by knowing man in the entire endowment of his being, that is, in all the riches of that mystery of creation, on which theological anthropology is based. This knowledge, that is, the study of the human identity of the one who, at the beginning, is "alone," must always pass through duality, 'communion." (John Paul II, General Audience of 21 November 1979).
Accessible at https://www.ewtn.com/library/PAPALDOC/jp2tb10.htm

- 2) Complementarity is a biological reality and the differences between woman and man provide for the possibility for procreation and the presence of both male and female are mutually enriching.⁹⁹
- 3) Both men and women are created in "the image and likeness" of God. This revelation "constitutes the immutable basis of all Christian anthropology." ¹⁰⁰
- 4) There is an equality between men and women made in the image of God, and there is to be equality in the relational union between husband and wife, which reflects the oneness of God.¹⁰¹
- 5) This complementarity between man and woman plays out in different ways, demonstrated by Scripture and Tradition. In many passages God's love is presented as the "masculine" love of the bridegroom and father (cf. Hos. 11:1-4; Jer. 3:4-19), but also sometimes as the "feminine" love of a mother (*MD*, 8).

The last feature has been heavily criticized by many theologians, who see in the Pope's use of Scripture and saints a reaffirmation of historic gender roles that limited the position of women to either mother or virgin. Theologians have remarked that this aspect

of the woman, whereas only the equality resulting from their dignity as persons can give to their mutual

relationship the character of an authentic communio personarum."

⁹⁹ As Genesis 2:23 already shows, femininity finds itself, in a sense, in the presence of masculinity, while masculinity is confirmed through femininity. Precisely the function of sex, which is in a sense, "a constituent part of the person" (not just "an attribute of the person"), proves how deeply man, with all his spiritual solitude, with the never to be repeated uniqueness of his person, is constituted by the body as "he" or "she." The presence of the feminine element, alongside the male element and together with it, signifies an enrichment for man in the whole perspective of his history, including the history of salvation. All this teaching on unity has already been expressed originally in Genesis 2:23 (John Paul II, "General Audience," November 21, 1979, accessed March 5, 2015, http://www.ewtn.com/library/PAPALDOC/jp2tb10.htm

100 John Paul II, *Mulieris Dignitatis*, Apostolic letter on the Dignity and Vocation of Women, sec. 6.

Vatican web site, March 10, 2015, http://w2.vatican.va/content/john-paul-ii/en/apost_letters/1988/documents/hf_jp-ii_apl_19880815_mulieris-dignitatem.html.

101 In the relationship between husband and wife the 'subjection' is not one-sided but mutual. *MD* 24. Cf. *MD* 10 "This 'domination' indicates the disturbance and loss of the stability of that fundamental equality which the man and the woman possess in the "unity of the two": and this is especially to the disadvantage

of TOB asserted an antiquated and subservient view of womanhood by describing woman with an emphasis on her capacity for sex and fertility (or abstinence).

Some Catholic theologians, such as Todd A. Salzman and Michael G. Lawler, have proposed a "reconstructed complementarity" that is better suited to include differences in both sexual orientation and genital anatomy. Patricia Beattie Jung innovatively posits complementarity not in opposite sex, but *apposite sex* that is another person who is "apt for the task of making love and forging bonds through the mutual sharing of sexual delights." These theologians build upon the principle of "the human person adequately considered" from *Gaudium et Spes* as the basis of all ethics and morality. Other Catholic intellectuals like Patrick Lee and Robert P. George affirm John Paul II's biological basis for complementarity. 105

Charlie Curran, who is largely critical of TOB, commended John Paul II for his vision of equality among women and men in marriage. Curran says the pope "strongly supports the equality of men and women in marriage and expressly opposes any subordination of the woman to the man."

TOB has reinvigorated a conversation for articulating the Catholic view of the body. The great strength of TOB is to renew a positive view of the body and sexuality.

¹⁰² Todd A. Salzman and Michael G. Lawler, "Catholic Sexual Ethics: Complementarity and the Truly Human," *Theological Studies* 67 (2006): 629.

¹⁰³ Patricia Beattie Jung, "God Sets the Lonely in Families" in *More than a Monologue: Sexual Diversity and the Catholic Church*, ed. J. Patrick Hornbeck II and Michael Norko (New York: Fordham University Press, 2014), 121.

¹⁰⁴ Lisa Sowle Cahill, "Same Sex Marriage and Catholicism: Dialog, Learning, and Change" in *More than a Monologue: Sexual Diversity and the Catholic Church*, ed. J. Patrick Hornbeck II and Michael Norko (New York: Fordham University Press, 2014), 147.

¹⁰⁵ Patrick Lee and Robert P. George, "What Male-Female Complementarity Makes Possible: Marriage as a Two-in-One-Flesh Union," *Theological Studies* 69 (2008): 641-662. Cf. Introduction from *More than a Monologue*, 1-24.

See Charles Curran, *The Moral Theology of Pope John Paul II*, (Washington, DC: Georgetown University Press, 2006), 4, 5, 46, 168, 188.
 Ibid. 188.

Catholicism has always wrestled with varieties of gnosticism (i.e., dualisms of soul/body and matter/spirit). John Paul II also re-envisions sexual desire as a positive divine gift. The idea that the desire for sex is a consequence of the Fall started with St. Augustine and has been present in Western Christianity since the 4th century. While Augustine interpreted Adam and Eve covering their genitals with fig leaves as an indication of how genitals were shameful body parts and sources of lust and concupiscence, John Paul II ordered the leaves to be removed from the Sistine Chapel, because the Lord has created the human body and pronounced it good. TOB offers a positive view of the body and sexuality that attempts to cast off notions affirming that sexual desire is inherently evil and to re-imagine sex as human cooperation in God's life giving work, which is a major theme of John Paul II's teaching. Additionally, for John Paul II, the Incarnation of Jesus Christ as fully human and divine helps to dispel the anti-body prejudice of some streams of Christianity.

While TOB promotes a positive view of the human body and sexual desire, many theologians have stated that there are conceptual and moral inadequacies of John Paul II's complementarity model. Because ICs/DSDs blur the biological boundaries between male and female, they expose a lacuna in the complementarity model and the existential malefemale binarism in John Paul's philosophy of personhood. The biological conditions of ICs/DSDs bring forth realities not anticipated within the complementarity model. If we

Body," (Boston, MA: Pauline Books & Media, 2003), 337.

¹⁰⁸ "For it was not fit that his creature should blush at the work of his Creator. But by a just punishment, the disobedience of their genitals was the retribution to the disobedience of the first man, for which disobedience they blushed when they covered with fig-leaves those shameful parts which previously were not shameful . . . They were suddenly so ashamed of their nakedness, which they were daily in the habit of looking upon without embarrassment, that they could now no longer bear those sexual members naked, but immediately took care to cover them! Did they not thereby perceive those members to be disobedient to the choice of their will, which certainly they ought to have ruled like the rest (of their body) by their voluntary command?" (Augustine, *Anti-Pelagian Writings*. [Grand Rapids, MI, Eerdmans, 1971] XXXI).

¹⁰⁹ See Christopher West, *Theology of the Body Explained: A Commentary on John Paul II's "Gospel of the*

apply Navarrete's canonical principle to these extraordinary cases, the Catholic Church's mission becomes promoting the good for both the individual and society as a whole (i.e., the common good). The section that follows will gather writings by Catholic theologians attempting to create a platform for nurturing the good of individuals with ICs/DSDs and their communities.

III. A Complement to Complementarity

TOB should be commended for its sophisticated presentation of the traditional teaching of natural law and retrieving the sanctity of human sexuality and the body. Catholic theologians, however, have raised critiques about the idealism of John Paul II's teachings and his selective use of scripture. Using the writings of Catholic theologians, we can begin to construct a theology of the body and personhood that aims at addressing the gaps in TOB. Following a brief description of John Paul II's complementarity model, I will present writings on ICs/DSDs by Catholic theologians including Albert M. Harvey, Margaret Farley, Susan Ross, Natalie Kertes Weaver, Cardinal Urbano Navarrete, David Ozar, and Christine Gudorf.

