

University of Missouri, St. Louis

IRL @ UMSL

---

Dissertations

UMSL Graduate Works

---

4-1-2020

## Intersex Experiences, Activists' Perspectives, and Counseling Implications

Cynthia J. Mulit

University of Missouri-St. Louis, [cynthia.mulit@me.com](mailto:cynthia.mulit@me.com)

Follow this and additional works at: <https://irl.umsl.edu/dissertation>



Part of the [Counselor Education Commons](#), and the [Gender and Sexuality Commons](#)

---

### Recommended Citation

Mulit, Cynthia J., "Intersex Experiences, Activists' Perspectives, and Counseling Implications" (2020). *Dissertations*. 930.

<https://irl.umsl.edu/dissertation/930>

This Dissertation is brought to you for free and open access by the UMSL Graduate Works at IRL @ UMSL. It has been accepted for inclusion in Dissertations by an authorized administrator of IRL @ UMSL. For more information, please contact [marvinh@umsl.edu](mailto:marvinh@umsl.edu).

Intersex Experiences, Activists' Perspectives, and Counseling Implications

Cynthia J. Mulit

A.A., Menlo College, 1973

B.A., Stanford University, 1979

M.A., Fairleigh Dickinson University, 2012

A Dissertation Submitted to the Graduate School at the University of Missouri–St. Louis  
in partial fulfillment of the requirements for the degree of  
Doctor of Philosophy in Education with an emphasis in Counseling

May  
2020

Advisory Committee

R. Rocco Cottone, Ph.D.  
Chairperson

M. Lee Nelson, Ph.D.

Mark Pope, Ed.D.

Ruxandra Ritter, Ph.D.

## ABSTRACT

Intersex people are born with sex development differences; for example, atypical genitals. The intersex community is the only sexual minority population subjected to medical treatments in infancy designed to make their bodies conform to cultural expectations for male and female bodies. Intersex activism to stop the medicalized treatments began in the late 1990s. No other qualitative study has focused on the experiences of intersex activists. Four leading activists were interviewed in depth regarding their personal, activist, and counseling experiences. Data were collected through semistructured interviews and analyzed using interpretative phenomenological analysis. A 3-stage intersex identity development model was formulated to explain the psychological growth involved in moving beyond society's pathologizing notion of intersex variations. The model stands in contrast with other identity models as it emphasizes three social frameworks (i.e., contexts) at its highest level and places the individuals' processes or states of being at a lower level. The intersex identity development model's 3 social contexts are Stage 1. Binary-only framework: intersex as a medical disorder, Stage 2. Breaking the binary-only framework, and Stage 3. Beyond the binary-only framework: intersex as a natural bodily variation. An identity development model developed specifically for intersex people will help counselors appreciate the unique psychological challenges of an underserved population. The counseling profession is directly implicated in optional intersex infant sex-related surgeries through the 2006 Consensus Statement on Management of Intersex Disorders, which includes professional counseling as a part of multidisciplinary teams that offer irreversible intersex surgical treatments. Findings from this study may help to better inform counseling professionals

so they can distinguish themselves from mental health professionals who cooperate with medical professionals who deny infants their right of self-determination. In recognition that the mental health and medical communities have often acted on behalf of intersex people against their wishes, this study was reviewed by all four activist participants.

*Keywords:* intersex, intersex identity, sexual minority identity, intersex counseling, intersex activism, disorders of sex development, DSD, infant genital mutilation, 2006 Chicago Consensus

## DEDICATION

For every intersex child and adult who has cried in the darkness: You are not alone.

For all children harmed for bodily difference: Your body is not shameful.

For intersex activists: Your daily courage for the sake of children brings me to tears, then inspiration and action. You are the human soul at its finest.

For future intersex counselors who will undo the intersex history of harm from mental health professionals: I dream of you.

For my husband, David, who literally had me at hello and engaged three weeks later: I love you dearest friend, sounding board, partner in this work, patron, lover, and companion in parenting.

For my two children, Matt and Ashley, and their wonderful spouses, Liza and Pat: You are when I began to understand love.

For my family, friends, and teachers: I am in awe and grateful. You have inspired me to stretch for my best. Your love and support sustain me.

For my father, Thomas Hardy Jackson, Jr., who knew women were just as capable as men and so I never questioned.

For my mother, Ruth Ford Jackson, who believed I had a book in me but did not live to see it. “Mom, I found the thing I had to say.”

## ACKNOWLEDGMENTS

I would like to thank all the participants in this study. Your trust in me to carry your stories forward into the field of counseling is one of the greatest honors of my life.

I am grateful to Mx. Anunnaki Ray Marquez, an intersex activist who builds bridges of support from one field to another. I am honored to call him my friend.

My deep appreciation goes my doctoral committee: Dr. R. Rocco Cottone, for his leadership as chair, his calm, supportive wisdom, always warm friendship, and his scholarship in social constructivism and counseling paradigms; Dr. Mark Pope, for his LGBTQ+ guidance and belief in me as a trustworthy ally; Dr. Ruxandra Ritter, for introducing me to an unmet need in our field and for her support that sustained me at just the right moments throughout masters, doctoral studies, and licensure; and Dr. Mary Nelson, for her perception about and support for my commitment to activists.

I would like to acknowledge prior intersex scholars from other fields, including Katrina Karkazis and Sharon Preves. Their work, in turn, depended on the courage of the earliest intersex activists including Tiger Devore, Mani Mitchell, and those from the first U.S. intersex advocacy organization, the Intersex Society of North America.

I gratefully acknowledge with love Dr. R. Eugene Bales, my professor of philosophy and friend for decades. He first introduced me to the treasures of academic rigor and taught me the analytic tools I needed to question systems of thought. In his classes, I first saw my soul. I acknowledge with love Dr. Onkar Manjrekar, my quantitative research tutor. Out of my greatest academic fear, I gained a son. Thank you to those who kindly read drafts and provided editorial suggestions: activists, members of my dissertation committee, and friends.

I would like to acknowledge my associates at OASIS—Haven for Women and Children. My work life there gives me faith that the “real world” can be sane. Their talent, good humor, and dedication to others inspires me. My special appreciation goes to Chief Operating Officer Jim Walsh, who sees needs to be filled instead of locked doors.

I acknowledge with love my parents, Ruth and Hardy Jackson, Jr., for their love and emphasis on education, and my in-laws, Don and Barbara Mulit, who loved me like their own. I am indebted to Pip, my canine best friend, for her total devotion and periodic reminders to get up and go for a walk. Thank you, Chris Peters, for our loving friendship.

From every atom in my heart, I would like to thank my husband, David Mulit, who gave his blessing for a sabbatical from our married life for 2+ years so that I could move to St. Louis to work with Dr. Cottone and Dr. Pope. David and I shared morning phone calls during those years. He talked me down from ceilings of frustration and fear at least weekly and told everyone who questioned our sanity that this work was important and I had to do it. His love for me has been my breath for 40 years.

TABLE OF CONTENTS

ABSTRACT ..... ii

DEDICATION ..... iv

ACKNOWLEDGMENTS ..... v

LIST OF TABLES ..... xiv

LIST OF FIGURES ..... xv

LIST OF APPENDICES ..... xvi

CHAPTER 1: INTRODUCTION ..... 1

    Importance of Counseling for the Intersex Population ..... 8

    Dearth of Counseling Literature About a Hidden Population ..... 9

    A Hidden Population Surfaces to Protest Intersex Infant Surgeries ..... 10

        Intersex Experience: Story of an Activist ..... 10

        Cultural Approaches to Intersex People Before the 1950s ..... 12

        The First Medical Protocol ..... 15

        Activist Protest: The First Medical Protocol ..... 19

        Activist Paradigm: Binary-Only Is Myth, Surgeries Are Heteronormative ..... 21

        Activist Impact: The Second Medical Protocol Involving Counseling ..... 23

    Growth of Intersex Organizations ..... 27

        Role of the Internet ..... 27

        Intersex Activist Political Organizations ..... 28

        Intersex Support Groups ..... 31

    Activist Vantage: Frontline Perspectives of Intersex Experiences ..... 32

    Problem Statement ..... 34

    Purpose of the Study ..... 36

    Significance ..... 36

    Research Design ..... 38

        Qualitative Paradigm ..... 39

        Interpretative Phenomenological Analysis ..... 39

    Research Questions ..... 41

    Definitions of Terms ..... 42

    Assumptions ..... 53

    Delimitations ..... 55

    Limitations ..... 55

    Ethical Framework ..... 56

    Conclusion ..... 56

CHAPTER 2: REVIEW OF THE LITERATURE ..... 60

    Overview of Sex Differentiation ..... 61

    Intersex Variations With Atypical Chromosomes ..... 63



|   |     |
|---|-----|
| Intersex Variations With Typical Chromosomes.....                                   | 63  |
| 46,XX (Female) Variations.....  | 63  |
| 46,XY (Male) Variations .....   | 64  |
| Intersex Diversity in Sexual Orientation and Gender Identity.....                   | 65  |
| Intersex Variations May Be Conflated With Transgender Experience .....              | 66  |
| Activist Characteristics .....  | 67  |
| Medical Literature Emphasis: Disorders/Differences of Sex Development               |     |
| Multidisciplinary Team Clinics and Parent Counseling .....                          | 70  |
| Legal Role of Parents in Medically Unnecessary Intersex Infant Surgeries .....      | 72  |
| Arguments in Favor and Against Parental Proxy Consent .....                         | 73  |
| Potential Legal Challenges to Medically Unnecessary Intersex Infant Surgeries ..... | 74  |
| Legislative Approach.....   | 74  |
| Judicial Approach: Potential Claims.....  | 74  |
| An Informed Consent Violation.....  | 75  |
| Sex Discrimination.....   | 77  |
| Disability Discrimination.....  | 78  |
| Professional Counseling Resources and Competency Guidelines.....                    | 78  |
| Intersex Client Categories.....   | 78  |
| Multicultural Texts.....  | 79  |
| Useful Resources .....  | 80  |
| Competency Guidelines .....   | 81  |
| Additional Counseling Competency Detail .....                                       | 83  |
| Parents and Guardians.....  | 83  |
| Medical Personnel.....  | 88  |
| Friends.....  | 91  |
| Schools and Educators .....   | 92  |
| Preves’s Intersex Study Findings Using Cass’s Sexual Minority Identity Development  |     |
| Model .....   | 94  |
| Preves’s Stage 1. Recognizing One’s Nonconformity.....                              | 96  |
| Being an Object of Study (Shame, Stigma, and Isolation) .....                       | 96  |
| Fearing the Unknown (Monstrosity).....  | 97  |
| Erasing Difference .....  | 97  |
| Performing (Fit in/Ease Stress/Please).....   | 98  |
| Doing Gender (Empowered Performance) .....  | 98  |
| Preves’s Stage 2. Acknowledging One’s Difference .....                              | 98  |
| Putting an End to Secrecy (Rejecting Stigma).....                                   | 100 |
| Personal Archeology (Locating Personal History) .....                               | 101 |
| Reclaiming the (Destroyed) Self.....  | 102 |
| Self According to Biological Logic (Privileging New Information) .....              | 102 |
| From Shame to Anger to Empowerment .....  | 103 |
| Telling Others (Breaking Secrecy and Isolation).....                                | 103 |
| Preves’s Stage 3. Validation of Self .....  | 103 |
| Preves’s Stage 4. Pride in the Marginal Identity.....                               | 104 |
| Preves’s Stage 5. Identity Synthesis and Integration .....                          | 105 |
| Conclusion .....  | 107 |

|  |     |
|--|-----|
| CHAPTER 3: METHODOLOGY .....   | 110 |
| Lessons Learned During Study Prehistory, 2014–2019 .....                   | 110 |
| Introduction to Interpretative Phenomenological Analysis Study Design..... | 119 |
| Rationale for IPA .....  | 120 |
| IPA’s Philosophical Foundations.....                                       | 121 |
| Husserl .....  | 121 |
| Heidegger .....  | 122 |
| Merleau-Ponty.....   | 122 |
| Sartre .....   | 122 |
| Hermeneutics .....   | 123 |
| Idiography .....   | 125 |
| Introduction to Data Collection and Data Analysis .....                    | 126 |
| IPA Methodology According to Smith et al. (2013).....                      | 126 |
| Context and Process Adapted From Corbin and Strauss (2015).....            | 127 |
| Additional Methodological Adaptations.....                                 | 130 |
| Data Collection .....  | 130 |
| Institutional Review Board Approval .....                                  | 130 |
| Researcher Roles and Research Questions .....                              | 131 |
| Target Population, Participant Criteria, Sample, and Recruitment.....      | 131 |
| Participant Protections and Procedures.....                                | 135 |
| Informed Consent.....  | 135 |
| Anonymity, Safety, Privacy, and Confidentiality .....                      | 136 |
| Interviews.....  | 137 |
| Transcripts.....   | 139 |
| Memos, Journals, and Other Data.....                                       | 140 |
| Data Analysis .....  | 141 |
| Step 1: Reading and Rereading.....   | 141 |
| Step 2: Exploratory Commenting/Initial Noting.....                         | 142 |
| Step 3: Developing Emerging Themes .....                                   | 144 |
| Step 4: Searching for Connections Across Emergent Themes .....             | 147 |
| Step 5: Moving to the Next Case .....                                      | 147 |
| Step 6: Looking for Patterns Across Cases .....                            | 148 |
| Presenting Results.....  | 149 |
| Criteria for Evaluating Study Quality .....                                | 149 |
| Researcher Bias.....   | 149 |
| Conclusion .....   | 152 |
| <br>   |     |
| CHAPTER 4: RESULTS.....  | 153 |
| Intersex Activists’ Experiences.....                                       | 156 |
| Intersex Experiences of Activist Angelo (formerly Angela) .....            | 156 |
| Overview.....  | 156 |
| Angelo’s Biology .....   | 158 |
| Angelo’s Physical Health.....  | 160 |
| Angelo’s Psychological Health.....   | 165 |
| Intersex Experiences of Activist Mitt .....                                | 176 |
| Overview.....  | 176 |