Germane to ICs/DSDs, Jennifer Bader, Stephen Pope, and Christine Gudorf point out that the major lacuna in John Paul II's anthropology is a limited engagement with biology. Bader describes how biology reveals a gap in TOB, and how the gap can be addressed:

A closer look at the human body itself calls into question these unchanging, sacred archetypes.....Science tells us that the human body varies from person to person even in the physical markers of maleness and femaleness. While most

(although by no means all!) people consider themselves male or female depending on which genitalia they possess— and whether or not they contribute a sperm or an egg to the process of human reproduction— the scientific, bodily reality of sex is much more complex and involves chromosomes, hormones, brain structure and chemistry, and the like, that vary from person to person. 110

As heirs of the Catholic tradition, we ought to keep our theology of the body real. What is revealed in nature should be the starting point for a Catholic theology of the body.

In her introduction to *Sexual Diversity and Catholicism: Toward the Development of Moral Theology*, Beattie Jung raises up Stephen Pope, who critiques a subtle move made by proponents of the complementarity model from truths revealed in nature to a truth revealed in Scripture. Pope notes, "These teachings are no longer based on 'a rationally developed philosophical analysis nor a scientifically informed account of human nature but a direct and straightforward appeal to biblical revelation." Questioning the foundation of bodily complementarity places the teaching in a precarious position, because it would seem that the truth of nature and the truth of revelation are in discord, and that revealed truth cannot be contradicted by the truth found in nature and vice versa, because God is the author of both.

Complementarity and the natural occurrence of ICs/DSDs seem to be irreconcilable. Within complementarity, there is no mention of ambiguity or uncertainty. Complementarity assumes clarity within biological sex. Generally, infants do have a

¹¹⁰ Jennifer Bader, "Personhood and Sexuality" in *Human Sexuality in the Catholic Tradition* (Lanham, MD: Rowman & Littlefield Publishers, 2007), 103.

¹¹¹ Patricia Beattie Jung, Introduction to *Sexual Diversity and Catholicism: Toward the Development of Moral Theology* eds. Joseph A. Coray and Patricia Beattie Jung (Collegeville, MN: Liturgical Press, 2001), 252-3.

clear biological sex, but the many people with ICs/DSDs who might have an uncertain sex at birth do not readily fit in the categories of male/female. As David Ozar describes,

For the sets of concepts and words that we commonly use to refer to sexual orientation, biological classification of sex and gender exclude large numbers of our fellow human beings altogether. By excluding these persons conceptually they also exclude their concerns and interests, the good or harm done to them, their rights, and the respect due to them as person counting at all in our reflections about how people ought to act toward one another. Indeed, our standard concepts about these matters exclude large numbers of people from being counted in the human family at all, even by people who care very much about being inclusive. This is the most radical form of exclusion, that the persons excluded do not so much as exist in the minds of others.

While Bader presents the philosophical limitations and scientific short-comings in TOB, Thomas Stegman S.J. spots some weaknesses in the biblical interpretation contained in TOB. Stegman offers an insight into John Paul II's method of biblical interpretation, that also helps us to situate the teachings of his TOB especially complementarity. TOB belongs to a genre to teaching that is below both a papal encyclical (e.g., *Redemptor Hominis*) or an apostolic letter (e.g., *Spiritus Domini*). Stegman suggests that TOB is more homiletic than systematic. This helps us to situate it within the Catholic tradition's teaching on the body.

TOB "does not specifically engage in 'scientific' or 'professional' exegesis," but rather John Paul II calls it "catechesis" on the book of Genesis, the Sermon on the Mount,

¹¹² Ibid.

and Ephesians.¹¹³ Stegman proposes that John Paul II interprets Scripture by way of *actualization*, often used in homilies and liturgy.¹¹⁴ Stegman explains the three principles of actualization:

- 1) Biblical texts contain a wealth of meaning that gives them value for all times and all cultures.
- 2) These texts are historically conditioned, thus necessitating a hermeneutical process to bring their essential message to bear on present, actual situations.
- 3) The living tradition of the Church stimulates the task of actualization
 In implementing the process of actualization, the key is to draw from the fullness
 of meaning *contained in* the texts those elements that speak to the present
 situation in order to convey the saving will of God in Christ. 115

In the method of *actualization*, a text is approached with certain topics (i.e., marriage, sexuality, the body). That being said, much of John Paul II's biblical interpretation is very sophisticated. John Paul II's interpretation presents a teaching of marriage that emphasizes equality between wife and husband. He rightly places Eph. 5:21 as the key to understanding Eph. 5:22-23. John Paul II states, "Wives, be subject to your husbands" was a cultural value at the time. To address the difficulty of this text, John Paul II exhorts, "Love excludes every kind of subjection whereby the wife might become a servant or slave of the husband, an object of unilateral domination. Love

¹¹³ Thomas Stegman, S.J., "'Actualization': How John Paul II Utilizes Scripture in The Theology of the Body." in *Pope John Paul II on the Body: Human, Eucharistic, Ecclesial* ed. John Gavin and John McDermott (Philadelphia: St. Joseph's University Press, 2007), 50.

¹¹⁴ Ibid., 49-50.

¹¹⁵ Ibid.

¹¹⁶ Cf. with historical-critical types of exegesis, which attempts to find the literal sense by first fleshing out the authorship, audience, genre, culture, and history of the text's composition and transmission.

makes the husband simultaneously subject to the wife, and thereby subject to the Lord himself, just as the wife to the husband.¹¹⁷

While Stegman praises TOB for its broad themes of covenantal love, centrality of Christ, equality, and *imitatio Christi*, he has concerns about John Paul II's use of Scripture in regards to the body and marriage. Stegman points out that TOB highlights the perfection of the marital union "from the beginning" and "the eschatological fulfillment of human existence." Stegman points out the selectivity of John Paul II's choice of texts. "Of course, the biblical worldview contains more than these two ends of the spectrum."

By founding his theology on Scriptural texts focused on creation and heaven,
John Paul II's conclusions in TOB "raise up a pristine, pre-Fall condition of the first man
and woman as the ideal for marriage... and he holds up the eschatological, resurrected
bodily existence as the *telos* to which celibate existence points." This idealized view of
the body and marriage does not seem to accurately depict the biblical view of marriage
and the body, nor does it offer much utility and guidance for single mothers and fathers,
divorced Catholics, and gay Catholics struggling with their vocations. Especially absent
from TOB are people with ICs/DSDs, who are left concluding that their bodies do not fit
into God's plan for humanity from the beginning or in the future.

This being said, I find John Paul II's desire to give human personhood a biological as well as a socio-cultural basis to be consistent with the Catholic tradition,

¹¹⁷ John Paul II, "General Audience," August 11th, 1982. Available at https://www.ewtn.com/library/PAPALDOC/jp2tb88.htm

^{118 &}quot;In which men and women neither marry nor are given in marriage, but are like angels in heaven" (Matthew 22:30).

Stegman, "Actualization" 57. Cf. Neutral to the positive view of polygamy in the Old Testament, Jesus allowed for divorce (Matthew 19).

which always aims to synthesize what has been revealed in creation with what has been revealed in tradition. ¹²⁰

While Catholicism has a rich tradition of reflections on the body, particular contributions on ICs/DSDs by Catholic theologians have been minimal. The goal of this chapter is to present the emergent responses of Catholic theologians to ICs/DSDs, which have been twofold:

- 1) Bioethical critique of the infant surgeries for non-life threatening cases.
- 2) Theological critique of the binary-sex model.

Within Catholic theological ethics, the virtue of prudence can help to refocus our efforts on caring for the patient rather than socio-cultural norms of biological sex. Prudence examines the goals of a situation and seeks to find the most appropriate way to achieve those goals. Re-prioritizing the autonomy of the patient (in the case of ICs/DSDs, an infant who is unable to make future decisions about their identity) can guard against potential paternalism and create circumstances for better education and decisions. When reflecting upon the ICs/DSDs and considering treatments, the first element of the Catholic tradition that should be lifted up is prudence. Whenever we encounter something that is unanticipated or unaccounted for in our categories of thought and practice, the primary Christian response is to apply prudence, understanding, generous mercy, and the conditions for flourishing.