|  |     |
|--|-----|
| Mitt’s Biology.....  | 176 |
| Mitt’s Physical Health.....  | 176 |
| Mitt’s Psychological Health.....   | 177 |
| Intersex Experiences of Activist Marsha .....  | 185 |
| Overview.....  | 185 |
| Marsha’s Biology.....  | 185 |
| Marsha’s Physical Health .....   | 186 |
| Marsha’s Psychological Health.....   | 189 |
| Intersex Experiences of Activist Val/Valerie .....   | 192 |
| Overview.....  | 192 |
| Val’s/Valerie’s Biology .....  | 193 |
| Val’s/Valerie’s Physical Health.....   | 194 |
| Val’s/Valerie’s Psychological Health.....  | 196 |
| Introduction to the Intersex Identity Development Model .....  | 204 |
| Intersex Identity Development Model Stage 1. The Binary-Only Framework: Intersex as<br>a Medical Disorder..... | 208 |
| Born Under the Binary-Only Framework.....  | 209 |
| Being “Fixed” or “Normalized” as a “Disorder” .....  | 211 |
| Not Knowing About an Alternate Framework to Binary-Only .....  | 212 |
| Experiencing Confusing Discrepancies .....   | 214 |
| The Binary-Only Influences of Culture or Religion.....   | 215 |
| Not Allowed to Exist: Exterminated, Annihilated, Eugenics .....  | 215 |
| Discovering One’s Variation Later in Life .....  | 217 |
| Harm From All Social Sources .....   | 218 |
| Abuse: Physical, Emotional, and Sexual .....   | 220 |
| Force Fitting: Body and Behavior.....  | 221 |
| Toxic Labeling .....   | 221 |
| Family Rejection and Scapegoating.....   | 222 |
| Isolated, Secrecy, Lies, and Stigma .....  | 223 |
| Pity .....   | 224 |
| Harm From Mental Health Professionals .....  | 224 |
| Psychiatric False Diagnoses and Drugs .....  | 225 |
| Gender Brainwashing.....   | 225 |
| Erasure Through Invisibility .....   | 227 |
| WPATH Standards Misapplied.....  | 227 |
| Harm From Medical Professionals .....  | 230 |
| Medically Induced “Trans”.....   | 230 |
| Surgically Erasing Intersex.....   | 231 |
| Hormonally Erasing Intersex .....  | 232 |
| Loss of Their Natural Intersex Body .....  | 232 |
| Robbed of Normal Quality of Life.....  | 232 |
| Lies and/or Secrecy.....   | 233 |
| Objectified As a Medical “Thing” .....   | 233 |
| Neglected or Unaddressed Medical Needs .....   | 234 |
| Iatrogenic Harm .....  | 236 |

|   |     |
|---|-----|
| Harmed Responses .....  | 236 |
| Shame Internalized: Sex-Related Phobias .....                                   | 236 |
| Emotional Castration, Psychic Mutilation .....                                  | 237 |
| Freak, Monster, Alien .....   | 238 |
| Genital Exposure Trauma .....   | 239 |
| Fear of Doctors .....   | 240 |
| Survivor Guilt .....  | 241 |
| Other Emotional Disturbances .....  | 242 |
| Intersex Identity Development Model Stage 2. Breaking the Binary-Only Framework | 244 |
| Discovering and Investigating .....   | 244 |
| Connecting With the Intersex Community .....                                    | 245 |
| Realizing Intersex Exists and I Have an Intersex Variation .....                | 246 |
| Being Affirmed (External Support) .....   | 249 |
| Support From Intersex People .....  | 249 |
| Support From Close Family and Friends .....                                     | 249 |
| Positive Counseling .....   | 250 |
| Adapting (Internal Support).....  | 250 |
| Self as Superhero or Powerful Alien .....                                       | 250 |
| Defensive Faking or Lying .....   | 251 |
| Ending Secrecy, Accessing Medical Records.....                                  | 251 |
| Self-Soothing: Self-Protection, Self-Care, Humor, and Spirituality.....         | 251 |
| Intersex Identity Development Model Stage 3. Beyond the Binary-Only Framework:  |     |
| Intersex as a Natural Bodily Variation.....                                     | 252 |
| Clarity .....   | 253 |
| Sex and Gender Are on Continuums .....  | 253 |
| Money’s Model Was a Devastating Error .....                                     | 254 |
| Gender, Chromosomes, and Genitals Do Not Always Align .....                     | 254 |
| Self-Determination of Gender and Body Is the Goal.....                          | 255 |
| Terminology Matters: “Disorder” Harms .....                                     | 256 |
| Core LGBTQ+ Variance: Intersex Medical Harm.....                                | 257 |
| Intersex Medical Needs Are Not Binary.....                                      | 258 |
| Intersex People Are Not All Infertile.....                                      | 260 |
| Some Intersex Men Give Birth .....  | 261 |
| Many Intersex People Are Heterosexually Oriented .....                          | 262 |
| The 2006 Chicago Consensus Did Not Stop Infant Sex Surgeries.....               | 262 |
| No Happy Silent Majority With Infant Surgeries .....                            | 266 |
| Surgical Results Are Dissatisfactory .....                                      | 267 |
| Informed Consent Process Is Dissatisfactory .....                               | 269 |
| Infant Surgeries Create, Not Prevent Stigma.....                                | 270 |
| Intersex People Have Great Sex Without Surgeries .....                          | 271 |
| Automatic Gonad Removal Harms .....   | 272 |
| Infant Anesthesia Harms.....  | 274 |
| Controversy: Biology Only and/or Identity? .....                                | 275 |
| Controversy: “Delay is Okay” Versus “No Body is Shameful” .....                 | 276 |
| Controversy: Medical Treatment: Misguided or Diabolical? .....                  | 278 |
| Controversy: Are Intersex Birth Certificates Important?.....                    | 281 |

|  |     |
|--|-----|
| Action: Activism or Individual Empowerment.....  | 282 |
| Motivations and Need .....   | 282 |
| Prior Conditions .....   | 283 |
| Activities .....   | 283 |
| Vision .....   | 284 |
| Activist Infighting.....   | 284 |
| Intersex Community Subgroups .....   | 285 |
| Activist Hardships.....  | 292 |
| Activism Changes Over Time.....  | 293 |
| Activism Responses .....   | 294 |
| Activism Successes .....   | 294 |
| Future in Activism .....   | 295 |
| Self-Actualizing .....   | 295 |
| Activists’ Perspectives on Positive Intersex Counseling .....  | 296 |
| Overview .....   | 296 |
| Current Status: Needed, Low Availability, Uninformed .....   | 297 |
| Connects Clients With the Intersex Community .....   | 299 |
| Comprehends the Unique Intersex Experience of Nonexistence.....  | 299 |
| Proficient in Intersex Variation Differences and Implications .....  | 300 |
| Holds the Monstrous, Exterminated, Alien Self .....  | 302 |
| Reflects and Strengthens the Lovable, Human Self.....  | 303 |
| Supports Parents and Ensures Comprehensive Informed Consent .....  | 305 |
| Addresses Transitional Care .....  | 307 |
| Conclusion .....   | 307 |
| <br>   |     |
| CHAPTER 5: DISCUSSION.....   | 310 |
| Intersex Identity Development Model Compared to Preves’s Sexual Minority Identity<br>Model .....                           | 314 |
| Limitations .....  | 325 |
| Delimitations.....   | 327 |
| Implications: Counselor Practice, Training, and Research.....  | 330 |
| Avoiding Common Terminological Errors.....   | 330 |
| Addressing the Counseling Training and Research Vacuum .....   | 331 |
| Trauma, Grief, and Other Avenues for Needed Research .....   | 333 |
| Develop Intersex Counseling Competency by Variation.....   | 334 |
| Final Observations .....   | 335 |
| Using Medicine Appropriately to Address Actual, Not Imagined Intersex Medical<br>Needs.....                                | 335 |
| Operant Quantum Physics Observation Principle and the Binary-Only Prison .....   | 335 |
| Descartes Has Something to Say .....   | 338 |
| This is Eugenics .....   | 338 |
| Medical Hubris and Law of Unintended Consequences: Stigma Created, Not<br>Prevented.....                                   | 339 |
| AND Thinking Is a Muscle.....  | 340 |
| Ethical “Con” Argument Trumps A Surgical Prowess “Pro” Argument: Infants<br>Should Have A Right of Self-Determination..... | 344 |

|   |     |
|---|-----|
| Counselors Should Be Involved With interACT .....                   | 344 |
| Counselors: Erase Pity, Pity Kills, Cherish Diversity Instead ..... | 346 |
| References .....  | 348 |

## LIST OF TABLES

|  |     |
|--|-----|
| Table 1. Comparison of Stages in Cass’s and Preves’s Sexual Minority Identity Models .                                   | 95  |
| Table 2. Preves’s Intersex Findings Using Cass’s Sexual Minority Identity Model .....                                    | 107 |
| Table 3. Participant Demographics .....  | 154 |
| Table 4. Intersex Identity Development Model Stages and Themes .....   | 206 |
| Table 5. Comparison: Intersex Identity Development Model Themes and Preves’s Sexual Minority Identity Model Themes ..... | 316 |

## LIST OF FIGURES

|   |     |
|---|-----|
| Figure 1. Intersex Identity Development Model ..... | 205 |
|---|-----|



## LIST OF APPENDICES

|   |     |
|---|-----|
| APPENDIX A. U.S. Hospitals With Intersex/DSD Multidisciplinary Clinics.....     | 365 |
| APPENDIX B. Participant Demographic Information.....                            | 366 |
| APPENDIX C. Quality Rubric .....  | 369 |
| APPENDIX D. Participant Information Sheet.....                                  | 371 |
| APPENDIX E. Participant Consent Form .....                                      | 375 |
| APPENDIX F. Participant Debrief .....   | 378 |
| APPENDIX G. Modified Participant Debrief Per Activist Hotline Suggestions ..... | 380 |
| APPENDIX H. Interview Schedule .....  | 382 |
| APPENDIX I. Quality Report.....   | 384 |
| APPENDIX J. Activist-Prepared Intake Questions for Intersex Clients .....       | 386 |

## CHAPTER 1: INTRODUCTION

Imagine a world where overweight infants, by medical protocol, are surgically altered to reduce them in size to the average infant's weight. Imagine a world where infants of color, by medical protocol, are surgically altered to have a more "acceptable" skin color. Imagine that these protocols have been established without long-term studies to demonstrate that children grow up happier being surgically altered to be thin or a different color. Surely these imaginings would be impossible. Parents would never consent. The world would never allow it. Activists would protest. These examples are not real, but a similar medical practice is both real and commonplace.

Since the 1950s, intersex infants have been subjected by medical protocol to "normalcy" surgeries on their genitals to make them appear more like the majority as male or female. Intersex infants are the only sexual minority group who are subjected, without their consent, to surgical eradication of their differences. Parents provide consent (Karkazis, 2008). Minus Portugal and Malta, the world allows it (Guilbert, 2018). These surgeries are performed without long-term studies demonstrating quality of life improvement (Karkazis, 2008; Human Rights Watch & interACT Advocates for Youth, 2017). Activists are indeed protesting (Human Rights Watch & InterACT Advocates for Youth, 2017). These activists are dedicated to making illegal medically unnecessary surgeries designed to make intersex infant genitalia conform to the majority. Four of their experiences were the focus of the present study.

This chapter is an introduction to the intersex population, a hidden population without strong counseling support. I present an overview of the medical protocols that formalized hormonal and surgical approaches to transform intersex babies into appearing

male or female. I describe the activism that began in the late 1990s and continues today to stop intersex infant sex-related surgeries. I also provide an overview of the methodology employed in this study. This study was methodologically designed to investigate activist perspectives about what it means to have been born with an intersex variation, worked as intersex activist, and experienced the quality of counseling available for intersex people.

*Intersex natural bodily variations* or *intersex variations* are terms for sex development occurrences in which the average step-by-step process of sex differentiation in a fetus does not occur, resulting in uncommon anatomical variation (Wisniewski et al., 2012). Prevalence statistics vary given underreporting and disagreement as to which forms qualify as intersex. A commonly cited aggregate prevalence estimates that 1.7% of the population is born with an intersex variation (Fausto-Sterling, 2000). The 1.7% estimate is the approximate equivalence to the prevalence of redheaded people (Intersex Campaign For Equality, 2020). As the U.S. population was estimated at just over 331,300,000 in 2020, 1.7% equates to approximately 5,600,000 (Macrotrends, n.d.).

Aggregate prevalence is not the same as a particular variation's prevalence. Some intersex variations are exceedingly rare, and others are relatively common. The following are some examples of prevalence statistics. Complete androgen insensitivity has been estimated at 1 in 20,400 births. Partial androgen insensitivity variation has been estimated at 1 in 130,000 births. Klinefelter syndrome has been estimated at 1 in 500 to 1 in 1,000 births. Turner has been estimated at 1 in 2,500 births (Alderson, 2013). Hypospadias variation has been estimated at 1 in 200 to 300 births (Alderson, 2013; Dreger, 2016).

Though not necessarily visible, intersex variations are present from birth (congenital) and, as mentioned, vary in type. There are over a dozen different intersex forms with varying etiologies, including chromosomal, hormonal, iatrogenic, and unknown origin (Preves, 2003; Wit et al., 2007). In some intersex variations, chromosomes may be extra or missing. In other forms, the chromosomal patterns are typical but hormonal imbalances result in 46,XY karyotype males having feminized features or 46,XX karyotype females having masculinized features (Wisniewski et al., 2012). The atypicality may be evident at birth, not evident until puberty, or may remain undetected. In some presentations, visible differences of development may occur at birth such as enlarged clitoris, smaller than typical penis, or absence of penis. Few intersex variations are life threatening (Gomez-Lobo, 2014; Karkazis, 2008). The only circumstances requiring immediate surgical intervention on an intersex infant involve threat to life such as cloacal exstrophy (infant born with inner abdominal walls exposed) or a hormonal salt wasting crisis. Not all intersex individuals are infertile, and most have life expectancy similar to the general population (Wisniewski et al., 2012).

Though most intersex infants are born healthy, intersex births are controversially subsumed under the medical domain as *disorders (or differences) of sex development (DSDs)*. Labeling the variations as disorders implies that the variations need medical management (Karkazis, 2008). Under the current medical protocol, infants identified as intersex are medically analyzed to determine their intersex variation. The analysis process involves genetic, hormonal, and other testing to diagnose the particular variation (Karkazis, 2008; Lee et al., 2006). Any of the rare life-threatening conditions are identified and dealt with immediately.

In addition to addressing life threats, the medical goal in the assessment phase is to immediately assign girl or boy gender to the child (Lee et al., 2006). The physical assessment attempts to discern the likely path of future sex development so that a projection can be made for the most likely (binary) boy or girl gender that the child will assume in the future. Gender assignment is fallible given that gender identity, body parts, and desire/orientation do not always align. Gender assignment is more problematic in some cases than others (Karkazis, 2008). Gender assignment could wait until the child declares their own gender. Most intersex persons are believed to retain the gender assigned at birth (Dreger, 2016).

Once a gender assignment is made, parents are offered the opportunity for optional surgery to align the child's external genitalia with the chosen gender and/or remove internal body parts that supposedly do not align with the chosen gender (Karkazis, 2008). For example, a child with the variation complete androgen insensitivity syndrome (CAIS), 46,XY karyotype, assigned female/girl, might have her testes removed. A child with the variation congenital adrenal hyperplasia (CAH), 46,XX karyotype, assigned female/girl, might have her clitoris reduced in size or recessed (Karkazis, 2008). The surgeries are irreversible.

In contrast to medical practices conducted to restore bodies to physical health, intersex infant surgeries are performed on healthy infants for social and psychological reasons. The parent and physician presumption is that healthy intersex children will be saved from social ostracism, low self-esteem, and/or suicide by having the optional surgeries (Karkazis, 2008). Another goal is to surgically alter the infants based on heteronormative assumptions and values (Dreger, 2016). Males with 46,XY karyotype

have been assigned female if their penis is too small for penetration. Infants born without a vagina have had vaginas constructed. An artificial vaginal construction procedure is conducted for the pleasure of a hypothetical penis, not for the direct pleasure of an intersex person (Karkazis, 2008). Another recognized social goal behind the surgeries is to reduce parental distress. The belief is that parent–child bonding might be improved if the child’s genitalia appear similar to other children’s genitalia. Another reason these surgeries have been conducted is to ease parental distress over possible homosexuality (Dreger, 2016; Karkazis, 2008). Variant genitals are presumed to inhibit opposite-sex attraction and promote same-sex attraction.