As the history of people with ICs/DSDs has shown, it is not enough just to intend to do the right thing. In the case of a person with an IC/DSD, there must be a "keen

¹²⁰ Michel Foucault and the heir to his philosophy Judith Butler have done much to show how much society and culture affect gender. The Church has a great deal to learn about gender as a part of one's personhood. However, ultimately Money's theory favored the social over the biological, which had disastrous consequences in the case of Joan/John.

assessment of circumstances, careful deliberation and reflection, and a moral imagination healthy enough to enable us to judge different possibilities for appropriate action. This is what prudence provides, and it explains why it ranks first among the cardinal virtues."¹²¹

The Catechism of the Catholic Church defines prudence as, "The virtue which disposes a person to discern the good and choose the correct means to accomplish it. One of the cardinal moral virtues that dispose the Christian to live according to the law of Christ, prudence provides the proximate guidance for the judgment of conscience." Aquinas writes that "prudence is right reason in action." It is also called the "charioteer of the virtues" because it guides the other virtues. Prudence is the application of moral wisdom to the particulars of real life. In regard to the treatment with people with ICs/DSDs, prudence guides us to listen to their voices, learn how they have been treated, and discern the good and how to accomplish it. Prudence acknowledges reality and then helps us to do what is right, just, and good within a given reality. What is good accords with reality, and in the previous chapters we have presented the biological reality of ICs/DSDs and also the reality of the imprudence of surgical interventions for non-life-threatening conditions.

If prudence is the virtue that guides the ethical response, hospitality is the attitude guiding pastoral care for people with ICs/DSDs and their families. As Thomas Ogletree explains,

¹²¹ Patricia Lamoureux and Paul Wadell, *The Christian Moral Life: Faithful Discipleship for a Global Society* (Maryknoll, NY: Orbis Books, 2010), 124.

¹²² Catechism of the Catholic Church, 2nd ed.(New York, NY: Doubleday, 2003), 1806.

¹²³ Aquinas writes, "As regards the individual nature, woman is defective and misbegotten, for the active force in the male seed tends to the production of a perfect likeness in the masculine sex." Thomas Aquinas, *Summa Theologiae*, trans. Thomas Gornall, vol. 4 (London: Blackfriars, 1964), ST I-I 92.

¹²⁴ Josef Pieper, *The Christian Idea of Man*, (South Bend, IN: St. Augustine's Press, 2011), 16.

To offer hospitality to a stranger is to welcome something new, unfamiliar, and unknown into our life-world. On the one hand, hospitality requires recognition of the stranger's vulnerability in an alien social world. Strangers need shelter and sustenance in their travels, especially when they are moving through a hostile environment. On the other hand, hospitality designates occasions of potential discovery which can open up our narrow provincial worlds. Strangers have stories to tell which we have never heard before, stories which can redirect our seeing and stimulate our imaginations. The stories invite us to view the world from a novel perspective. Hospitality offers welcoming words and caring presence to those in our midst, who might have come as a surprise. 125

For James Keenan, "Hospitality is the virtue that God practices." ¹²⁶ In his life, Jesus responded to an inhospitable world by acting with hospitality and instructing his followers to do likewise. In his feeding of thousands, his welcoming of children, his healing of diseases, and in his parables, especially the Good Samaritan and the Prodigal Son, Jesus always gives human attentiveness and companionship to the stranger and to those who are labeled as strange. In the case of ICs/DSDs, social views of the human person have become inhospitable to these biological variances, and the surgeries function to make them "more presentable" to an unwelcoming ideology, which does not accept otherness or ambiguity in biological sex. Hospitality for ambiguity can be a principle of care for people with ICs/DSDs.

¹²⁵ Thomas Ogletree, *Hospitality to the Stranger: Dimensions of Moral Understanding* (Louisville, KY: Westminster John Knox Press, 2003), 2.

¹²⁶ James Keenan, S.J., Virtues for Ordinary Christians (Kansas City, MO: Sheed and Ward, 1996), 108.

Neither Scripture¹²⁷ nor Tradition provides any direct answers for understanding people with ICs/DSDs and promoting their flourishing.¹²⁸ Scripture, however, does provide us with principles and attitudes for treating those who have been marginalized, abused, shamed, and ignored. The Gospels and the Catholic tradition both continually offer us this principle in Jesus' way of interacting with those excluded (i.e., lepers, prostitutes, gentiles, and Samaritans) and in the works inspired by the virtues of prudence and charity. Prudence is the art of "controlled readiness for the unexpected." Prudence can offer a two dimensional starting point asking, "What pastoral support can a community offer individuals with ICs/DSDs?" and "What theological underpinning can guide our pastoral practice in regards to vocation and intimate relationships to promote human flourishing?"

When we encounter the unexpected or recently discovered, prudence, as practical reason, advises us to examine reality and action. We should first seek to learn what we can about this unanticipated reality, and allow our actions to be informed by that knowledge. In both knowledge and action, we ought to direct ourselves to learning the

¹²⁷ People have suggested the that "Eunuchs for the Kingdom" (Matthew 19:12) to be a possible analog, and while I do think that this may have some merit, the historical categories and the warrant for eunuchs (i.e., slavery, intentional castration, harems, concubinage) make it difficult to apply. I am not sure how accurately eunuchs really describe people with ICs/DSDs. Also, Galatians 3:28 "In Christ there is no male or female" has been cited as potential text of scripture that speaks to intersexuality. Paul, however, was writing about equality in Christ and calling for an end to social structures that create hierarchy and oppression, not biological conditions.

While scripture does not specifically address ICs, the Talmud (200-500 A.D.) does. The Rabbinic texts refer to both the *tumtum*, those of unknown or "hidden" sex, and *androgynous*, a person of ambiguous sex. In fact, "*Tumtum* appears 17 times in the Mishna; 23 times in the Tosefta; 119 times in the Babylonian Talmud; 22 times in the Jerusalem Talmud and hundreds of times in midrash, Commentaries, and Halacha. *Androgynos* appears 21 times in the Mishna; 19 times in the Tosefta 109 times in the Babylonian Talmud and countless times in midrash and Halacha." (Kukla, Elliot, "A Created Being of Its Own: Toward a Jewish Liberation Theology for Men, Women and Everyone Else." Http://www.transtorah.org/. January 1, 2006. Accessed February 17, 2015. http://www.transtorah.org/PDFs/How_I_Met_the_Tumtum.pdf.). "Rabbi Yose says: 'An androgynos is a created being of its own.' The Sages could not decide if the androgynos is a man or a woman. But this is not true of a *tumtum*, who is sometimes a man and sometimes a woman" (Mishna Bikkurim 4:5).

¹²⁹ Josef Pieper, *The Four Virtues*, (Notre Dame, IN: University of Notre Dame Press, 1966), 22. ¹³⁰ Ibid., 11.

truth and seeking the good. In seeking to respond with prudence, several Catholic thinkers have explored the reality of intersexuality and the ways that this impacts Catholic theology of the body.

Scripture and virtues together inform Catholic teachings about the human body and the foundation of Catholic anthropology. Below are short descriptions of traditional principles used to reflect upon the body.

- God in the image of God, and God's creative acts are always good and purposeful.

 Imago Dei is a foundation concept in Catholic theology of the person, but it is vague in particulars. There is some ambiguity in the concept, and this is perhaps a great strength that allows it to have significance through history. They are two articulated features of Imago Dei: relationship and charity. God is Trinity, a community of three, and humanity is made to be a community that lives in mutuality. Living in community calls us to act as God acts in charity.
- 2) *Dignity* All human beings have absolute and inviolable dignity. Brian Benestad describes dignity as having two components: static and developmental. ¹³¹ Each person has an inalienable personal dignity, which is inviolable. Each person also has the responsibility to protect the dignity of others. Any type of physical or mental abuse harms a person's dignity. Disability, disease, and illness can all cause suffering, but nothing can take away a person's dignity.
- 3) *The Incarnation* "And the Word was made flesh and dwelt among us." Jesus Christ, human and divine, took on flesh with all the weaknesses of humanity, warts,

¹³¹ Brian Benestad, *Church, State, and Society* (Washington, DC: Catholic University of America Press, 2011), 42.

moles, scars, crooked teeth, and broken bones. 132 Christ is never a stranger to the weaknesses and limits of the human body. The Gospels present Jesus as desiring to be close to those who suffer and whose dignity has been harmed. 133 Further, the Incarnation is not just a one-time event in history, but the Body of Christ is continually made flesh in the Christian community.

4) *Vocation* – God calls humanity to personal and communal flourishing. All are called to holiness through our personal vocations to marriage, celibacy, or the single life. 134

John Paul II highlights *Imago Dei* within relationships. As God is the giver of life, we, who are made in God's image, can also be givers of life. 135 Personal relationships are the heart of human vocations. While each person has unique features in their particular vocation, every person is called to experience joy, new life, and renewed relationships.

These facets of the Catholic anthropological groundwork provide the frame and the grounding for pastoral and theological responses explored below. The first time that Catholic bioethicists gathered to address the issues raised by ICs/DSDs was in 1981.

Two years later, the John XXIII Medical-Moral Research and Education Center 136 produced a publication entitled *Sex and Gender: A Theological and Scientific Inquiry*.

Sex and Gender was composed of the papers and discussions from a workshop of

¹³² The Greek word for flesh in the New Testament is *sarx*. *Sarx* has a lexical spectrum ranging from the actual skin of a person or animal to the weaknesses of the body.

Among the Gospel there are myriad examples: woman caught in adultery (John 8:1-11), the Samaritan woman at the well (John 4:1-26), and Zacchaeus the tax collector (Luke 19:1-10).

¹³⁴ Lumen Gentium, 5 is entitled, "The Universal call to Holiness." It reads, "Thus it is evident to everyone, that all the faithful of Christ of whatever rank or status, are called to the fullness of the Christian life and to the perfection of charity."

John Paul II, "Wednesday audience," 2/20/1980. Available at http://www.ewtn.com/library/PAPALDOC/jp2tb18.htm

¹³⁶ In The John XXIII Medical-Moral Research Center later became the National Catholic Bioethics Center in 1996/7.

theologians, medical doctors, biologists, and psychologists to advise U.S. Catholic Bishops on "Human Sexuality and the Person". The forward-thinking collection of articles has thirteen chapters most of which are divided into two articles: An article from the field of science authored by a biologist or psychologist followed by a response by a theologian.

In his theological response to the practice of surgery on the genital organs of infants with ICs/DSDs, Fr. John Harvey, OSFS (1918-2011) responded, "The Catholic moralist has problems with this kind of solution to questions of identity confusion." Harvey's criticism, like that of Milton Diamond, did not support Money's theory of gender plasticity and early intervention to mitigate gender confusion. In response to Money's advocacy of infant surgery, Harvey writes, "There is no way one can morally justify such operations." While Harvey argues against infant surgery, he does so based upon the inability of the family and doctors to determine the newborn's biological sex. "The complementarity of male and female presupposes the completion of the developmental process. It is illogical to expect such complementarity where normal and valid developmental needs have not yet been fulfilled. It is a mistake to try and cure people of legitimate needs." Harvey's statement both asserts the immorality of infant surgery and affirms the binary sex-model.

In the comments and discussion section at the end of *Sex and Gender*, compiled by Albert Moraczewski, the assertion against surgery is further developed into practical advice.

¹³⁷ John Harvey, "A Reflection on Chapter Twelve," in *Sex and Gender: A Theological and Scientific Inquiry* eds. Mark F. Schwartz, Albert Moraczewski, and James Monteleone (St. Louis, MO: Pope John XXIII Medical-Moral Research and Education Center, 1983), 341.

¹³⁸ Ibid., 347.

¹³⁹ Ibid., 348.

One should not act as if it were possible to say that a person arbitrarily can choose to be a boy or a girl. Rather, as professionals we can recommend to the parents when there is some doubts as to which direction to go, that the parents raise the child as a boy or girl. But that advice is made on the basis of many factors including the anatomy, behavioral limitations and future sexual activities. As much as possible, the recommendation to be made should be compatible with whatever biological reality is present. 140

In this view, an operation like the one performed in the Joan/John case would never be permissible because it neglects the present biological reality.

The articles from both scientists and theologians viewed infant surgeries as built upon an empirically weak theory of the human body and psychology. Rather than doctors assigning a biological sex to the child, James Sullivan (1934-2012), who was trained in theology, psychiatry, and neurology, called for a team of people to assist, educate, and counsel the family. "The team should include an obstetrician, urologist, pediatric endocrinologist, geneticist, psychiatrist/psychologist, and social worker." Sullivan also stated that "a period of delay is far better than future reversal of the sex assignment." This might seem like common sense, but the influence of Money and the practice of infant cosmetic/"corrective" surgeries have proven difficult to dislodge. Sullivan's final page is entitled, "Implications for Theology." He writes,

Theologizing is the enterprise which incorporates empirical data into religion in order to manifest how the data relate to revelation and salvation – the two

¹⁴⁰ Albert Moraczewski, OP, "A General Discussion Interchange of Speakers/Authors," in *Sex and Gender*, 355

¹⁴¹James Sullivan, "A Reflection on Chapter 2," in Sex and Gender, 82.

¹⁴² Ibid.

¹⁴³ Ibid., 97.

essential elements of Theology. Theologians need to theologize concerning the biological data of sex and gender. Sex and gender have a powerful impact on religious and faith practices. Theologians must incorporate the results of their theological analyses in order to weigh the value of the decisions made by the health care sciences and parents/guardians. The purpose of decision-making is to select values and channel behavior. 144

In the past few years, a number of prominent Catholic theologians have responded to that call for increased engagement of empirical scientific data. While Catholic bioethicists should be applauded for joining the conversation, there has been little development of the medical treatments, spirituality, theology, and pastoral care of those with ICs/DSDs. While the publication of *Sex and Gender* was forward-looking and hopeful, theological reflection on ICs/DSDs did not gain traction if the 1995 Catholic League for Religious and Civil Rights (CLRCR) statement indicates anything. The CLRCR statement discussing biological sex variance affirmed that: "Every person knows that there are but two sexes, both of which are rooted in nature." This statement gives us a snapshot of the state of Catholic reflection around intersexuality in the 90s. 145

In the United States, Catholic Bishops seem to be unaware of the existence of people with ICs/DSDs. In the past few years, I have written to several bishops across North America, and while they responded with empathy for those with ICs/DSDs, they offered little pastoral or theological guidance. For this reason, I was happy to see an article by Cardinal Urbano Navarrete, S.J. (1920-2010), the late dean of the Gregorian

¹⁴⁴ Ibid.

¹⁴⁵ Suzanne Kessler, *Lessons from the Intersexed*, (New Brunswick, NJ: Rutgers University Press, 1998), 121, taken from New York Times, 9/3/95 (http://70.40.202.97/wp-content/uploads/2011/09/voice-of-sanity.pdf).

Pontifical University in National Catholic Bioethics Quarterly Fall 2014. The article addressed canonical issues around psychology and transexuals, but Navarrete also devoted some attention to an IC/DSD called Klinefelter syndrome, where a Y and X chromosome "converged in the same ovum at the same time in the initial genetic stage, and therefore there is an ambivalent (bipollens) chromosomal formula: XXY."¹⁴⁷ In a description of text-book quality, Cardinal Navarrete explains the three sex-indicators with their chronological manifestations in the progression of human maturation. 148

- Genetic sex determined from the moment of conception. A spermatozoid (containing twenty-two chromosomes and either an X or Y sex chromosome) fertilizes an ovum (containing twenty-two chromosomes and an X sex chromosome). Depending on the sex chromosome from the father's spermatozoid, the child will be either XX (genetic female) or XY (genetic male), or in the case of Klinefelter syndrome, XXY.
- Gonadal sex is manifested before five weeks after conception. Male gonads typically become testes; female gonads become ovaries.
- Phenotypic sex is determined by the visible genital organs, which is not always an easy determination. Often observable at birth, phenotypic sex is not fully developed until after the age of puberty, when secondary sex characteristics appear (i.e., voice, hair, physical structure/musculature, and sexual psychology).