A 2006 consensus statement by the U.S. and European Pediatric Endocrine Societies attempted to discourage some of the aforementioned motivations, which by reverse implication means that the groups’ leaders believed that the motivations should be addressed (Lee et al., 2006). The consensus statement stated that there were (a) no outcome studies demonstrating that the surgeries worked to ease parent distress, (b) homosexuality is not indicative of incorrect gender assignment, (c) and reductions of clitoris size should only be undertaken if the clitoris is “extremely large” (Lee et al., 2006). Consensus guidelines are not binding upon society members (Karkazis, 2008). The precise length and width of what would constitute a too large clitoris was not specified.

Implicit in operating on healthy infants are two assumptions (both untested by long-term outcome studies). The first is that optional infant sex-related surgeries supposedly work to accomplish the psychosocial ends of protecting the child from stigma

and lessen parental distress. The second is that the surgeries allegedly accomplish those two ends without countervailing negative repercussions.

These assumptions are controversial for several reasons. First, medicalized treatment has actually created the stigma it sought to prevent (Karkazis, 2008; Kessler, 1998; Preves, 2003). Second, as mentioned, there is no evidence that these procedures reduce parental stress (Karkazis, 2008). Third, ethical issues are raised by operating on a person for the benefit of someone else (Dreger, 1999; Feder, 2014). Fourth, surgical good intent is not the same thing as surgical success. Physical harm has occurred (Blair, 2016; Lev, 2006; Preves, 2003). The harm included surgical scarring, infection, pain, and loss of sensation in extremely sensitive areas (Devore, 1999; Dreger, 1999). Unsuccessful surgeries have created the need for more surgeries to repair problematic surgical effects. What looks presentable in infancy does not necessarily grow proportionately to the same effect in adulthood. Clitorises have shriveled and atrophied due to surgeries conducted in infancy (Karkazis, 2008).

Terminology is fraught with controversy (Feder & Karkazis, 2008). In medical environments, intersex variations are known as disorders of sex development (DSD). (Lee et al., 2006; Sandberg et al., 2017). The term DSD is disfavored by many intersex people as the word “disorder” carries a connotation of pathology instead of naturally occurring variance. The United Nations uses the term intersex natural bodily variations in its effort to normalize intersex variations and stop unnecessary medical surgeries on intersex infants. The United Nations asserts that conducting medically unnecessary surgeries is infant torture (United Nations Office of the High Commissioner for Human Rights, 2015).

The term intersex is controversial. There is division among parents, physicians, scholars, and intersex persons about which variations qualify as intersex. Furthermore, some individuals are offended because the term intersex supposedly carries an unacceptable connotation of a valid third biology, in other words, male, female and intersex. Others counter that a third distinct intersex biology is politically and medically crucial to recognize. Without a separate recognized intersex biology, people are squeezed into the too narrow constructions of male or female, resulting in unnecessary treatments that both harm and deny infants their right of self-determination (Marquez, n.d.).

In the present study, I used the term intersex variations as shorthand for intersex natural bodily variations. Intersex was used most often as an adjective, not a noun, in this study. The reasoning was that intersex as a noun seems to imply that intersex is all that the person is, whereas in reality an intersex variation is only one factor of personhood. Further, I used the term intersex variations instead of DSD. Construing healthy infants as disordered and operating on them without their direct consent is a violation of the 2004 American Counseling Association's (ACA) Resolution on Protecting Intersex Children From Unwanted Surgery, Secrecy, and Shame, passed in 2004. In the present study, the term intersex variation (or variations), is used broadly to describe all congenital sex-development variations, yet some people with those variations do not see themselves as having an intersex variation. In other words, the biology of what constitutes an intersex variation is controversially viewed either broadly or narrowly. My using the intersex variation term broadly is not meant to take away self-determination of anyone by ascribing an intersex variation to those who do not own having one. Instead, this usage is meant to depict the controversy.



## **Importance of Counseling for the Intersex Population**

Support from licensed counselors is important for intersex individuals and their families. Counseling has been recommended as necessary to help parents adjust to the diagnosis, bond with their infants, cope with making infant surgery decisions, and adjust to the impact of the diagnosis (Consortium on the Management of Disorders of Sex Development, 2006a). Intersex individuals have reported challenges in developing their personal gender identity; learning how and when to disclose their intersex status; and coping with the shame, stigma, and isolation that might be associated with a diagnosis and/or medical treatments (Devore, 2013; Karkazis, 2008; Preves, 2003).

Intersex status as a sexual minority is particularly relevant for counseling (Alderson, 2013; Singh et al., 2010). Having sex development variations means that an intersex individual does not fit the binary conceptualization of sex as male or female only. Not being in the majority as male or female has social implications in terms of discrimination, stigma, and oppression.

The intersex population has unique counseling needs related to lifelong interface with the medical profession. Addressing these needs is critical. Countless individuals have been and are being surgically altered without sufficient understanding of its long-term impact (Alderson, 2013). As expressed by an endocrinologist with 50 years of practice, “A broad section of society looks upon sexual ambiguity as a shameful stigma. No challenge in the practice of medicine requires more knowledge, tack, and skill than the management of these children” (Wilson et al., 2012, p. 340). The scope of needed counseling services for intersex individuals is broader than merely a focus on medical issues. Intersex counseling involves issues germane to all persons because intersex individuals are first and foremost persons, not their sex classification (Singh et al., 2010).

## **Dearth of Counseling Literature About a Hidden Population**

The counseling field has developed few sources to support the needs of the intersex population (Singh et al., 2010). LBGTQI+ textbooks increasingly contain chapters on intersex counseling needs but use resources developed outside the field of counseling (Alderson, 2013; Burnes & Richmond, 2012; Ginicola, 2017; Goodrich & Luke, 2015; Singh et al., 2010). Counselors have also begun to address intersex counseling competencies. In *Counseling Competencies for Counseling with Lesbian, Gay, Bisexual, Queer, Questioning, Intersex, and Ally Individuals*, a taskforce for the Association for Lesbian, Gay, Bisexual, and Transgender Issues included a section on the counseling competencies required for working with intersex individuals and their families (ALGBTIC LGBQIA Competencies Taskforce, 2013). Counseling issues and competencies are discussed in more detail in Chapters 2 and 5.

One obvious reason for the paucity of counseling education resources for intersex needs relates to the following point: counseling services cannot be well developed for a hidden population. From the 1950s through 2006, parents were advised to hide the fact of an intersex variation and the medical treatment received from both the child and the public in order to allegedly improve the child's mental adjustment (Feder, 2014; Schweizer et al., 2017). In the late 1990s, courageous intersex individuals came out of hiding to tell their difficult and highly personal stories involving their own genitalia and medical treatments (Dreger, 1999; Marquez, n.d.; Morris, 2004; Vilorio, 2017). The revealed stories led to increased attention in the social sciences. Intersex psychological issues are now beginning to receive thoughtful attention (Lev, 2006; Liao, 2016; Liao & Roen, 2014; Liao & Simmonds, 2014). A future era of improved counseling services for intersex individuals is thus within view.

## **A Hidden Population Surfaces to Protest Intersex Infant Surgeries**

### **Intersex Experience: Story of an Activist**

Tiger Devore is an intersex spokesperson, clinical psychologist and sex therapist (Devore, n.d.). As an intersex activist, elements of Devore's intersex experience and political stance are public record (Motta, 2011). Devore was born with severe hypospadias. In this form of intersex, the typical male sex development process in utero does not occur in which the urethra migrates to the tip of the penis. Instead, the urethra opening exits somewhere along the penis shaft. Hypospadias is common, affecting approximately 1 in 200 males (Urology Care Foundation, 2018). Since the 1950s, hypospadias surgeries have been performed for the social purpose of standing to urinate (Devore, 1999). Yet, skin graft tissue is not the same as natural urethra tissue that is designed to withstand daily urine acidity. Devore had over 21 surgeries, which resulted in urethra scarring, surgeries to correct the internal scarring, loss of sensation, and repeated skin grafts that scarred external skin. Hypospadias surgeries are known to be so problematic (scarring, fistulas, leakage at the original opening, infections, need for repeat surgeries, and need for regular catheterization) that a pejorative term has arisen, "hypospadias cripples" (Dreger, 2016). Repeat hypospadias surgeries are so common as to be considered a "bread and butter" component of urology (Dreger, 2016; Karkazis, 2008).

Devore (2013) reported that his surgeries were not medically necessary. Although surgically unaltered hypospadias might be socially messy unless sitting down to urinate, surgery to relocate the urethra opening to the penis tip is not a medical necessity (Devore, 1999). In other words, Devore's surgeries were optional and conducted for a social purpose. Devore (1999) described his childhood as one of pain and isolation. He

described emotional reactions of embarrassment, guilt over being a family burden, feeling obligated to withstand the hell in isolation, hopelessness, and suicidality in his teen years (Devore, 1999, 2017). Devore stated that his life changed when he realized that the medical profession was wrong in its bias that happiness and healthy relationships required typical-looking genitals (Devore, 1999).

Devore is a former president of an intersex support group, the Hypospadias and Epispadias Association. (Epispadias is similar to hypospadias in that the urethra opening exits on the shaft of the penis. The difference between the two relates to which side of the shaft the opening exits. An exit on the topside of the shaft is called epispadias, and an exit on the underside of the shaft is called hypospadias.)

Devore is also a former member of the Intersex Society of North America (ISNA), the first major intersex activist organization, (Hyena, 1999). In 1984, Devore reported his belief that, through his appearance on *People Are Talking Baltimore* with cohost Oprah Winfrey, he was the first person with genital variation to come out on television as having an intersex variation. Since the early 1980s, Devore (n.d., 2011) has publicly protested that the social goal of men standing to urinate is not worth the pain of failed surgeries, leaking, drugs, scarred body, and frequent tissue breakdowns.

In a 2015 open letter, Devore described complete frustration with the progress of activism since 2006, which was when the medical protocol changed (Dreger, 2015). Beneficially physicians had become more open in discussions with parents about the diagnosis and surgical options. Nevertheless, Devore reported that he no longer wished to cooperate with the medical profession. He stated that the salient feature resulting in great harm had not changed, namely that optional sex-related surgeries on intersex infants were

continuing. In his view, the medical profession used the 2006 change in medical protocol to co-opt intersex activism to provide cover for the fact that surgeries were continuing. Intersex activists had argued for surgeries to stop being performed in secrecy. Since 2006, with the new and more open process of parent provided consent, physicians were allegedly absolved from responsibility. Devore concluded that legal action was the only way to stop the surgeries by recognizing a child's right to bodily autonomy and self-determination (Dreger, 2015).

This brief window into intersex activism through Devore's story illustrates the following: An intersex person's experience is influenced by the person's particular intersex variation, the medical treatment for that variation, and the degree of atypical severity. Severity impacted Devore's number and scope of medical interventions. Devore's story also illustrates that being a public intersex activist is a relatively recent phenomenon commencing at the end of the 20th century. Finally, Devore's story illustrates that the power held by the medical profession is core to understanding intersex experiences, especially intersex activism. Intersex activism has largely pivoted around protest against two successive medical protocols regarding intersex infants, one instituted in the 1950s and the more recent one instituted in 2006, both of which allow medically unnecessary sex-related surgeries on intersex infants.

### **Cultural Approaches to Intersex People Before the 1950s**

The history of how intersex individuals have been treated over time by the institutions of religion, law, and medicine has been addressed in depth by historians (Dreger, 1998; Karkazis, 2008; Reis, 2009). Only a cursory summary is provided next as background to the medicalized experiences intersex individuals find themselves in today. Intersex variations are not new phenomena. Historically, people have pondered whether

intersex is male or female, both male and female, or neither male nor female (Karkazis, 2008).

Until the turn of the 20th century, births were home events managed by midwives. As such, intersex bodies may never have come to the attention of physicians (Karkazis, 2008). Some intersex individuals may not have themselves known that they were variant in their physical appearance. Medicine had little capacity to intervene prior to the 1950s. Instead, science and medicine focused on how to classify variations and treat hermaphrodites (a previous but now disfavored term). Karkazis (2008) observed that classification and treatment debates have not been fully resolved, resulting in very real and sometimes irreversible impact on the lives of intersex people today.

Interest regarding hermaphroditism has varied over the centuries. In the 1500s, interest was high due to associating hermaphrodites with all forms of sex variance, including sodomy and pornography (Karkazis, 2008). Legal definitions were strict so as to maintain a binary designation of either man or woman due to marriage and property rights laws. By the 1700s, medical literature was more admitting of complexity but, for social and political reasons, defining and maintaining separation between the sexes increased in importance. Despite medical research to the contrary, the binary model of two separate sexes with separate roles became entrenched by the 1700s (Karkazis, 2008).

In the 1800s, interest focused on which biological markers should be used in classification (Karkazis, 2008). Known facts were confounding; for example, some men did not ejaculate, some women did, some women menstruated, and others did not. Toward the end of the 1800s, classifications of true hermaphrodite and pseudohermaphrodite were proposed. True hermaphrodites had both male and female

gonad tissue whereas pseudohermaphrodites were supposedly really male or female, but their external anatomy hid their “real sex” of either male or female. This period in classification marked an emphasis on gonads instead of external genitalia (Dreger, 1998, 2016; Karkazis, 2008). Gonad sex classification was problematic as the classification was hard to test without an autopsy. Furthermore, clear exceptions were evident. Some people who were clearly identified as women had testes (a variation now called CAIS). Also, waiting for an autopsy was not practical as people needed a gender identity to function in society (Karkazis, 2008).

In the early 20th century, scientific advances occurred in a variety of fields including surgery, endocrinology, and urology (Karkazis, 2008). Chromosomes and gonadal secretions were discovered in the early 1900s. By the 1920s, the scientific community understood that chromosomes and hormones were playing key roles in sex development. Atypical hormones levels could alter typical chromosomal sex developmental paths. As mentioned, during this time, intersex births were placed under the medical (not midwife) domain. These scientific and cultural changes set the stage for infant genital surgeries (Karkazis, 2008).

During the scientific advances of the early 20th century, physicians labored independently without a protocol to guide their clinical approach to intersex births. In other words, intersex infant treatment varied. Urologists tended toward surgeries; endocrinologists tended toward hormonal treatments (Karkazis, 2008). Both disciplines aimed to align intersex bodies with either male or female appearance. Gender identity increased in importance.

Some physicians and surgeons considered it cruel to assign a “true sex” that conflicted with their patient’s experienced identity. Thus, doctors were evidencing a shift from “true sex” based on gonads to determining a “best sex” based on biological markers and a “gender identity in evidence” or a “gender identity likely to emerge.” This approach was still in keeping with a binary model, in other words, “best sex” was either male or female (Karkazis, 2008). The options of being both or neither male nor female were disregarded.