In typical human development, these three indications of sex (i.e., genetic, gonadal, and phenotypic) align in the course of the embryogenesis and the secondary sex characteristics are strengthened in puberty. "In [the phenotypic] stage, especially after

¹⁴⁶ Urbano Navarrete, S.J., "Transexualism and the Canonical Order," *The National Catholic Bioethics* Quarterly 14, no. 1 (2014): 105-18. The article originally written in Latin appeared posthumously translated in English.

¹⁴⁷ Ibid., 109. 148 Ibid., 106.

puberty, the perception of one's own sex develops at the same time in the psychological strata of the personality, together with a sense of identification with it." In nature. however, there are a variety of developmental paths, which have come to be known as intersex conditions. Intersex conditions like AIS, CAH, Klinefelter syndrome, and 5-αreductase deficiency, all present some discord between an individual's genetic, phenotypic, and gonadal sexes.

Navarrete's description of an atypical embryo-genesis illustrates the complexity of the development of human beings in regard to biological sex. In addition to Klinefelter syndrome, the first chapter of this thesis described some other intersex conditions, which complicate the determination of the biological sex of newborns.

Navarrete ends his article with a surprising paragraph:

When it is the question of cases that are altogether extraordinary and not foreseen by the law, juridical norms that were legislated for common contingencies cannot be applied to these cases that depart so radically from the norm. Therefore, it must be determined what path should be taken in order to find a solution that salvages as much as possible everything that is to be salvaged: namely the good of both the patient and the community and the church in which they are a part. 150

Navarrete was a professor of canon law at the Pontifical Gregorian University, and his final paragraph reflects the 1983 Code of Canon Law's 1752th and final canon,

¹⁴⁹ Ibid., 107. ¹⁵⁰ Ibid., 118.

which contextualizes the whole code, and sums up its ultimate goal: "Salvation of souls, which must always be the supreme law in the Church, is to be kept before one's eyes." ¹⁵¹

Almost paralleling the last canon, Navarrete's final paragraph acknowledges that there are extraordinary cases unanticipated by our norms, customs, and laws. In these cases, the good of both the community and the person should be prudently pursued as the priority. This stance provides a better foundation for practical theology and medical care than statements or speculations on the limits of biological sex and socio-cultural gender.

Christine Gudorf composed a sophisticated Catholic theological reflection in her essay "The Erosion of Sexual Dimorphism: Challenges to Religion and Religious Ethics," applies the prudential ethic of "learn and relate" to ICs. Gudorf writes that "the dimorphic sexual paradigm" of male-female binary categories has been challenged by discoveries in "biology and social sciences." Gudorf acknowledges that religions such as Catholicism have not taken account of ICs/DSDs in their constructions of sex.

Sacred texts, mythologies, and codes of behavior assume that maleness and femaleness are exclusive and complementary types. Yet, while many (but not all) cultures accepted the binary model, many of these societies "operated not only with a concept of humans divided into males and females but also with a category or categories of exceptions, usually described in terms of some combination of maleness and femaleness.¹⁵³

Gudorf calls this "weak sexual dimorphism," because while the binary/dimorphic model is present, it has some flexibility for exceptional individuals. She writes, "Some

¹⁵¹ c.1752, in *The Code of Canon Law: Latin-English Edition* (Washington, DC: Canon Law Society of America, 1983), 538.

¹⁵² Christine Gudorf, "The Erosion of Sexual Dimorphism: Challenges to Religion and Religious Ethics," *Journal of the American Academy of Religion*, 69, 4, (2001), 863.

153 Ibid., 866.

societies that tolerated exceptions to the dimorphic sexual pattern created special social roles, which brought honor and leadership responsibilities to affected persons."¹⁵⁴

Gudorf cites the sheer number of biological occurrences of ICs/DSDs, over 5.5 million, ¹⁵⁵ as the strongest case against the "strong sexual dimorphism," which does not acknowledge any exception. Gudorf challenges the sexual dimorphism that has been assumed throughout Western history and in a less rigid way in the East. This dimorphism is present in our Bible, laws, bathrooms, and every form has boxes where we indicate male or female. Gudorf points out that in East historically and presently, there has been a social place for these people (*hijras*, as they are known in India). ¹⁵⁶

Gudorf's work also advocates for community education in lieu of infant surgeries. "Instead of reassignment in order to fit the norms of sexual dimorphism, children should be taught to accept and appreciate themselves as sexual beings regardless of the sexual configuration of their bodies." Gudorf's work advocates for an end to surgeries, but also calls the Church to be more engaged with science and less interested in defining sex. In Gudorf's words:

While traditional western religions all assumed sexual dimorphism, Moses, Jesus, and Muhammad and the legions of theologians, scholars, and judges who followed them all managed to avoid defining sexuality. For religions to define nonreligious concepts is not only to act outside their area of expertise and therefore to expose themselves to attack, it is also to take unnecessary risks with

¹⁵⁴ Ibid., 869.

¹⁵⁵ Ibid., 874. Data on ICs/DSDs are very hard to obtain. Because of both the lack of clarity of what they are and the reluctance of doctors to keep data and do follow up. Shame and secrecy has also led to the destruction of medical documents.

¹⁵⁶ The level of social acceptance of Hijras in India is disputed. While having a hijra son might bring dishonor to the family, Hijras do form themselves into supportive communities that have their own rituals and structure.

¹⁵⁷ Gudorf, "The Erosion of Sexual Dimorphism," 879.

their authority among the faithful. Concepts are both interdependent and fluid. There is no way to issue "ultimate" definitions; what we mean by nature, culture, male, female, homosexual, and heterosexual, among many other terms, is in transition, and new concepts ("transgendered," "third sex") that alter the meanings of existing concepts are constantly arising. There is nothing morally problematic with this dynamism.¹⁵⁸

The occurrence of ICs/DSDs challenges the framework of sexual dimorphism. In Christianity, intersexuality is especially thorny because Christian sexual ethics depend on the dimorphic/binary framework. TOB has promoted complementarity, a neuralgic assertion for many theologians, as one of the fruits of the binary model.

While Christine Gudorf is among the few Catholic theologians who have written in depth on intersexuality, a number of Catholic theologians have addressed it in a tangential way that relates to the body or sexual ethics.

In *Just Love*, Margaret Farley writes, "We have learned, mainly from people's experience but also from scientific exploration, that these clearly defined male or female configurations are not universal among humans. To tend to differences in this regard is no longer a marginal or minor concern. There are human bodies that are neither entirely female nor entirely male; they do not fall neatly into binary sexual division." Farley mentions the movement to delay or abstain from any treatment until the person is able to participate in the decision, which is in accord with the desires of advocates and medical

¹⁵⁸ Ibid., 885. This is only the first of Gudorf's four suggestions. The second is "Religious communities should decanter sexuality." This is something that Pope Francis has encouraged the Church to do in his tone and actions.

¹⁵⁹ Margaret Farley, *Just Love: A Framework for Christian Sexual Ethics* (New York: Continuum, 2006), 149.

personnel, but has not yet gained much momentum. Farley acknowledges these people and the controversy of care around their conditions, but does not offer anything constructive for what might qualify as authentic Christian care.

Susan Ross, chair of the theology department at Loyola University Chicago, has reflected on ICs/DSDs in her book, *Anthropology: Seeking Light and Beauty, Engaging Theology: Catholic Perspectives*. In her chapter entitled "The Body and Sexuality," she acknowledges that, "Sexual indeterminacy is an area that has received little attention from Christian theologians and ethicists and deserves far more investigation." Ross contributes to the Christian reflection on ICs/DSDs by writing that,

A small but not insignificant percentage of babies are born with ambiguous sexual organs. Most often, these ambiguities become "resolved" through surgery, with physicians and parents making a determination that a child will be male or female, despite a lack of clear indication one way or the other. Intersex babies are seen as presenting pathological conditions that must be corrected with surgical practices that can cause tremendous physical and psychological pain later in life when the person discovers that his or her own sexual feelings do not "match" his or her gender. 162

Ross' understanding of ICs/DSDs is supported by biology and the voices of the people with ICs/DSDs.