### **The First Medical Protocol**

A major event occurred in the 1950s in the form of the first unified protocol involving theory and practice guidelines for infant intersex medical treatment. The formal medical protocol was instituted by psychologist John Money at Johns Hopkins University (Feder, 2014; Karkazis, 2008; Money & Ehrhardt, 1973). The protocol is called the *optimal gender of rearing model*, or by less flattering names, the *concealment model* or the *genitals make gender* model. The names reference respectively (a) Money’s emphasis on rearing (nurture) as the optimal feature to consider in assigning gender, (b) the model’s recommended procedure of keeping the variation concealed from the child until gender was allegedly imprinted through consistent rearing, and (c) the model’s emphasis on surgically conforming external genitalia to supposedly enhance the imprinting of the assigned gender (ALGBTIC LGBQQA Competencies Taskforce, 2013; Feder, 2014; Karkazis, 2008).

At the time, Johns Hopkins University was the leading organization in intersex research and surgeries. When the protocol was published, it rapidly became the standard for intersex infant treatment and remained the protocol for roughly 40 years (Karkazis, 2008). The conflation of sex with gender greatly increased at this point in history.



As previously mentioned, in the 1950s, medical emphasis had evolved away from typing male or female sex by visible markers such as gonads to finding sex in consideration of other less visible biological markers such as chromosomes and hormones (Karkazis, 2008). According to Karkazis (2008), Money was aware, however, that gender assignments based on chromosomes were also often faulty. Money theorized that all biological markers were important but not sufficient to explain gender acquisition. Money's protocol outlined several sex variables: chromosomes, gonads, accessory internal genitalia, hormones, secondary sex characteristics, external genitals, gender role (including orientation/desire), and assigned sex/sex of rearing. Money allocated the greatest role to psychological influence (once the child was born); in other words, to assigned sex/sex of rearing (Karkazis, 2008). The protocol thus emphasized a more environmental conceptualization of gender than the previous historical approaches. In other terms, Money placed a nurture emphasis on gender assignment and surgical alteration (Karkazis, 2008).

Under Money's protocol, living as an unaltered intersex person and/or raising such a person was considered a nonviable social experience that demanded intervention (Karkazis, 2008). The new protocol recommended that physicians consider biological factors, assign the most reasonable gender, and then direct parents to create a home environment that consistently nurtured the assigned gender (Money & Ehrhardt, 1973). The protocol goal was to create "an optimal gender of rearing" instead of find a "true sex" (through gonads only) or to find a "best sex" (by considering biological markers and evidence of an existing gender). Biological markers were to be scientifically assessed to take into account their likely impact by puberty. Once a gender identity was selected,

however, it supposedly could be assured with an environment of consistent rearing according to gender norms (Karkazis, 2008; Money & Ehrhardt, 1973).

Infants supposedly needed social influences to trigger their gender. In infancy, gender imprinting had not happened yet. Money proposed a window from birth to around 18 months during which time the baby could be assigned a chosen gender (Money & Ehrhardt, 1973). However, the preferred timing for assignment was during the first weeks of life. As a part of the protocol, parents were advised to allow surgeons to operate as soon as possible to construct a male or female appearance according to the assigned gender. The surgeries were conducted so that the parents and child could allegedly believe with consistency in the child's gender assignment (Karkazis, 2008).

Under the protocol, parents were directed to be secretive and not let the child know until much later that there had been a sex development difference (Karkazis, 2008). Secrecy about diagnosis and treatments would aid consistency in the imprinting environment. A consistent gender environment would allow young children to absorb the belief that they were born typically male or female (Money & Ehrhardt, 1973). The children would thereby achieve greater gender identity adjustment as boy/man or girl/woman (Karkazis, 2008; Money & Ehrhardt, 1973; Preves, 2003; Reis, 2009).

Money's guidelines had a heteronormative framework. Money recommended that babies with 46,XY karyotype should be judged on the basis of their projected phallus size for copulatory purpose and castrated if deemed "inadequate." Leaving these children as boys supposedly led to an unsatisfactory sex life; a female sex assignment supposedly offered them possibilities in romance and marriage (Karkazis, 2008). Supposedly, CAH, 46,XX karyotype, should always be assigned female as the individuals were fertile.

Feminizing surgeries such as clitoral reductions would then be performed so they would be perceived as women (Karkazis, 2008).

Money published prolifically in medical journals beginning in the 1950s and the protocol was widely adopted (Karkazis, 2008). Money and coauthor Anke Ehrhardt (who treated one of the activists in the present study with negative consequences) achieved worldwide recognition in *Man & Woman, Boy & Girl, Gender Identity From Conception to Maturity*, published in 1973, which summarized Money's theories for the mass market (Karkazis, 2008; Money & Ehrhardt, 1973). The idea that environmental influence was the core influence in gender creation was absorbed into the feminist movement and other social sciences, thus Money's influence extended to many fields outside of medicine (Karkazis, 2008).

Money's work was discredited in a highly public manner around the same time as early intersex activism commenced, at the beginning of the 21st century (Colapinto, 2000; Feder, 2014). Money had touted verification of his nurture theory of gender development through an identical twin study of two brothers. The study involved a botched circumcision and the alleged successful rearing of a twin boy, David Reimer, as a girl named Brenda. The public pseudonym for the case made famous by Money was John/Joan. Though this was not an intersex case, Money cited the findings as evidence of applicability of the protocol to intersex cases. In fact, "Brenda/Joan" was revealed to be deeply unhappy as a girl/woman and had transitioned back to man. The Reimer story was covered in *As Nature Made Him: The Boy Who Was Raised As a Girl* (Colapinto, 2000). Colapinto interviewed Reimer and detailed the horrific experiences he and his family lived through in trying follow Money's protocol. Colapinto depicted Money as an

unethical researcher who knew that the Brenda case was not the success he had claimed it to be. Furthermore, Money was depicted as a perverse man whose therapy sessions involved asking the Reimer twins to perform sex practices in the therapy sessions. Both David and his brother ultimately committed suicide.

Perspectives on Money and his work are varied. The theory that gender is completely malleable in infancy is no longer in favor (Karkazis, 2008). Some clinicians and medical scholars may value his prolific publishing record, quantity of empirical studies, development of a systematic protocol for intersex medical treatment, and innovative emphasis on environmental influences in gender development (Karkazis, 2008). Furthermore, some may believe that Money's career was discredited unfairly due to media attention (Karkazis, 2008). Others, including intersex activists, likely regard Money as a fame-mongering psychologist with pedophilic tendencies who institutionalized the practice of genital mutilation to great harm for the intersex community (Colapinto, 2000). Money is also considered by some to be an unethical academic researcher who lied to keep the truth about Reimer from being made public (Colapinto, 2000). Money's research carries a dark cloud of ethical taint (Karkazis, 2008). Surprising to some, Money continues to be cited favorably in the psychological literature despite being discredited as a researcher with an integrity issue.

### **Activist Protest: The First Medical Protocol**

Thirty years after Money's protocol became the standard for medical treatment, the first infants reached maturity. Some became activists, opposing the medical practice of medically unnecessary surgeries on intersex infants. Activists claimed that the surgeries were physically and psychologically devastating (Devore, 1999; Intersex Society of North America, 2008; Vilorio, 2017). Intersex surgeries had caused negative

medical outcomes including poor postoperative results, scarring, more surgeries to correct the scarring, loss of orgasm, and sometimes incorrect sex assignment (Intersex Society of North America, 2008; Viloría, 2017). Surgeries were not the only issue. Activists also protested many nonsurgical intersex medical practices such as photography of nude intersex bodies, objectifying medical examinations, and an unnecessary quantity of invasive medical examinations for physician curiosity (Dreger, 1999; Karkazis, 2008; Kessler, 1998). The psychological effects of stigmatizing medical interventions included shame, isolation, identity confusion, and impaired ability to enter and/or maintain relationships (Lev, 2006; Preves, 2003). Hidden medical records and family secrecy added to the trauma (Dreger, 1999; Lev, 2006; Preves, 2003; Viloría, 2017).

Activists rejected the authority of the medical field and claimed dominion over deciding what was best for their own bodies. They protested the necessity of the infant surgeries and demanded acceptance and humane treatment for their biological diversity (Intersex Society of North America, 2008). Some in the movement rejected the notion that intersex bodies should be seen as flawed at all. The notion that sex biology was binary only (male or female only) was denounced as myth (Viloría, 2017). They also objected to the presumption of heteronormativity that undergirded the surgeries (Karkazis, 2008).

Activists rallied support from media. Intersex stories about medicalized trauma appeared in print and on television (Devore, 1999; Dreger, 1999; Kessler, 1998). The increasing coverage in the 1990s was in clear contrast to previous decades of silence under Money's protocol (Intersex Society of North America, 2008; Karkazis, 2008; Kessler, 1998). Early intersex activists publicly demonstrated at medical conventions. As

a result of this publicity, the topic of medically unnecessary surgeries captured mainstream journalistic coverage (Davis, 2015; Vilorio, 2017).

### **Activist Paradigm: Binary-Only Is Myth, Surgeries Are Heteronormative**

How does a hidden, ashamed population who has grown up with medical reconstruction as the norm develop an alternate paradigm, one that can penetrate an intellectual ceiling so as to wrest power from the medical field? What intellectual authority could activists rely on to claim that the medical field should not have authority over intersex infant bodies? In the 1990s, scholars in the fields of sociology, biology, gender studies, and science history, played an influential role in challenging the cultural assumptions that promoted medically unnecessary surgeries on intersex infants. The scholarship focus was not accidental; founding activist Cheryl Chase worked to make it happen (Dreger, 2016; Karkazis, 2008). The role Chase played in spurring supportive scholarship cannot be overestimated. She introduced scholars to intersex persons. She sent intersex stories to social psychologist Suzanne Kessler, who was working on gender issues. In 1998, Kessler published an influential text, *Lessons from the Intersexed*. Chase developed a significant partnership with science historian Alice Dreger, who published *Intersex in the Age of Ethics* in 1999. Chase and Dreger worked actively in fostering the ISNA's development and outreach (Dreger, 2016). Chase did not merely protest, she wielded activist power to create a new narrative. Chase's reputation later suffered greatly for her role in fostering the term disorder and in closing the ISNA without input from its members, but her role in starting the activist movement is undisputed (Davis, 2015).

Early scholars documented the stories of psychological and physical damage in intersex adults due to the concealment model (Dreger, 1999; Karkazis, 2008; Kessler, 1998; Preves, 2003). Scholars produced qualitative findings that surgeons altered intersex

infant bodies to approximate standards for male and female under the belief that heteronormative gender identity would follow. In practical terms, surgeons altered these infants so that heteronormative penetrative sex could take place (Dreger, 1999; Karkazis, 2008). A “too small” penis could not penetrate, so the gender assignment was likely female and then infant surgeries were conducted to feminize 46,XY karyotype genitals. Furthermore, surgically constructing a penis is harder than surgically constructing a vagina, so in cases with a high degree of atypicality, assignment was also to female. Supposedly, men had a social mandate to stand to urinate, so males with hypospadias had medically unnecessary surgeries to make the urethra hole exit at the tip of the penis (Karkazis, 2008). A female born without a vagina was assumed heterosexual and therefore also in need of an acceptably sized vagina, so an artificial one was constructed. Females who had a clitoris deemed too large were assumed heterosexual. The females supposedly had no need for a penetrative organ in order to be penetrated themselves, so their clitorises were reduced or removed (Karkazis, 2008).

By virtue of the medical practices previously discussed, social science scholars charged that the medical profession was acting as the social enforcers of the prevailing cultural notion that sex and gender should be heteronormative and binary only (Dreger, 1998; Kessler, 1998; Preves, 2003). Scholars detailed the various ethical principles being violated by the normalizing medical practices on infants such as the right of the individual to bodily autonomy and the medical obligation to do no harm (Dreger, 1999). Hope and triumph were also documented. Scholars found that some intersex individuals emerged stronger from their experiences of shame, stigma, and secrecy (Dreger, 1999; Preves, 2003).

## **Activist Impact: The Second Medical Protocol Involving Counseling**

In 2006, in response to intersex activist protest, a new multidisciplinary medical protocol was developed. The protocol was produced as the outcome of a medical consensus-building conference hosted by the U.S. and European Pediatric Endocrine Societies in Chicago (Lee et al., 2006). The protocol is sometimes referred to as the 2006 Chicago Consensus or the 2006 Consensus. Under the new medical protocol, intersex variations were named disorders of sex development, (DSD). The protocol involved a DSD multidisciplinary team (DSD MT).

Under the protocol, optional infant genital surgeries would be allowed to continue. However, provisions were made to protect intersex infants from the damage of secrecy and isolation through an open, informed, and shared decision-making process involving the infant's parents and a multidisciplinary team of experts versed in DSD. DSD MT clinics, now over 20 in number, are generally located in children's hospitals (see Appendix A for a list of these facilities).

The recommendation for expert composition at a DSD MT clinic involved pediatric subspecialties of surgery, genetics, gynecology, endocrinology, neonatology, psychiatry/psychology (counseling), nursing, medical ethics, and/or social work (Lee et al., 2006). Though the aspiration may be a full cadre of experts functioning as a team, DSD MT clinics may vary in number of experts and mode of operation (Lee et al., 2016). For example, at one end of the spectrum, clinics may operate with the full set of experts on clinic day who discuss and make recommendations together. At the other end of the spectrum, experts are fewer and may function more autonomously.

DSD MT team goals include assessing the infant, implementing the sex/gender assignment process, and conducting surgical procedures as well as helping parents bond



with the infant and learn about intersex/DSD biology (Lee et al., 2006). Though DSD MT care may continue through adolescence, the particularly intensive clinic care pertains to the early phases of diagnosis, sex assignment, and possible surgeries. The medical experts conduct a variety of medical tests prior to assigning a sex designation as male or female (Wisniewski et al., 2012). Even with testing, the sex designation may not be conclusive (Gomez-Lobo, 2014). After the infant receives sex assignment, optional genital surgeries may be performed to promote greater alignment of the infant's body with the assigned biological sex (Wisniewski et al., 2012).

Since the adoption of the 2006 Chicago Consensus, the quantity of literature emphasizing the medical management of intersex/DSD has significantly increased (Lee et al., 2016). Significant attention has been paid to organizational issues regarding how to set up a DSD MT team (Consortium on the Management of Disorders of Sex Development, 2006a; Douglas et al., 2012; Hiort et al., 2014; Moshiri et al., 2012). Medical literature on team set-up has focused on proper protocols for evaluation, (including palpitation, genetics and biochemical analysis), hormonal treatments and surgical procedures (Lee et al., 2016). The process of assigning gender can utilize statistical averages per variation but exceptions occur (Lee et al., 2016). Pediatric professionals have recognized an absence of long-term studies tracking hard to define quality of life psychological outcomes (Lee et al., 2016). Less attention has been paid to counseling protocols.

The 2006 Chicago Consensus recommends a process of parent counseling prior to parents giving proxy consent for optional sex-related surgeries for their intersex infants (Lee et al., 2006). In their journal article detailing the 2006 Chicago Consensus protocol,

Lee et al. (2006) described the counselor role as that of working with parents to facilitate medical, hormonal, and surgical options. As the function of counseling is specifically included in the 2006 Chicago Consensus protocol, for the first time in history mental health professionals are involved as integral members of teams that provide optional sex-related surgeries on intersex infants. The aspirational content of parent counseling in context of the DSD MT clinic has been the attention of recent research (see Chapter 2 for more detail). However, comprehensive research on the counseling actually being provided in the various clinics has not yet been produced.

Parent decisions are controversial. Proponents claim the surgeries help these children avoid damaging stigma. Opponents claim normalizing surgeries create rather than prevent psychological damage and add permanent physical damage in the process (Greenberg, 2012; Karkazis, 2008). Furthermore, opponents claim that informed consent processes have not been sufficient regarding, for example, possibilities of incorrect sex assignment, inadequate surgical results, and lost sexual sensation. Alternatives may not be offered. Nor has the experimental nature of the surgeries based on the lack of long-term studies always been made clear (Karkazis, 2008). Opponents have argued for a moratorium and/or enhanced informed consent to make the potential undesirable and/or unknown consequences clear to parents (Greenberg, 2012).

Some research has addressed parent experiences under DSD MT care (Dayner et al., 2004; Sanders et al., 2008). Although parent satisfaction with DSD MT care has been reported, this is likely not the definitive perspective on DSD MT practices. Intersex controversies under the 1950s concealment model did not surface from parents. Controversies surfaced 30 years prior from intersex individuals who had been altered by

medically unnecessary surgeries (Intersex Society of North America, 2008; Karkazis, 2008; Vilorio, 2017). Satisfied parents who are interviewed close to when medically unnecessary surgeries are performed are reporting when the children are not old enough to complain. Furthermore, research collected from parents of minor children considers information from parents who are current or recent consumers of DSD MT care that they themselves authorized. Parents who provide consent might feel internal pressure to see the surgeries as successful.

Even with scientific advances since the 1950s, gender assignment for intersex infants has not been conclusively resolved and remains a contentious subject. A biological basis for gender identity carries strong favor. The data, however, are not conclusive (Karkazis, 2008). Some variations are highly variable in terms of associated genders such as 5-alpha reductase deficiency, partial androgen insensitivity syndrome (PAIS), and aphallia. Clinicians generally do not contest some of the other gender assignments such as girl for CAIS and girl for CAH with moderate virilization (Karkazis, 2008). Exceptions do occur even with intersex variations that supposedly have uncontested gender assignments. The exceptional cases result in a type of “trans” situation in which intersex persons transition (or emancipate) their gender because of an incorrect gender assignment made at birth (Blair, 2016; Marquez, n.d.).

Early assessment of the medical impact of DSD MT care showed that nonemergency infant sex-related surgeries are continuing under the 2006 Chicago Consensus protocol. Parents have legal authority over their children and continue to opt for the surgeries (Lee et al., 2016). In the United States, parents have an unfettered right

to provide proxy consent for medically unnecessary sex-related surgeries for their intersex infants and minor children (Greenberg, 2012).

In summary, the evolution from the 1950s concealment model to the 2006 Chicago Consensus protocol did not eliminate infant intersex surgeries. Surgeries are continuing in spite of the new standard of transparent, shared decision-making involving counseling support and increased information sharing with family. The fact that medically unnecessary surgeries are continuing without the children's consent remains the critical ethical and legal issue for intersex activists (Astorino & Vilorio, 2012; Devore, 2015; interACT Advocates for Youth, 2019a; Intersex Campaign For Equality, 2017). Under the new protocol, for the first time in history, counseling is involved and/or implicated in medically unnecessary sex-related surgeries on intersex infants and minors.

### **Growth of Intersex Organizations**

Although intersex variations are not new, intersex activism in the United States is a relatively new phenomenon (Karkazis, 2008). The first major activist organization in the United States, ISNA, was founded in 1993. At present, perhaps a half dozen or so of intersex activist organizations can be identified with outreach in the United States, including the Intersex Campaign for Equality (IC4E), interact Advocates for Youth, and the Organisation for Intersex International (OII).

### **Role of the Internet**

The Internet, developed in the 1960s in part as military technology for distributed leadership in advent of nuclear destruction (Leiner et al., 1997; Sterling, 1993), became publicly accessible in the early 1990s. Chase, the founder of the intersex activist movement, was trained at Massachusetts Institute of Technology. She used her

technology skills in the 1990's to launch the website of the first U.S. activist organization, the ISNA (Davis, 2015; Karkazis, 2008).

Through the ISNA website, a hidden, shamed, and relatively small population of intersex individuals and activists coalesced, and the ISNA membership increased (Davis, 2015). The Internet provided early intersex activists the means for mobilizing protest activities against the medical community and for launching new organizations (Davis, 2015). The internet continues to be an important part of intersex activism by providing a relatively small group of geographically dispersed people with the opportunity to share information, strategize, and promote activist activities.

Intersex organizations can be conceptually divided according to two major divisions. First, intersex organizations are either a political organization or a support group. Second, intersex organizations either insist on a total ban of medically unnecessary intersex infant surgeries or they are willing to work with physicians and surgeons who conduct medically unnecessary hormonal treatments and surgeries on intersex infants.

### **Intersex Activist Political Organizations**

As mentioned, intersex political organizations that serve the United States include the OII; the IC4E, its U.S. affiliate; and interACT. Although ISNA was dissolved in 2008, its website is still online and disseminates information. Each of these political organizations was or is dedicated to a total ban on medically unnecessary surgeries on intersex minors (interACT Advocates for Youth, 2019a; Intersex Campaign For Equality, 2017; Intersex Society of North America, 2008; Organisation Intersex International, n.d.).

ISNA was the most influential intersex umbrella organization in the United States for about 15 years, from 1993 to 2008. ISNA initially opposed all medically unnecessary

surgeries. By 2006, however, Chase believed that cooperation with the medical community was necessary (ISNA, 2008). After the 2006 Chicago convention, Chase felt that ISNA had no future role because physicians and surgeons did not want to work with the organization given its previous activist protest activities (Davis, 2015; ISNA, 2008). Without input from others in ISNA, Chase controversially dissolved the organization in 2008. With support from Chase, a new organization, Accord Alliance (a.k.a. Accord), was launched for the purpose of working with the medical profession (Accord Alliance, n.d.; Intersex Society of North America, 2008). Accord initially assumed the role of perfecting the 2006 Chicago Consensus standard of care as a convener of all stakeholders. Several members of the ISNA served on Accord's advisory board. Accord did not replace ISNA as the major membership organization for intersex individuals, nor does it serve as an organizational hub for intersex activists given its mission to collaborate with the medical profession. Accord currently implements its vision as a distributor of information resources (Davis, 2015).

Some activists in ISNA did not agree with Chase's support of the "disordered" terminology or with her willingness to collaborate with the medical profession (Davis, 2015). In 2003, Curtis Hinkle, an intersex activist staunchly opposed to medically unnecessary surgeries for intersex minors, launched OII (OII, n.d.). OII has collaborated with other human rights organizations outside of intersex groups pursuant to the goals of banning intersex infant surgeries (OII, n.d.). OII is a decentralized global network of intersex organizations designed to connect intersex persons worldwide. The organization asserts that it is the world's largest intersex rights group (OII, n.d.). Affiliates include

Belgium, China, Europe, France, Germany, Iceland, Italy, Netherlands, Philippines, Scandinavia, and South Africa.

The two most active affiliates, OII USA and OII Australia, renamed themselves. OII Australia is now Intersex Human Rights Australia (<https://ihra.org.au>) and OII U.S. is now the Intersex Campaign for Equality (<https://www.intersexequality.com>). The websites of the U.S. and Australian affiliates are robust and current. Both provide resources, educate, blog, and promote legislative and policy change. In contrast, since 2015, the archives of the OII website appear inactive although the newsfeeds from affiliates on the OII website are more recent.

Founded in 2006, interACT has a mission of supporting the human rights of intersex youth (interACT Advocates for Youth, 2019a). The organization has a highly visible presence in intersex activism including an active website, legislative efforts, and published materials distributed online and at conferences. interACT's legislative and legal emphasis is evident by staff composition of lawyers. The organization provides positive identity publications and networking opportunities for youth. To provide empowering role models for youth, interACT incorporated another project into, Interface, its umbrella of activities. Interface is a website collection of personal video stories from intersex leaders and activists (Interface Project, 2012).

Some activists may be a member of one or more organizations seeking outright ban on medically unnecessary intersex infant surgeries and also a member of an intersex support group that cooperates with the medical profession (Davis, 2015). Other activists will not participate in any group that interacts with the medical community (Davis, 2015). Some intersex activists are not primarily identified via their allegiance to either a support

group or a political activist organization. This professional independence may occur for a personal or political reason; for example, as a way to avoid the animosities that exist among activists. Independent activist activities may include blogging, leading an online discussion group, or performing individual acts to foster policy change. Unaffiliated activist Mx. Anunnaki Ray Marquez is the first person to achieve a state-issued birth certificate designating intersex. He moderates online discussion groups for intersex parents and gender nonconforming individuals (Marquez, n.d.). Cary Gabriel Costello, a sociologist at the University of Wisconsin–Milwaukee, authors two blogs, *Intersex Roadshow* and *TransFusion* (Costello, n.d.).

### **Intersex Support Groups**

In contrast with intersex political organizations, intersex support groups are generally organized around a particular form of intersex, for example, androgen insensitivity. The purposes of intersex support groups are to share medical information, educate, and provide online and in-person social opportunities (Karkazis, 2008). Some very active support group participants may consider themselves intersex advocates, not activists, given a willingness to work in collaboration with the medical community and a desire to be sensitive to a negative connotation of activism for some in the medical community.

Androgen Insensitivity Syndrome–Differences of Sex Development (AIS-DSD) is the one of the largest intersex support groups (AIS-DSD, 2017). AIS-DSD hosts yearly conferences for teens, families, and professionals. Past conferences have included some sessions for clinicians on improving medical and psychological care for infants and their parents. In 2017, 2018, and 2019, conferences were held at DSD MT clinics in Denver, Phoenix, and Chicago.



Gender is an issue in intersex support group membership criteria. Membership may evolve over time reflecting attitudes about intersex and gender. AIS-DSD, now open to those with gender identity man/boy, was originally only open to those with a gender identity of woman/girl even if the person's variation was not AIS. Girls/women with CAIS, PAIS, and 5Alpha, etc., were welcome at AIS conferences. Membership criteria may also reflect a perception about whether a biological variation is intersex. The leadership of the Turner's syndrome support group does not associate its group with the label intersex, even though some women with Turner's syndrome have a 46,XY karyotype (Turner Syndrome Society, n.d.).

### **Activist Vantage: Frontline Perspectives of Intersex Experiences**

The present study was an investigation into intersex experiences from the perspective of the first wave of intersex activists, from 1990s to the present, with a focus on the United States. Intersex activist perspectives were considered important to research for several reasons. Activists can provide a frontline perspective of the experiences in the intersex population. Activists, as defined in this study, have gone through their own physical and affective experiences of having one or more intersex variation, for example, CAH and polycystic ovaries. Activists are highly conscious and well informed, having given thought to the issues affecting the intersex community. As public figures, activists are lightning rods who attract feedback from the intersex community as a whole. Their public activities keep them aware of past and present political climates and of the corollary emotional issues affecting the intersex community.

Intersex activist stories are both similar and diverse from each other. Therefore, their stories can be windows into the variety of intersex issues relevant to counseling. Some aspects of the emotional journeys of intersex activists may be shared, including

(a) having developed a personal identity as an intersex person, (b) having felt hidden and shamed but moved into public activism anyway, and (c) having developed a political position about medical protocols designed to allegedly “normalize” intersex variations. Some aspects of the emotional journeys of activists may be diverse. For example, intersex activists may have different forms of intersex variations. Accordingly, the medical treatments they received may have varied. Some activists received medically unnecessary surgeries in infancy, but others were not surgically “normalized” as minors. Intersex activists may vary regarding their gender identity. Gender identity options may include woman, girl, man, boy, or something else from the plethora of gender variations (Marquez, 2019). Activists vary in orientation; for example, some are heterosexual, but others are lesbian, bisexual, and so on. Activists may vary regarding how comfortable they feel working with the medical profession. Activists may vary regarding belief in the importance of having an intersex passport or birth certificate to signify a distinct intersex biology.

Intersex births are not new, but intersex activism is relatively new, beginning in the 1990s and continuing to the present. Intersex activism can be generally understood during its first 30 years as an effort to ban the effect of two successive medical protocols, namely, medically unnecessary sex-related surgeries on intersex infants and minors. Intersex activists are opposed to the physical and psychological harm that they believe derives from those medical protocols.

In summary, intersex activists grapple with what it means to have an intersex variation and then they develop a willingness to reveal themselves in public as both intersex and activist. U.S. intersex activism can be dated to the founding of the first

intersex organization, ISNA, in 1993. ISNA developed an online presence in the early days of public access to the Internet. The advent of the Internet enabled a hidden, small, shamed group of individuals to find and support each other. The Internet also enabled intersex activists to organize public protests regarding medically unnecessary surgeries on intersex infants. The two major types of intersex organizations are political organizations seeking a ban on medically unnecessary intersex infant surgeries and support groups formed around an intersex variation. ISNA, the influential early political organization, dissolved in 2008, but other organizations sprang up in the void in the United States and around the world. Intersex activists provide a helpful window into the experiences of the intersex community as a whole.

### **Problem Statement**

Some information related to life as an intersex activist has been produced, but significant gaps remain. Sociologist Sharon Preves (2003) conducted an in-depth qualitative study that addressed adult intersex journeys through shame, stigma, and secrecy. Several other scholars have interviewed intersex individuals, families, and clinicians in depth and produced important historical, feminist, and bioethical scholarship (Karkazis, 2008; Kessler, 1998; Reis, 2009). Several scholarly texts have described key events in the early years of intersex activism (Davis, 2015; Karkazis, 2008; Reis, 2009). A report on the structural aspects of intersex activist organizations has been published that covers, for example, funding, and activist burnout (American Jewish World Service et al., 2017). Human Rights Watch and interACT developed a timeline of intersex activism (Human Rights Watch & InterACT Advocates for Youth, 2017). Two activist memoirs have been recently published (Viloria, 2017; Zieselman, 2020). In 2016, New York City altered birth certificate forms to include the option of intersex in addition to

male or female (O'Hara, 2016). In 2018, California became the first U.S. state to pass a resolution condemning medically unnecessary surgeries on intersex infants though efforts to achieve a legislative ban did not succeed (interACT Advocates for Youth, 2018). Also in 2018, Mx. Anunnaki Ray Marquez became the first person to successfully lobby a state, Colorado, to alter his birth certificate to designate intersex as his biological sex (Marquez, 2018).