Natalie Weaver of Ursuline College builds from the fundamental starting point for any Christian reflection on the body: *Imago Dei*. She writes, "If the human is the *imago*

¹⁶⁰ Ibid., 153.

¹⁶¹ Ross, Anthropology, 104.

¹⁶² Susan Ross, *Anthropology: Seeking Light and Beauty, Engaging Theology: Catholic Perspectives*, (Collegeville, MI: Liturgical Press, 2012), 104.

dei in creation, one must conclude that this image is in all humans... if intersexed persons bear the image of God, then is it worthwhile to consider that God bears the image of the intersexed?" Taken a step further, in the case of non-life-threatening conditions, why should surgery be a corrective for a problem that does not exist? The surgeries illustrate that we have adopted and perpetuated the belief that people with ICs/DSDs are not created in the image of God, and their bodies must be shaped into the image of God. This idea is untenable in Christian belief of every person created in the image of God. Weaver continues, "God is the font of diversity, variety, and newness. That disability, non-conformity, and bodily challenges are also intimate to God." Weaver challenges the imagination to see all of humanity as made in God's image in a creative and diverse way. Every part of creation has diversity, which ultimately supports evolutionary fitness and future longevity. The human person in all its variations and differences reveals a view of a God of surprises and inventiveness.

Patricia Beattie Jung and Aana Marie Vigen summarize well the preponderance of evidence concerning the complexity and diversity of human biological sex beyond binarism juxtaposed with the Catholic teachings on the body and undergirded by the complementarity model. They write, "The emergence of this multiplex concept of gender among biologists seems to be reinforced by the analyses of gender emerging from social dimorphic account of gender complementarity that many official church teachings and Christian ethicists take to be axiomatic." ¹⁶⁵

¹⁶³ Ibid., 104, quoting Natalie Kertes Weaver, "Made in the Image of God: Intersex and the Decentering of Theological Anthropology," (paper presented at the annual meeting of the Catholic Theological Society, June 9, 2010 Cleveland, OH).

¹⁶⁵ Patricia Beattie Jung and Aana Marie Vigen, "Introduction" in *God, Science, Sex, and Gender: An Interdisciplinary Approach to Christian Ethics* eds. Patricia Beattie Jung and Aana Marie Vigen. (Chicago: University of Illinois Press, 2010), 8.

While there has not been a tremendous amount of theological discourse on intersexuality and Catholicism, there are seeds of future imaginative possibilities. In my conclusion, I add vocational possibilities as part of the way in which Catholicism imagines the human person. All vocations revolve around commitment to healthy relationships. Whether a person is single, married, or celibate, God has called that person to live with supportive relationships that encourage people to mature and be full of life. People with ICs/DSDs are no different. I see no reason why marriage, celibacy, or the single life should not be vocational possibilities for people with ICs/DSDs.

As in the Gospels, praxis and theory mutually refine each other if we're willing to question our assumptions. Theology has the ability to absorb and integrate the wisdom of science and the other disciplines. Science can present the data, and theology can offer an anthropological lens to view difference with reverence and awe for God's creation. A theological anthropology that integrates human experience and scientific inquiry couples with Gospel practices of merciful accompaniment by responding to God's communication in all of humanity without exception.

Randy Sachs reminds us that, "no one can ever claim to have plumbed the depth of human experience. There is another mode of being human which is different than mine, perhaps radically different, and just as human." This is true whether one is male, female, or intersexed.

IV. Moving from theory to practice

¹⁶⁶ John R. Sachs, *The Christian Vision of Humanity: Basic Christian Anthropology*, (Collegeville, MN: Liturgical Press, 1991). **43**.

The intent of this chapter is to show the Catholic responses to ICs/DSDs. The voices of this chapter point to,

- A cessation for the use of so-called "corrective" surgeries on infants with nonlife-threatening ICs/DSDs.
- 2) A refinement and expansion of John Paul II's TOB to include the millions of people whose body is not represented by the complementarity model. As John Paul II himself wrote, "Although the human body in its *normal* constitution, bears within it the signs of sex and is by its nature male or female, the fact, however, that a human being is a 'body' belongs to the structure of the personal subject more deeply than the fact that in his somatic constitution she or he is also female or male." John Harvey's statement also summarizes the friction between the complementarity model and the reality of ICs/DSDs: "The complementarity of male and female presupposes the completion of the developmental process. It is illogical to expect such complementarity where normal and valid developmental needs have not yet been fulfilled." 168

To implement these theological insights into practice, I make the following recommendations for pastoral care-givers, educators, and hospital staff:

- Further acknowledgement and education of the reality and suffering of individuals with ICs/DSDs.
- 2) Respond to these people with specialized pastoral care, spirituality, and vocational possibilities of marriage, celibacy, or the single life.

¹⁶⁷ John Paul II, "Original Unity of Man and Woman," General Audience Wednesday, 7/11. Emphasis mine

¹⁶⁸ John Harvey, "A Reflection on Chapter Twelve," in Sex and Gender, 348.

- 3) Within Catholic hospitals, ethics committees can promote strategies to educate doctors, nurses, and pastoral care-givers as well as improve policies for discouraging cosmetic surgery for infants.
- 4) Work to reduce infant surgeries for babies born with DSDs to only those conditions like salt-wasting CAH, which is life-threatening without surgery.
- 5) Develop education materials, workshops, and presentations for education at ageappropriate levels on ICs/DSDs.

Summary of Chapter Four

ICs/DSDs are unanticipated by Catholic theology and expose a lacuna within Catholic theological anthropology. The Catholic tradition, however, has a number of tools (i.e., *Imago Dei*, Incarnation, dignity, vocation) that theologians have utilized to undergird a Catholic response to the suffering and mistreatment of people with ICs/DSDs. Prudence is essential to evaluating the circumstances of what is biologically given by God, and hospitality is the appropriate Christian virtue to care for those who have been misunderstood and mistreated.

Chapter 5

Care and Community: Promoting Flourishing and Vocation

"Our faith in Christ, who became poor, and was always close to the poor and the outcast, is the basis of our concern for the integral development of society's most neglected members." 169

-Pope Francis

Imago Dei, dignity, autonomy, prudence, hospitality, incarnation, and human flourishing can influence pastoral care to help people with ICs/DSDs and their caregivers. The best practices of pastoral care or counseling understand people not as isolated individuals, but rather people who are members of families, churches, and communities. The pain and suffering caused by the medical treatment of ICs/DSDs is not just an individual issue. Isolation of people with ICs/DSDs perpetuates the attitudes of shame and secrecy that undergird and perpetuate surgical intervention. The suffering of people with ICs/DSDs is an issue that affects social and ecclesial communities, as well as families.

In caring for people with ICs/DSDs, there is an urgent need for gentle reception to address anxious fear. The issue of infant surgery is particularly neuralgic for the Intersex community. A large number of people with ICs/DSDs have experienced multiple genital surgeries as infants, which are most often medically unnecessary. Intersexed persons largely report these surgeries as a violation of their integrity and a mutilation of their normally functioning genitalia. Pain, infections, and poor healing from infant surgeries often lead to more surgeries in adulthood.

¹⁶⁹ Evangelii Gaudium §186.

Because surgeries usually create more problems than they solve, one of the chief goals of the Organization Intersexed International (OII) is to educate surgeons not to perform surgery on intersexed infants and to view intersexed conditions as difference not disease. "None of us [advocates] object to surgery that preserves health or life," says intersex activist Thea Hillman, "but [surgeries on intersexed infants] are performed for social reasons, not medical ones." From a medical point of view, surgery is a therapy to alleviate pain and promote healing from specific situations and diseases. ICs/DSDs (with the exception of salt-wasting CAH) are not diseases that require surgery and this type of intervention has been shown to cause suffering rather than relieving it. Cornwall states that, "The paradigm of early surgical intervention for intersexed conditions, often beginning neonatally, has been criticized for making medically non-pathological bodies into social 'emergencies." While a "social emergency" does necessitate special care, therapy should be offered in lieu of surgery to improve quality of life.

In the "John Money era," care for people with ICs/DSDs was limited to just surgical intervention. In the past ten years, however, the literature on care for people with ICs/DSDs has begun to adopt a more holistic approach that addresses psychological, emotional, and spiritual dimensions, in addition to the physical body. This approach requires the use of a team who can offer care to the whole person and their family.