The inner world of the intersex person turned activist has not been addressed in the literature. An activist is first an intersex person who has suffered under the binary-only world in which all that is supposed to exist is either male or female. To know that intersex individuals are born in a world that privileges the binary concept of sex as male and female, one need only look at the myriad of forms filled out every day with options only for male or female. Also common are conflation of gender and sex such as forms with boxes for man or woman when the desired information was actually male or female. Furthermore since 2006, intersex individuals are labeled medically as disordered. Thus, an intersex person's very existence challenges fundamental societal notions of what biological sex should be. Accordingly, an adult individual born intersex faces a formidable emotional and mental predicament. Is the medical profession, with parent proxy consent, correct in concluding that intersex infants are appropriately "fixed" surgically? Does the individual who deeply believes that irrevocably altering intersex babies surgically is wrong nevertheless stay silent in fear of personal and professional jeopardy? Or does one give up the protection afforded by staying silent and publicly fight for intersex human rights? What is it about intersex activists that motivates them to enter

a public debate on intersex rights in defiance of implicit social messages about concealment, shame, and/or nonexistence? Did any received counseling help or harm?

### **Purpose of the Study**

I conducted this study to investigate the intersex experience from the perspective of the first wave of intersex activists. The general time span covers intersex activism from its beginning in 1990s with the advent of the first intersex organization, ISNA, to the present with its major activism successes. In conducting this study, as far as I know, I was the first researcher to address intersex experiences from the perspective of adults who cope with their own atypical bodies and then determine to go public in activism when the implicit social messages are to hide in shame.

### **Significance**

Professional counselors affiliated with the ACA have a largely unfulfilled ethical duty to support intersex individuals and their families. The counseling voice is largely absent from peer-reviewed literature (Alderson, 2013; Singh et al., 2010). Since the 1990s, academic professionals in the fields of medicine, psychology, sociology, gender studies, nursing, law, and bioethics have been addressing intersex issues (Davis, 2015; Karkazis, 2008; Preves, 2003; Schweizer et al., 2009). Yet, professional counselors are professionally, legally, and ethically distinct from psychologists and psychiatrists (Cottone, 2017). Professional counselors identify with a wellness orientation rather than a pathologizing approach to human variance (Mellin et al., 2011). When professional counselors add an affirming voice of wellness to research in support of marginalized populations, they are implementing professional ethical values of social justice and beneficence (ACA, 2014; Pope, 2015). In conducting this study, I provided benefit by addressing a vacuum in professional counselor education. Results from this study may

help to raise professional counselor awareness of the mental health needs of intersex activists, intersex individuals, and their families, and in so doing address a counseling duty of service to an underserved population.

This study has importance for the broader group of helping professionals, including counselors, psychologists, psychiatrists, and social workers, by calling attention to counseling involvement in medically unnecessary intersex infant surgeries under the 2006 Chicago Consensus protocol. For the first time in history, licensed counseling has a recognized position on a team that produces recommendations for medically unnecessary surgeries on intersex infants. As the broader profession of counseling is now implicated in medically unnecessary surgeries, at some point in the future the helping professions can expect to receive patient and activist comment.

It is too soon for intersex babies treated under the new 2006 protocol to express as adults their opinions about what was done to their bodies without their consent. Yet, based on history, in the next 30 years or so, those who received infant genital surgeries under the new protocol will judge those who had agency in irreversible treatments performed without their consent. Will the fine distinction be made that those representing the counseling profession in DSD MT clinics were typically psychologists, psychiatrists, or social workers but not professional counselors? Or will the historical verdict be that the entire counseling profession did not do more to stop medically unnecessary surgeries? That the reputation of professional counseling may be on the line is a problem for the entire profession. How many professional counselors know about intersex/DSD? How many professional counselors know that counseling is now a part of the 2006 Chicago Consensus medical protocol? Findings from this study may help professional counselors

realize that the helping professions are now implicated in medically unnecessary surgeries on intersex infants.

Finally, findings from this study raise awareness of positive advocacy already accomplished through the ACA. In 2004, under the leadership of past president Mark Pope, the ACA's Governing Council approved and adopted a groundbreaking intersex resolution, the Resolution to Protect Intersex Children from Unwanted Surgery, Secrecy, and Shame. The resolution was made a full 10 years in advance of a similar resolution issued in 2015 by the World Health Association. The ACA resolution outlined the ethical responsibilities of professional counselors toward intersex individuals. The ethical responsibilities include protecting children too young to consent to medically unnecessary surgeries and supporting advocacy groups in their struggle to end those surgeries. The present study both raises awareness of the ACA's 2004 resolution and attempts to follow its mandate.

### **Research Design**

The initial question for academic researchers delving into human psychological experience is whether to approach the study quantitatively or qualitatively. Both paradigms are scientific approaches: both aspire to systematic methodology and bias minimization (Patten & Newhart, 2018). The two paradigms for developing knowledge, however, differ in important ways. In quantitative research, data are often collected via survey. Quantitative findings are generated from evaluating the data against hypotheses designed to test a prior theory. The findings of quantitative analysis support statistical comparisons. In qualitative research, data collection is often by semistructured interview. Qualitative findings proceed inductively from the experienced phenomenon to the analytic development of themes or theories. The findings of qualitative analysis involve

human judgement about perceiver meaning and are presented as words (Patten & Newhart, 2018). From the vantage of research questions, the variances between the research paradigms lead to respective strengths and weakness (Patten & Newhart, 2018). Research studies that seek to measure frequency align with quantitative research that measures variables and their interactions. On the other hand, quantitative research is weak when the phenomenon is new or there is no prior theory to guide the development of quantifiable research questions.

### **Qualitative Paradigm**

The interest in this study is “the what” and “the how” of intersex activists’ experiences. Qualitative research analyzes (a) the what of experience by exploring the parts and the whole of experience and (b) the how of experience by exploring process, context, and temporal unfolding (Patten & Newhart, 2018). Qualitative research aligns with uninvestigated and/or unobservable phenomena such as human meaning making. A living researcher is the primary instrument of data collection and analysis. Live agency allows a researcher to be flexible with subjects as they explore their own meaning making. A qualitative design was thus appropriate for investigating the unexplored inner world of four representatives from the first wave of intersex activists. A weakness of qualitative data is its propensity for researcher bias, an unavoidable reality that must be addressed through rigorous and transparent methodology (Merriam, 2016).

### **Interpretative Phenomenological Analysis**

Selecting an optimal methodological approach follows from the nature of the research questions themselves. I was interested in the inner world of human meaning making so I selected the broad category of phenomenology. In one sense, all qualitative research may be considered phenomenological given that all qualitative research focuses



on inner human meaning making (Wertz et al., 2011). However, within the broad category of phenomenology, many subtypes have been developed by researchers, including one that I chose confusingly known by the same name as the broad category, phenomenology. Other phenomenology subtypes, for example, are grounded theory, narrative study and case study. I looked at the merits of those subtypes and eliminated all but phenomenology given my research questions. Then I chose yet again an additional subtype within the subtype phenomenology named interpretative phenomenological analysis (IPA).

To state again and in more depth, the term phenomenology has come to mean a methodological approach distinct from other subtypes of phenomenological qualitative research. This subtype approach called phenomenology can be contrasted, for example, with a grounded theory approach that seeks to develop theory out of perceivers' meaning, or with a narrative approach that seeks to tell the story embedded in a perceiver's meaning, or with a case study approach that emphasizes a specific bounded experience (Merriam, 2016; Wertz et al., 2011). Intersex activism is not like human experiences so common that they share predictable human responses, hence a grounded theory research approach was not selected. A narrative research approach was not selected as themes, not only stories, were the general emphasis in the present study. A case study research approach was not appropriate as intersex activism is not a specific, bounded human experience.

Phenomenological inquiry reflects two key approaches: Husserlian or Heideggerian (hermeneutic emphasis). I chose a Heideggerian hermeneutic approach for this study. The hermeneutic approach is valued for its ontological recognition of the

inescapability of researcher influence on the research process. Researchers are understood to be human beings whose language and culture cannot be entirely separated from their work. Accordingly, the importance of addressing researcher bias is built into the methodology (Lavery, 2003).

Within the hermeneutic tradition, I selected the IPA subtype of phenomenology given its emphasis on individual nuance as well as themes (Smith et al., 2013). On the one hand, activist themes were of interest in this study. For example, did the activists share the themes of family rejection and/or overcoming suicide? Yet, themes held in common were not the only findings important for this study. The full spectrum of human responses is important in counseling, not just commonality. Individual variation is important as well. Variation helps counselors appreciate individuality and diversity in human experience. IPA focuses on idiographic variation. For this study, IPA was useful because while I expected to find some shared themes in the activists' experiences, some of their experiences would likely vary significantly. In summary, I selected IPA as the specific qualitative phenomenological design for this study given its emphasis on both themes and variation. I discuss this study's methodology in more detail in Chapter 3.

### **Research Questions**

Qualitative research questions are considered preliminary, broad, and open-ended so as to guide the researcher into the data. Unanticipated questions are expected to arise during the collection and analysis process (Corbin & Strauss, 2015). The overarching primary questions in the present study were:

1. What has it been like having an intersex variation?
2. What led you to become an intersex activist?
3. What is your life like now as an intersex activist?

4. How has the 2006 change in medical protocol impacted intersex people?
5. What has any personal experience with intersex counseling been like?
6. What would improve counseling for intersex individuals and families?

### **Definitions of Terms**

*Activist/activism:* A case can be made that anyone who publicly identifies as having an intersex variation has functioned as an activist (Davis, 2015). Such a population would include artists, sports figures, and poets. For the purpose of this study, however, intersex activism was delineated as (a) self-identification as having an intersex variation and (b) intentionally and publicly engaging for more than 1 year in activities designed to affect policy change for other intersex individuals regarding unnecessary medical surgeries and other medical treatments performed without consent on an intersex minor. Activist effort was considered to include, for example, lobbying for legislative change, publicly demonstrating, telling their story orally or in print, making public appearances, blogging, authoring articles or books, and/or making Ted Talks or other Internet-distributed productions.

*Ambiguous genitalia versus atypical genitalia or intersex genitalia:* Of the first two terms, ambiguous genitalia versus atypical genitalia, atypical genitalia is the more appropriate and less offensive term than ambiguous genitalia. The issue pertains to the sensibility that no matter how variant an intersex person's genitals may look to others, intersex individuals themselves would not likely experience their own genitalia as ambiguous. One activist preferred intersex genitalia over ambiguous or atypical genitals.

*Assent to optional sex-related intersex surgeries:* The older the child, the more the child may have participated in optional surgery decision making and provided a lesser form of consent called assent. To sidestep discussions about assent versus consent, I

generally referred to infant intersex surgeries instead of sex-related surgeries on intersex minors given that no infant can be said to either assent or consent.

*Binary biological sex, binary gender identity, and/or binary heteronormative orientation versus biological continuum, gender variation, and/or orientation variation:* For some people, there is only male or female sex, man or woman gender, and man and woman desiring each other, i.e., binary sex, binary gender, and binary heteronormative orientation. In this view, everything else born is a defect, in other words, “disordered.” Another formulation is that sex has so many varying elements that binary-only sex categories make no sense. Sex development variance can occur with any of the many physical sex elements, (e.g., chromosomes, gonads, hormones, and genitals); therefore, it is scientifically factual to say that sex occurs along a continuum. Under this view, intersex variations are understood to exist anywhere along the continuum between the two poles of typical male and female. A similar continuum viewpoint about variance may be held regarding gender variation and sexual orientation.

*Biological sex versus gender identity and gender expression versus sexual desire:* Biological sex terms include male, female, and intersex. Biological sex has to do with the physical part of sex, such as gonads, genitals, chromosomes, and hormones. As mentioned, male and female are referred to as the two more common categories of biological sex. Intersex is considered the biological term for other than male and female biology.

Gender identity terms are numerous and include, for example, girl/woman, boy/man, nonconforming, and queer. Gender identity is one’s gender self-concept, in other words, one’s internal experience of gender. Intersex, when construed as a gender

identity, not only as a biology, is very controversial and frowned on by activists who seek to emphasize the human rights issue that is happening because of intersex biology.

Gender roles and gender expression refer to the functions and behavior categorized by culture or religion as belonging to a gender. Cultures vary in how they view gender behaviors. A controversial issue of gender alignment with gender behavior arises in an intersex context, for example, if a person assigned girl is later seen playing as a tomboy and desiring other girls/women. Physicians and/or parents may interpret the behavior as indications that the earlier assignment as gender girl was incorrect. Such inference would be based on a presumed alignment of heteronormative behavior (gender role) and heteronormative orientation with heteronormative gender identity. Others might express the viewpoint that a combination of gender role/behavior of tomboy, the gender identity of a girl/woman, and a lesbian orientation is an example of natural variance in which gender identity, gender role, and desire are not always in heteronormative alignment.

Desire/sexual orientation terms are numerous and include, for example, bisexual, heterosexual, homosexual, polyamorous, pansexual, aromantic, and asexual. Desire/sexual orientation relates to the part of human sexuality in which people do or do not have sexual interest in others. Some say there is only one proper way for desire to manifest—“woman and man with each other”—and variance is perceived as an ethical aberration. Others say that healthy human sexuality options exist beyond woman and man with each other; for example, bisexual, homosexual, pansexual, trans man with trans woman, endosex man with trans woman, intersex woman with trans man, and so on. As previously mentioned, the issue of the alignment of desire/sexual orientation and gender

arises in an intersex context in which a physician or parent counts gender assignment a failure if the child grows up and desires in a manner other than heterosexually.

Sex-related categories of biological sex, gender identity, and desire/orientation are often conflated by professionals as well as the public. The confusion is not trivial because it impacts parent and clinician propensity toward medically unnecessary sex-related infant surgeries when the categories are interpreted as needing to align infant body parts heteronormatively. Debates and confusion regarding biological sex, gender identity, gender role, and desire/orientation are front and center issues for professional counselors who seek to develop an appreciation of intersex experience.

Confusion among the sex-related terms is not surprising. Being precise does not always match with common language usage. Effort at precision may lead to awkward language. For example, when a baby with female genitals is born, the expression is, “It’s a girl.” “Girl” is scientifically imprecise because gender does not always follow genitals. Yet it is culturally awkward and objectifying to say, “It’s a female.” Precision is, nevertheless, of vital importance for professional counselors to try to achieve. Through the effort of precision, heteronormative bias and the discredited belief that gender follows automatically from genitals is revealed. Furthermore, intersex individuals likely have a sensitive attunement to offensive connotations of biology and gender given the personal impact of heteronormative surgeries. For the sake of credibility, professional counselors will benefit from practicing precision by not conflating biological sex, gender identity, gender expression, and sexual and romantic orientations.

*Consent to optional sex-related infant intersex surgeries:* The intersex surgery controversy relates to an intersex person’s right to autonomy. In the United States, adults

have the right to bodily autonomy, and thus physicians must obtain informed consent before operating on adults. In the United States, parents have legal authority to give proxy informed consent for most optional and medically necessary surgeries on their minor children. Activists take the position, however, that parents do not have the proxy right to consent to optional, irreversible sex-related surgeries on intersex infants.

Activists believe that when parents exercise proxy consent for optional sex-related surgeries on intersex minors, they are violating their minor's right to self-determination.

*Cosmetic infant intersex genital surgeries:* Though the term cosmetic intersex genital surgery is common, I used the term *optional intersex infant genital surgeries* in this study. Perpetuating use of the term “cosmetic” may lead to the false belief that optional intersex infant genital surgeries invariably produce visually attractive surgical results. The actual visual effect may be otherwise: for example, genital surgical alterations made in infancy may fail to accommodate the adult body or skin grafts may leave a disfigured look.

*Counseling or psychosocial support:* This refers to (a) the professional activity provided by licensed members of a DSD MT clinic who answer to the ethical codes of their professional organizations, for example, the American Medical Association for psychiatrists and the American Psychological Association for psychologists; or (b) the professional activity provided by all licensed counselors who answer to the ethical codes of their professional organizations, such as professional counselors under the ACA. As a practical matter, DSD MT clinic counseling/psychosocial support activity is more likely provided by a psychologist, a psychiatrist, and/or a clinical social worker rather than a professional counselor given the hospital setting of DSD MT clinics.

*Disorders (or differences) of sex development (DSD):* DSD is the umbrella term used in the medical community for intersex variations, in other words, for various forms of congenital atypical sex development (Lee et al., 2016). Some speakers or institutions substitute differences for disorders to avoid the latter's stigmatizing connotation. It is imprecise to refer to disorders of sexual development because the term sexual refers to desire/orientation whereas sex development refers to the biological path. To avoid the connotation of disorder in this study, the term intersex variations was preferred over DSD. DSD cannot be avoided all together as the term is now widespread in medical and intersex support groups. In the discussions involving medical terminology or practices, the terms differences of sex development or DSD were preferred over disorders of sex development.

*Endosex:* An emerging term for biological typicality of male or female—that is, not intersex. Endosex addresses the need for a shorter term than “typical male” or “typical female.” Endosex is not related in meaning to endosexual.

*Infant genital mutilation (IGM) versus acceptable medical treatment for intersex infants:* Physicians state that their medical compassion behind the medically unnecessary surgeries means they are not conducting IGM. Some activists take the position that physicians' positive social intent does not matter given that the effect of intersex infant surgeries is IGM. Activist use of the term IGM to describe clinician actions is considered inflammatory by the medical community.

*Intersex (adjective); intersex variation or intersex natural bodily variation (nouns) versus intersex trait:* Intersex is the adjective used in this study as the umbrella term for congenital atypical biological sex differences. Following United Nations



guidance, noun versions used in this study are intersex natural bodily variation or intersex variation (United Nations Office of the High Commissioner for Human Rights, 2015). The present study's participants used the term intersex traits as a synonym for intersex variations many times. In literature as well, intersex variation and intersex trait may be used synonymously. I preferred to use the term traits for biological features that could be possessed by more than one intersex variation. For example, several intersex variations share the trait of a small penis.

Professional counselors who use the single word intersex as a noun instead of as an adjective may be dismissed by intersex clients as uninformed for two potential reasons. First, some intersex individuals may take offense at being called intersex instead of a person with an intersex variation because using the adjective as a noun may create the impression that intersex is the sum total of the person's identity as opposed to just a part. Second, others dislike intersex because it contains the word sex and thus may conflate erroneously a neutral biological variation with excessive sexuality. Third, some stakeholders reject intersex to distance from stigma. This situation relates to the fact that some biological sex development variations are more aligned than others in gender identity with either man or woman. Some stakeholders may prefer, therefore, to distance from intersex variation to view the "normalized" child as formerly "disordered" but now "fixed" through surgery as either boy/man or girl/woman. Examples where some stakeholders may distance from the term intersex or intersex variation include hypospadias/epispadias (if viewed always as a male/man variation), CAH (if viewed controversially only as a female/woman variation), Turner syndrome (if viewed

controversially as only a female/woman variation), and Klinefelter syndrome (if viewed controversially as only male/man variation).

Intersex variation was not used in this study as an antonym to DSD. The rationale is that some people may prefer using both terms. Some intersex individuals are comfortable using DSD in medical contexts and intersex variation in nonmedical contexts.

In this study, I did not intend the preferred terms of intersex natural bodily variation or intersex variation to carry a connotation of identity of a whole person. As previously mentioned, I acknowledged that parents may not see their child's sex development variation as an intersex variation. I did, however, include CAH, hypospadias/epispadias, Turner syndrome, and Klinefelter syndrome in my discussion of intersex variations as not all individuals exclude these variations as intersex variations.

*Intersex condition, intersex disorder, or intersex syndrome:* These terms were not used in this study as they imply that intersex variations involve a pathological condition or disorder. Professional counselors who use those terms and/or DSD may be dismissed by intersex clients as “not getting it.”

*Intersex natural bodily variation:* The United Nations fact sheet on intersex biological diversity discussed intersex variation as intersex natural bodily variation (United Nations Office of the High Commissioner for Human Rights, 2015). The term is intentionally designed to state the position that intersex variations should not be considered disordered. The distinction between natural and disordered is important in the intersex surgery controversy. The medical profession has been given legal authority to

treat disordered individuals but presumably their dominion is not the same over healthy individuals.

I would have preferred to use intersex bodily variation throughout this study instead of intersex natural bodily variation, but the United Nations developed the later term in conjunction with the intersex community. In point of fact, some intersex people become intersex not by nature but through iatrogenic harm. For example, diethylstilbestrol, a drug given to prevent miscarriages, has been associated with intersex births. My hope is that those who are intersex through iatrogenic reasons do not feel excluded by my usage in this study of the term natural within the larger term of intersex natural bodily variations.

*Intersex “trans” versus gender emancipation due to medical misassignment versus endosex trans:* An intersex “trans” experience of switching genders may happen for medical misassignment, surgical harm, or health needs. Terminology to distinguish endosex trans from intersex “trans” is unsettled as there are differences between the two types. One difference is physical. For example, to look at an intersex “trans” person naked, biological variance might be visible: for example, a penis but no testicles. An endosex trans person would either look typical male or typical female. In this study, when trans is associated with intersex, quotes are placed around “trans.” My intent in doing so is to try to be respectful by not erasing any physical or experiential differences between intersex “trans” and endosex trans. One of the participants in this study did not like trans as a self-descriptor and instead preferred gender emancipation due to medical misassignment. The other participant who transitioned their gender to woman as a result of surgical damage to his/her penis was fine with trans as a descriptor.

The distinction is important because it becomes political. An endosex trans person may think of “boy parts” and “girl parts” and seek surgeries to align body parts to internal boy or girl gender; an intersex “trans” person may think of all parts as belonging and not wish surgeries. (Not all endosex trans people seek surgeries either.) As another political example, surgeons who specialize in endosex trans surgeries and are revered in the trans community for doing so may also conduct intersex infant surgeries. For their performance of intersex infant surgeries, these surgeons may be considered perpetrators of IGM by the intersex community and thus violators of intersex human rights. Contrasting viewpoints on the need for surgeries leads to political impressions about World Professional Association for Transgender Health (WPATH) transition standards. (See the definition of WPATH.)

*Medical necessity versus psychosocial emergency:* Some physicians have considered optional intersex infant sex-related surgeries a social necessity for the child, the parent, or both, and use the term psychosocial emergency. Psychosocial emergency has been defined as potential for impaired parent–child bonding and potential for stigma in the child. Psychosocial emergency may then be used to justify intersex infant surgeries as medically necessary. Operating on the basis of a psychosocial emergency and calling it a medical necessary surgery is controversial. Scholars have claimed that construing a social cause as a medical necessity is a breach of the Hippocratic Oath (Ford, 2000). Activists are not opposed to medically necessary surgeries on intersex infants, only unnecessary ones based on the spurious rationale of psychosocial emergency. There is no political controversy, for example, if a surgeon creates a lifesaving opening in a child for eliminating bodily waste or if an adult opts to have optional genital surgeries.

*Optional intersex infant sex-related surgeries* synonymous with *medically unnecessary intersex infant sex-related surgeries*: These synonym terms are umbrella terms in this study for all optional, and hence controversial, sex-related surgeries on intersex infants. There is no medical necessity, for example, to recess or trim an oversize clitoris. I chose the broader term of sex-related instead of genital when discussing these surgeries to emphasize that some of the controversial surgeries are conducted on internal sex body parts. Although some of the controversial surgeries are genital surgeries with visible results, other surgeries, such as optional gonadectomies, are essentially invisible.

*Optional intersex infant genital surgeries*: A subtype of optional intersex infant sex-related surgeries that focuses on the visible or outer body. The purpose of optional intersex infant genital surgeries is to sculpt infant genitals to approximate typical male or female appearance and/or enable penetrative sexual experiences.

*Profit motivation versus patient-centered care*: Medically unnecessary surgeries being of financial benefit for the medical field was a theme that surfaced in the activist critiques. For example, intersex individuals may assert that a recommendation for gonad removal despite the low risk of cancer is evidence of the medical system using intersex bodies for financial reasons. The counter argument is that physicians are guided by principles of patient-centered care.

*Vaginoplasty and phalloplasty*: Vaginoplasty is the practice of constructing an artificial vagina out of another body part such as a section of the colon or surgically inverting a phallus. Vaginoplasty has been performed on infants, but the practice may have lessened since 2006. Not all female intersex persons menstruate. If menstruation is not a potential, the other functional reason to have a vagina is for penetrative intercourse,

which may or may not be a requirement of the adult. Surgically created vaginas do not self-lubricate and must be dilated regularly with dildos to prevent the opening from returning to closed state. When vaginoplasty is performed in infancy, parents must maintain the constructed vagina by stretching it using successively larger sized dildos. Activists and others consider this practice child abuse.

Phalloplasty, surgical construction of penis, is a less frequent surgery than vaginoplasty. The surgical results are considered generally unsatisfactory. The crude but commonly heard explanation is, “It is easier to construct a hole than a pole.”

*WPATH*: Pronounced by saying the letter *W* separately, then the word *PATH*, *WPATH* is the acronym for the World Professional Association for Transgender Health, a 501(c) (3) nonprofit, interdisciplinary professional and educational organization focused on the understanding and treatment of gender dysphoria. *WPATH* is the source for standards for transitioning from one gender to another. *WPATH*'s promotion of surgeries for gender transitioning is controversial in the intersex community.

### **Assumptions**

As discussed in the Ethical Framework section in Chapter 3, my work on this study was guided by the authority of the 2004 ACA Resolution to Protect Intersex Children from Unwanted Surgery, Secrecy, and Shame. Researchers ungoverned by this resolution might be obliged to spend more attention on physician discussion of the merits of medically unnecessary intersex infant surgeries. Under the umbrella of this resolution, however, I assumed that the activist position to promote a ban of unnecessary intersex infant sex-related surgeries was the ethically correct stance.

I assumed that the interviewees were truthful and attempted to answer the research questions to the best of their abilities. Adult intersex activists are mature in age.

They are proficient communicators, so their ability to correctly communicate their personal emotions and motivations was assumed. Activists by vocation seek to influence the behaviors of others. I assumed, therefore, that the activists would approach the interview process with an intentionality beyond mere interest in improving intersex counseling. One such possibility may have been the hope of extending their activist outreach through dissemination of study findings. As I did not perceive falsehood, multiple possible motivations for study participation were not assumed to have biased the study.

I assumed at the outset that my successfully completing this study would depend on endorsement by an intersex activist. My being a professional counselor–researcher was not an automatic asset in this study. In fact, my profession of counseling signaled a potential for harm given its similarity to the profession that started intersex damage in the first place—psychology. In intersex activist history, psychology professionals were the founders of medicalized harm. Money’s theory of optimal gender of rearing gave physicians a protocol to justify intersex infant sex-related surgeries to “normalize” intersex genitals to appear male or female. Furthermore, I assumed that continuous endorsement from the study participants would be necessary. The intersex activist community is small to the degree that it was likely that the study participants personally knew or had communicated online with every other activist in the community. If this study were to be “blackballed” by one or more intersex activists at any time, I likely would not obtain a sufficient number of interviews. My prospects seemed somewhat solid when I received an offer of support from an interACT leader and an endorsement letter

from an intersex activist. The activist's letter was included in the proposal but never used in the data collection as participants were obtained without my needing to cold call.

### **Delimitations**

Many intersex family members and other intersex allies have no intersex variation, yet they function as valuable activists. Their stories were outside of this study's scope. Second, for funding reasons, this study's geographic scope was limited to activists in the United States. Third, to capture a minimum depth of experience, I included only intersex activists with more than 1 year in activism, defined as public opposition to medically unnecessary sex-related intersex infant surgeries. Fourth, I emphasized the participants' opposition to medically unnecessary surgeries. Although this emphasis likely meant that the interviewees self-identified as activists, not advocates, the political stance, not the label, was the criterion. Finally, as I was interested in the inner world of intersex activists, I emphasized the interviews as the data source.

### **Limitations**

Memory as data is subject to limitations based on interviewees' recall ability, communication proficiency, and intentional or unintentional bias (Merriam, 2016). Second, I do not possess an intersex variation. In fact, I did not know anyone with an intersex variation until about 1 year before I wrote the proposal for this study. This study is therefore somewhat less rich than if I had an intersex variation or had known an intersex person or persons for a length of time. Merriam (2016) stated that an insider–outsider stance might negatively impact the fullness of information disclosed.

IPA strives for a demographically homogeneous sample (Smith et al., 2013), for only with homogeneity can similarity and difference among the few cases be related back to the comprehensive experience and not to some other difference. However,



homogeneity is less likely if the phenomenon is rare (Smith et al., 2013). I collected demographic information from the participants but did not use demographic homogeneity among activists in sample recruitment given the overall low number of members of the intersex activist population (see Appendix B).

### **Ethical Framework**

The *2014 ACA Code of Ethics* was the umbrella ethical lens for this study. Counseling professionals are guided by the ACA and this code. More specifically, the ACA published its position regarding optional infant sex-related surgeries in its 2004 Resolution to Protect Intersex Children from Unwanted Surgery, Secrecy, and Shame. This resolution holds that optional intersex infant sex-related surgeries are unethical. The ACA occasionally takes an ethical stance against harming actions that are nevertheless considered legal. For example, sexual orientation conversion therapy is considered legal in many states but considered unethical by the ACA. The ACA intersex resolution operates in parallel form to the ACA's stance regarding sexual orientation conversion therapies. Although ACA has taken a position against medically unnecessary sex-related surgeries on intersex minors, parents in the U.S. currently have an unfettered legal right to consent to optional sex-related surgeries for their minor intersex infants or children (Greenberg, 2012).

### **Conclusion**

As a biological sex minority, intersex people share shame and discrimination experiences with persons who are marginalized for their sexual and romantic orientations, gender identity, and/or gender expression. In contrast to all of these groups, intersex people are subject to explicit physical and psychological erasure. The physical erasure occurs first in sex development theory when biological sex is viewed as binary only, and

second through hormone treatments and surgeries in which physicians and surgeons try to physically erase intersex variations. The psychological effect of physical erasure is personhood erasure with devastating effect for many intersex persons.

Since the 1950s, intersex births have been handled in hospitals as psychosocial emergencies requiring treatment. This is the case even though, for the most part, the surgeries are not medically necessary. Two medical protocols, one active from the 1950s to 2006 and the second operant since 2006, have guided medical practices in the past 70 years. Modern intersex activism developed in the 1990s and inspired the changes in the 2006 protocol. Since 2006, intersex infants are commonly treated in DSD MT clinics. According to the protocol, parents are supposed to receive counseling and comprehensive information so that consent to optional intersex infant sex-related surgeries is informed. Many activists doubt the adequacy of the informed consent processes, remain unsatisfied with the new protocol, and work for a complete ban of optional sex-related surgeries on intersex infants.