Historically, treatments for children with ICs/DSDs have not been interdisciplinary and have focused on "normalizing" the child's body to relieve the anxiety of well-meaning parents and doctors who want these children to have a normal

¹⁷⁰ Thea Hillman, "Middlesex and the Limitations of Myth," *Mindfully.org*, Spring 2003, accessed March 8, 2015, http://www.mindfully.org/Reform/2003/Middlesex-Limitations-MythMar03.htm.

¹⁷¹ Susannah Cornwall, *Sex and Uncertainty in the Body of Christ: Intersex Conditions and Christian Theology* (London, UK: Equinox, 2010), 13.

and happy life. Tragically, the surgeries on these infants did not make possible the normal life for which the parents and doctors hoped. After pressure from intersex advocacy groups and the Accord Alliance's 2006 document, many children's hospitals have begun to utilize a care team composed of social workers, pediatric specialists, urologists, nurses, and psychologists to support the child and the family with attention also given to the parents. The best care demands an integrated and comprehensive approach that includes the parents' needs as well. Parents of children with ICs/DSDs are invariably shocked and distressed and benefit from receiving competent support. Pastoral counselors and chaplains have been underused in this area and can be a valuable part of a care team.

By being treated with compassion, parents hopefully will be able to be honest with their children and share with them age-appropriate information as their children grow. A pastoral response necessitates an *a priori* listening. Understanding the struggle informs, improves, and customizes the care. In the case of theologians, hearing about the particular plight of these individuals can lead to a thicker theology of sex and God's creation. A thicker theology can then provide an improved foundation for good pastoral care. In my research, I have found that the most helpful education on ICs/DSDs includes both biological data on the conditions coupled with the experiences of people whose lives have been affected by ICs/DSDs, whose lives have become invisible and whose voices have become muted. In our care for people with conditions that cause emotional and physical pain, we are caring for a person and a community, not a condition.

By giving voice to the experiences of parents and individuals with ICs/DSDs, I would like to echo a few quotes from the books, *Fixing Sex* by Katrina Karkazis and *Intersex and Identity* by Sharon Preves. Both books contain several interviews and

statements from doctors, parents, and adults with ICs/DSDs. The following quotes can lend us insight into the suffering, the shame, the complexity, and the difficulty faced by parents and doctors that pastoral care can address and seek to ameliorate.

From parents

On naming their child:

[The pediatric endocrincologist] found out we named her... him. He saw we had blue blankets and blue this, and she needed an identity. She was not an "it." And he came up to me and said, "I told you not to name the baby! How dare you name the baby!" I started crying and said, "How dare you tell me not to name this baby! This baby is not an "it." If I have to change the birth certificate, I will. This is Sam. ¹⁷²

On initial confusion:

They brought her back in all bundled up, and a whole bunch of people came in. The doctors, the nurses, and everyone and their mother. The pediatrician, the gynecologist, they all came in and I hadn't really met the pediatrician, so he introduced himself and said, "There's a problem."... I really don't remember what he said to me. I totally zoned out. I got all hot. I just stared at him. All I remember is something about salt, something between the legs, and "Do you see what I'm talking about?" He undid her diaper and said she didn't have any vaginal opening. He said she needs to get to a specialist right away, I remember after they left, we [she and her husband] just kind of held each other and cried. 173

On the damage of surgery on their older child:

She has tremendous scarring. They did the surgery at eighteen [years old] to try to remove the scar tissue and open the vagina up, because it had pretty much scarred over. 174

From doctors

On the pressure to perform cosmetic surgery:

Now a large percentage of women work, caregivers take care of the family, and the mother says, "I can't take my kid home looking like this, having nonfamily members changing the kid's diapers." There's much more pressure on doing the operation younger. Not because we want to. 175

From a pediatric endocrinologist, who supports considering alternatives to surgery:

As [the surgeon Justine] Schober says, "The intent of surgery is to make people feel better about their genitalia. Psychotherapy does the same thing, but isn't

¹⁷⁴ Ibid., 175.

¹⁷² Karkazis, *Fixing Sex*, 90.

¹⁷³ Ibid., 124.

¹⁷⁵ Ibid., 158.

irreversible." Will the child be bothered by scars in the genital area? You're not going to have something that looks normal, that doesn't have some residual trace... you have a difference, regardless of whether you do surgery or not. To a certain extent, the same argument can ally to the parent's problems dealing with it too... there's not one follow-up study showing that the kids who have had the surgery had a better psychological response, than kids who didn't. We're doing all this on a theoretical basis, not a pragmatic basis. 176

From adults with ICs/DSDs:

On what others should know:

A woman who had clitoral-reduction surgery at age twelve, against her wishes, adds, "I want parents to know that genital mutilation is not far removed from our culture and what is being done is irreparable. The individual should have a choice. Part of my message is that parents are capable of dealing with the birth of an intersex child without these drastic interventions, which exacerbate the problems and damage the relationships between the parents and children instead of fixing them." 1777

On the on-going struggle with shame and secrecy:

I was in therapy for thirty years, and the first twenty years I just couldn't talk about it. I've gotten to the point of being able to function as an apparently normal person, but there's so much that's still in there. 178

Describing the treatment by medical professional in her adolescence:

They would lay me on this table, and the first thing out of my doctor's mouth is, "Pull down your pants." And I never understood fully why. And then all these other people would walk in, and I'd lie there, completely exposed, while these strangers are probing and looking at me and writing notes. My mother would be in the room, but she would never say anything. Later I would tell her, "I don't understand why they're doing this." I asked her several times as a little girl, "Why do they do this?" And she would just say, "Because it's what they have to do." That would happen until I was probably fifteen or sixteen years old. And then I just quit going. 179

From an adult who was surprised to learn she had an IC/DSD:

When I was twenty, I had my first medical experience as an intersexed person. [The gynecologist] said, "Has your clitoris always been this large? I'd like to do some tests, 'cause I think maybe something's not normal." And she used the word "normal" specifically like something was not normal. It was the first negative association I'd had, and [I] started [having] this feeling that I wasn't normal. 180

¹⁷⁷ Ibid., 211.

¹⁷⁶ Ibid., 207.

¹⁷⁸ Ibid., 233.

¹⁷⁹ Ibid., 223.

¹⁸⁰ Preves, *Intersex and Identity*, 64.

From a 36 year-old grad student:

The primary challenge [of being born intersex] is childhood; parents and doctors thinking they should fix you. That can be devastating not just from the perspective of having involuntary surgery, but it's even more devastating to people's ability to develop a sense of self. I have heard from people that are really shattered selves, they don't have a concept of who they are. The core of their being is shame in their existence. And that's what's been done to them by people thinking that intersexuality is a shameful secret that needs to be fixed. So I think for most people the biggest challenge is not the genital mutilation, but the psychic mutilation. ¹⁸¹

From the above experiences, pastoral care of a child with an IC/DSD needs to begin with the child in the womb and extends to the parents. Parents also need timely counseling, adequate information, and group support. If the parents' needs can be met, they will be in a better position to love and accept their child unconditionally. Affection and bonding with the child along with peer group support are the most important ways to promote healthy psychological maturation.¹⁸²

In a clinically-focused book, *Transgenderism and Intersexuality in Childhood and Adolescence*, Peggy T. Cohen-Kettenis and Friedemann Pfäfflin suggest that "Professional assistance should help [parents] to appraise the situation in a realistic way, to deal with matters, and to get over disconcerting emotions. A thorough understanding of the situation may prevent needless fears." In addition to the stress about their child's health and future, parents do not know where to turn for support. Because parents typically avoid telling friends and family members out of shame, embarrassment, or confusion, professional support is imperative. 184

¹⁸¹ Ibid., 65.

Peggy Tine Kettenis and Friedemann Pfäfflin, *Transgenderism and Intersexuality in Childhood and Adolescence Making Choices* (Thousand Oaks, CA: SAGE Publications, 2003), 89.
 Ibid., 85.

¹⁸⁴ Ibid.

These conditions represent a challenge for both the person with the condition and their family. The reason why medical literature terms ICs/DSDs as "disorders" is because they typically are caused by some dysfunction in development and can cause other dysfunctions or atypicalities as the child matures. These atypicalities cause pain and suffering because of biological and social causes. From what these narratives show us, it seems that the lion's share of the burden comes from the social stigma of not being "normal" rather than the pain caused by the IC/DSD. While surgeries are often pursued as a therapy to ease the parents' anxiety and help the child to "fit in" in the future, the surgeries themselves only heap on the alienation, anxiety, shame and suffering that these people already experience. Thus, good pastoral care should address three fronts:

- 1) Prevention of unnecessary surgery
- 2) Easement of social and familial anxiety
- 3) Therapy/counseling for future flourishing

While non-coercive counseling with health-care professionals is the first layer of support for families with a child who has an IC/DSD, as the child matures, however, there is need for special considerations. In particular, "Parents worry about their child's chances for a happy life. They worry about partnership, sexual orientation, sexuality, and infertility, but may feel embarrassed to discuss such matters." Connecting parents to supportive communities is imperative.

Promoting spirituality and developing spiritual resources for people with ICs/DSDs is an underexplored area. Spirituality has been shown to be a therapeutic force for people struggling with both physical and mental illness, and in addition to counseling and support groups, spirituality could be a force of healing, reconciliation, and identity

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¹⁸⁵ Ibid., 85.

for people with ICs/DSDS. Pain and suffering can isolate people and create distance between people and their families and communities. Support groups provide a place for people to share experience and overcome alienation.

Sociologist Stephen Kerry has studied the connection between people with ICs/DSDs and spirituality. In his eight interviews, Kerry concluded that despite feeling general alienation from Christian churches, spirituality and articulating their spiritual journey was extremely helpful for people with ICs/DSDs. 186

While many of the parents' fears can be addressed and ameliorated, there is need to prepare for long-term strategies and follow-up, which has been absent from the majority of current medical management of ICs/DSDs. From the literature available, the most helpful thing for parents and children has been support groups. Brian Still's 2008 book, *Online Intersex Communities*, acknowledges that like all online communities there might be trolls and trouble-makers, but there is also an invaluable opportunity to connect and share experiences and stories with parents who are struggling with the same types of difficulties.¹⁸⁷

Among the most visited online communities are:

- "Bodies like Ours" www.bodieslikeours.org/forums/
- AIS-DSD support group aisdsd.org/
- The Interface Project a database of short videos about people with ICs/DSDs www.interfaceproject.org/
- InterAct Youth interactyouth.org/

¹⁸⁶ Stephen Kerry, "Intersex Individuals' Religiosity and Their Journey to Wellbeing," *Journal of Gender Studies* 18, no. 3 (September 2009): 277.

¹⁸⁷ Brian Still, *Online Intersex Communities: Virtual Neighborhoods of Support and Activism* (Amherst, NY: Cambria Press, 2008), passim 45-50.

Accord Alliance (an advocacy page formerly Intersex Society of North America)
 Care-givers would do well to connect families with these resources.¹⁸⁸

<u>Underexplored Spiritual Resources</u>

Beyond support groups and clinics, education for the larger population can help promote hospitality and eliminate the fear of the unknown. The reasons given for most of the surgeries revolve around the parents' fear that their child will be teased, ostracized, and isolated. Many doctors have gone on record saying that while they have ceased to suggest or endorse cosmetic surgeries for infants with ICs/DSDs, the parents still request surgery out of fear that their child will not fit into their peer group and become alone and depressed as they get older.

In her interviews, Preves described spirituality as essential to coming to terms and living comfortably as a person with an IC/DSD.

Participants [in the surveys] shared with me their beliefs about their personal relationships and a sense of empowerment... Several made emphatic statements about the role of certain beliefs in furthering their ability to validate themselves... intersexuals who have been able to avoid a permanently spoiled self-concept are those that have and active sense of spirituality. ¹⁸⁹

One person interviewed by Preves said,

All the people [who had] come to terms with [their intersexuality]... had one thing in common and that was our spirituality. That was it! The only thing that we all had in common was that we had some kind of spiritual [understanding] and

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¹⁸⁹ Preves, *Intersex and Identity*, 100.

the [intersex] people on the other side had no spiritual anything... [Spirituality] seems to be what saved us; what saved our lives. 190

An IC/DSD can be a traumatic thing to reconcile in one's life. Encouraged by the work of Kerry and Preves and Catholic theologians, I hope we can continue to work across disciplines to include chaplains in the care team for people born with ICs/DSDs to promote the spirituality of these people, which could be a powerful witness to the church and world about God's creation, fidelity, and love.

Hospital ethics committees could be a major vehicle for addressing this education gap. Ethics committees are generally composed of members of different disciplines including nurses, doctors, social workers, and ethicists. Ethics committees have three main missions:

- 1) Educate the staff
- 2) Provide consultations
- 3) Participate in policy making

In the appendix, I have included a pamphlet for use in Catholic hospitals that contains basic information for parents and caregivers. While there are unique and longterm challenges to people with ICs/DSDs and their families, most people with ICs/DSDs live out their lives as physically and mentally healthy individuals. ¹⁹¹

Summary of Chapter Five

This final chapter integrates the previous chapters to offer a proposal to remedy the poor medical care people with ICs/DSDs have received. The care team represents prudence and hospitality in action to assist the communal and personal flourishing.

¹⁹¹ Wisniewski and Chernausek, Disorders of Sex Development: A Guide for Parents and Physicians, 83.

Counseling and support groups are offered as alternative to surgery. Spirituality for people with ICs/DSDs is largely unexplored and hopeful source of healing and integration.

Conclusion: Variations in the Body of Christ

This thesis has shown the reality of intersex bodies. These human biological complexities are misunderstood by our social worldview, unanticipated by our theology, and surgically shaped by our medical practice. Theology and culture have both unwittingly inserted assumptions into the book of Genesis, and these assumptions have been re-affirmed in cultural body-rhetoric and theological formulations of complementarity. These readings have suggested that "God created them *only* male and female" with no ambiguity at any stage. Alternatively, a socio-cultural reading of Genesis might look like, "God looked at everything that God had made, and found it very good, *but a surgery could make it better*." In addition to distorting the text, these interpretations of Genesis do not account for the biological variations that accompany organisms that are as complex and sophisticated as human beings. The theologians that I have presented encourage us to welcome ambiguity with hospitality, compassion, and prudence and to scrutinize social claims about the body, which are not supported by biological reality.

The virtues of prudence and hospitality modeled by the ministry of Jesus offer a model for improving our care for people with ICs/DSDs to promote their flourishing and spirituality. The only prudent and hospitable response to the birth of a child with an IC/DSD is to do our level best to choose to raise them as a boy or girl and allow them to mature without surgery. As the child grows and secondary sex characteristics develop, the parents' choice will either be affirmed or their true identity will emerge as the child develops. The primary choice might prove to be incorrect after puberty. In the event that the other sex emerges, parents can welcome that as well. How we treat people who have

been neglected or ignored is the test of the Kingdom proposed by Jesus (Matthew 25:31-46). While *Imago Dei* is a broad and somewhat imprecise concept, that ambiguity functions well to ensure that all people are included and able to participate in community and grow in virtue and spirituality. People with ICs/DSDs present us with an opportunity to witness the vastness of God's creative power and God's everlasting covenant that brings people into community, which is the Body of Christ.

Everyone's body is different from other bodies in some way. The Christian community as the Body of Christ is a body with endless variance and every possible physical difference. As varied as the body is, it is through the body that God interacts with humanity. We are meant to flourish and thrive, and this flourishing continues in a bodily way even after death in the Christian profession of Resurrection. Our faith in the resurrection is the belief that God never discards our bodies, but rather God continually brings our bodies into closer union with God.

Variations in the body can make this flourishing and union difficult by placing a dual burden of physical atypicality and emotional anxiety from a culture has disregarded and disintegrated certain bodies. It is our Christian duty to be prudent and hospitable and to cease practices that alienate and wound in favor of practices that build up autonomy, integrity, Incarnation, *Imago Dei* to promote communal and personal flourishing.

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