Intersex variations have historically been described by several controversial synonyms. DSD is the term now used in medical contexts. Adopted after the 2006 Consensus, DSD is controversial because it labels people as disordered and thereby invites medical intervention. Activists reject the notion that intersex variations are disordered because doing so provides the medical profession with the authority to conduct medically unnecessary surgeries on intersex infants.

Knowledge about direct intersex experience, especially adult experience, has come in large measure through intersex activists or scholarly texts outside the field of counseling or psychology. Recently a zone of active research related to intersex

counseling focused on parent counseling needs in context of DSD MT clinics. Research has not yet focused on counseling needs for intersex individuals throughout the lifespan. Counseling education to support the needs of intersex individuals is in its infancy.

The field of counseling is at a time when developing services will require learning about intersex stories. In this study, I explored intersex stories from the vantage of intersex activists. Intersex activists are willing to publicly share their own painful experiences in order to stop medicalized harm. Modern intersex activism is a phenomenon facilitated by the Internet, which serves to unify a relatively small, geographically dispersed population. Scholars have assisted intersex activists by articulating the heteronormative assumptions that have been used to give the medical profession authority over intersex bodies.

This study's purpose was to provide insights into the experiences of intersex individuals as viewed from the lens of activists possessing intersex variations. This study's methodology was IPA. The research questions concerned the activists' experiences with having intersex variations, being intersex activists, and witnessing the quality of intersex counseling services. The psychological needs of this marginalized intersex population are largely unaddressed in counseling literature.

The study findings call attention to the counseling profession's implication in medically unnecessary intersex infant surgeries since the 2006 Chicago Consensus change in protocol. These findings also provide insights into activist perspectives about intersex physical, psychological, and counseling experiences to date. They call attention to the implications of intersex variation differences for psychological experiences. Intersex activists are both similar and different, and their perspectives in this study

provide a rich, up close vantage of issues affecting the larger community. Finally, these findings inform the development of an identity development model specifically tailored to intersex experiences.

## CHAPTER 2: REVIEW OF THE LITERATURE

This chapter expands on the introductory material in the first chapter. First, a discussion about intersex terminology is presented. Then the biology of sex differentiation is addressed. Several of the numerous intersex variations are summarized. The variations are organized according to two major categories, those that occur with atypical chromosomes and those that occur with typical chromosomes. Third, activist characteristics and legal issues related to intersex medicalization are addressed. Fourth, counseling resources and competencies are discussed. Finally, a study published in 2003 by sociologist Sharon Preves is covered in detail. Preves conducted a qualitative investigation that revealed harmful psychological experiences in over 20 adults from intersex medicalized treatments. The psychological detail Preves provided regarding the damage intersex people have endured from their medicalized treatments is particularly relevant for the field of counseling. Preves's study was an important building block for the intersex identity development model developed in this study.

Intersex natural bodily variation is one of several controversial umbrella terms that describe congenital occurrences of atypical physical sex development (Davis, 2015; Feder & Karkazis, 2008). Professions outside the medical domain commonly use the terms intersex or intersex variation (Davis, 2015; Singh et al., 2010). Intersex as a noun is not without critics. Some believe the term as a noun carries a connotation that a single quality of intersex defines the whole person and implies that the person has a failed identity (Feder & Karkazis, 2008). The historical term of hermaphroditism has been largely abandoned for its association with stigma (Pasterski et al., 2010; Reis, 2009).

Since 2006, professions aligned with medical diagnosis and treatment have employed the term disorders of sex development (DSD; Lee et al., 2016). DSD, which focuses on the etiologies of sex development differences, is meant to be politically neutral. Many activists, however, claim that the “disordered” element in the term stigmatizes and creates unjustified medical jurisdiction over infant intersex bodies (Motta, 2011; Marquez, 2016; Organisation Intersex International, n.d.). Other terms, for example, difference or diverse sex development, are circulating to avoid the disordered term. However, they are not yet in mainstream use (Liao & Roen, 2014). A convention using a slash, intersex/DSD, is now seen in discourses with both medical and nonmedical audiences. In its 2015 fact sheet, the United Nations uses the term intersex natural bodily variation in an explicit effort to replace DSD and prevent unnecessary surgeries on intersex infants.

### **Overview of Sex Differentiation**

To set the backdrop for the following discussion regarding the biology of intersex variations, I first present a general overview of sex differentiations in endosex males and females. Mothers and fathers each contribute one of the sex chromosomes. The mother contributes an X, and the father contributes an X or Y. In a step-by-step development process, the combination of 46,XX generally produces female development and 46,XY generally produces male development. The sex development process can be viewed in terms of sequential, linear influences involving chromosomes, genes, gonads, hormones, and genitalia.

In the very beginning of sex development, the fetuses are sex neutral; they have the duct types of both sexes, Mullerian (female) and Wolffian (male; Wisniewski et al., 2012). If the fetus has male chromosomes (46,XY), then from chemical reactions

triggered by the SRY gene (typically on the Y), testes (male gonads) develop. The testes produce (a) a large quantity of the Mullerian inhibiting hormone (MIS) and (b) the androgen testosterone. MIS causes the female sex ducts to remain undeveloped; testosterone causes the male Wolffian ducts to develop into male reproductive organs. If the fetus has female chromosomes (46,XX), testes do not develop unless an SRY anomaly occurs. Without testes, no MIS or testosterone are produced, therefore the Mullerian ducts develop and Wolffian ducts do not develop. In other words, depending upon the absence or presence of a sufficient amount of MIS and testosterone hormones, the ducts develop into either the male or female reproduction organs.

The Mullerian ducts develop into the female reproductive organs of fallopian tubes, uterus, cervix, and vagina. (Testes or ovaries, also part of the reproductive organs, were already developed). The Wolffian ducts develop into transport structures for sperm to leave the body: epididymis, vas deferens, and the seminal vesicles. Toward the end of sexual differentiation in males, a byproduct of testosterone triggers DHT (assuming an enzyme 5 $\alpha$ -reductase is present). DHT then spurs external male genitalia of penis and scrotum development. In the absence of DHT, the baby grows vulva (Wisniewski et al., 2012).

In summary, an endosex (typical) male has chromosomal sex of 46,XY, gonadal sex of testes, an ability to produce and absorb male hormones, internal male reproductive organs, and external male genitalia. An endosex (typical) female has chromosomal sex of 46,XX, gonadal sex of ovaries, female reproductive organs, and female genitalia. Innumerable variations can occur at any phase along the sex development path.

## **Intersex Variations With Atypical Chromosomes**

Some individuals are born with chromosomes that are variant from typical patterns of 46,XX (female) or 46,XY (male; (Wisniewski et al., 2012). Most with atypical chromosomes have typical internal reproductive organs and typical external genitalia. Hormone production, however, may be insufficient and fertility may be an issue. Hormone medical treatment may be provided for life for bone health and puberty development. Gonads are not usually removed. For example, Klinefelter syndrome is a variation in which the chromosomes are typically 47,XXY. External genitalia are generally but not always male typical. Gender identity is usually but not always as man. Testosterone treatment may be given for life. Men with this syndrome have a lower than average life expectancy. Another example is Turner syndrome, a variation in which the chromosomes are 45,X0. Gender identity is usually as woman, and life expectancy is shortened due to propensity for high blood pressure and cardiovascular disease. A third example of atypical chromosome intersex variation is chimerism, in which chromosomes differ among cells. There are multiple sex development paths for chimerism. As an example, chimerism may occur very early in development when two or more zygotes merge and grow into one fetus.

## **Intersex Variations With Typical Chromosomes**

### **46,XX (Female) Variations**

In this category of intersex variation, sex development commonly associated with females should develop. However, the fetus's adrenal glands or the mother's womb environment exposes the chromosomal female to an overabundance of masculinizing hormones (Wisniewski et al., 2012). Congenital adrenal hyperplasia (CAH) is the most common cause of 46,XX intersex variation. The overabundance of virializing hormones



in CAH is due to an enzyme deficiency, either 21-hydroxylase or 11 $\beta$ -hydroxylase. Commonly with CAH, the internal sex organs are female, but the genitals masculinize to a varying degree depending upon level of male hormone exposure. The clitoris may resemble a small penis, and the labia may have fused to some degree, approximating a scrotum. As mentioned, causes of hormonal virilization exist other than CAH such as hormones administered to the mother or a tumor in the mother, but those are rarer causes of 46,XX intersex variation (Wisniewski et al., 2012).

### **46,XY (Male) Variations**

In this category of variations, chromosomes are typical male but something happens in utero to produce feminization of features (Wisniewski et al., 2012). Causes of 46,XY intersex variation are more varied than for 46,XX. Half the cases are of unknown specific origin (Wisniewski et al., 2012). The overarching explanation, however, is that the chromosomal 46, XY male fetus was exposed to a smaller quantity of androgens required for typical development. The issue of why the quantity is smaller relates to both production and absorption. In other words, the issue might be that (a) the testes do not produce sufficient androgens or (b) the testes properly produce the hormones but the body does not absorb them (Wisniewski et al., 2012). If genitalia are under-masculinized, there can be a small penis that looks like a clitoris, a scrotum that looks like labia, undescended testes, and a urinary opening along the base of the penis. Several intersex variations related to androgen production or absorption insufficiency are described next.

Complete gonadal dysgenesis, also called Swyer syndrome, involves insufficiency of testosterone production (Wisniewski et al., 2012). The testes never formed or were absorbed in early development. No MIS is made; therefore, female sex ducts develop, leading to growth of internal reproductive organs of fallopian tubes, uterus, cervix, and

vagina. There are no ovaries, however, hence the infant is born infertile. Without testes no testosterone is made so (a) male sex ducts do not develop and (b) DHT is not made from testosterone, resulting in female genitalia.

Partial gonadal dysgenesis also involves insufficiency of testosterone production. (Wisniewski et al., 2012). Testes form but an insufficient amount of MIS is produced. Without full inhibition of Mullerian ducts, female sex ducts develop partially. With some testosterone, male sex ducts develop partially. As an insufficient amount of DHT is made from testosterone, genitalia masculinize only partially.

Complete androgen insensitivity syndrome (CAIS) involves androgen receptor insufficiency. Though testes develop and MIS and testosterone are adequately produced, the body is unable to absorb the masculinizing hormones. The inhibiting MIS hormone produced by the testes prevents female ducts from developing. Thus, in CAIS there are no female ducts and very little male duct development. Genitals are typical female. Testes may remain in the abdomen without a scrotum in which to descend.

Partial androgen insensitivity syndrome (PAIS) also involves an androgen receptor insufficiency but some testosterone is absorbed. Testes are typical. No female ducts develop due to MIS inhibition. Genitals may appear atypical.

### **Intersex Diversity in Sexual Orientation and Gender Identity**

As with all of humanity, intersex sexual orientation and intersex gender identity span a diverse spectrum (Astorino & Vilorio, 2012; TED, 2018). In sexual orientation, intersex individuals may identify as straight, gay, lesbian, bisexual, or other varieties of sexual orientation. In gender identity, persons identify as man, boy, woman, girl, both, two-spirited, intergender, neither, or uniquely defined. Some forms of intersex variations are more aligned with man or woman in identity (Wisniewski et al., 2012). As mentioned,

claims about the incidence of a particular gender identity in various forms are controversial. Medically unnecessary surgeries based on gender averages by variation lead to tragedy for the exceptions.

### **Intersex Variations May Be Conflated With Transgender Experience**

Erroneous conflation of intersex variations with transgender experience may occur, first, under a narrow usage of transgender (Intersex Initiative Project, 2003). Using transgender narrowly, the term pertains to gender identity variance with a typical male or female body of birth. Intersex variations pertain to biological variance from typical male or female development. A confusion may occur because people might not know that biological variance exists and think that intersex variation is a synonym for transgender.

Another possible conflation between intersex and transgender pertains to an erroneous binary gender assumption about intersex people who struggle with gender identity. If an intersex person experiences issues with gender identity, it does not always follow that they want to transition to a different binary gender identity (O'Hara, 2016). An intersex person may struggle with the uniqueness of their identity, but that is not to say that opting for typical man or typical woman gender identity will be experienced as the solution.

Another confusion may arise from a broad use of transgender. Transgender is sometimes used as an umbrella term for persons who challenge gender norms. In such a broad use of transgender, having an intersex variation is sometimes included. Unfortunately, conflating transgender and intersex experiences may miss the particularized struggles associated with each group. Dreger (2016) observed that transgender people struggle to get medical care; intersex people may be coerced into medical care they did not desire.

Confusions about the difference between transgender and intersex variations occur for another possibility besides the reasons of (a) ignorance that intersex variations exist, (b) a binary-based erroneous assumption about gender, or (c) an overbroad definition of transgender. A Venn diagram would show some degree of overlap of intersex and transgender categories. The overlap occurs for a unique reason. To gain access to medical treatments, an intersex individual may feel the need to become classified by licensed clinicians under *Diagnostic and Statistical Manual of Mental Disorders (DSM)* criteria as having gender dysphoria if the original gender assignment at birth was incorrect. Treatment access will require that the individual engage in some portion of the WPATH standardized clinical process required of transgender people seeking medical access to treatment to switch their birth assignment. For an intersex person, the standards can be experienced as having to lie to gain treatment access. The individual may have always internally identified as the gender for which they seek medical authorization. Their dysphoria was created externally by physicians and parents through incorrect assignment (A. Marquez, personal communication, March 23, 2019). To gain access to treatment, intersex “trans” person may have to engage in what feels like an untruth, namely they have to claim gender dysphoria. To add insult to injury, they then have to spend time and money to gain what was always their gender as a result of misassignment. The transition process can feel like the victim is being victimized under the WPATH standards (A. Marquez, personal communication, March 13, 2019).

### **Activist Characteristics**

I gathered data from intersex activists for the purpose of developing a frontline perspective on the experiences of the formerly hidden intersex population. Activist characteristics in other social movements provided a framework for intersex activist

experiences. As an overview, the literature on activist characteristics demonstrated that there are factors regardless of social movement that activists share in common. Much less scholarship, however, was available on the inner experience of activists as they initiate activism and then remain committed for a period of time (Savas & Stewart, 2018).

Activism is sometimes referred to as collective action (Savas & Stewart, 2018). Predictive factors for activism include (a) an assumption that one can make a difference, (b) a perception of injustice, and (c) membership in a politically oriented group (Savas & Stewart, 2018). Oppression is not sufficient to spawn activism; oppression must be perceived as injustice (Dutt & Grabe, 2014). Vision of just alternatives to oppression leads activists to work for more just experiences (Dutt & Grabe, 2014). By participating in collective action, activists deepen their understanding that injustice is maintained through political and social structures (Dutt & Grabe, 2014). Activists then engage in strategies to address the oppressing structures. Activists are attuned to ways to force the system to change from bottom up (della Porta, 2000). Social connections create a reinforcing system through shared friendships, beliefs, and activities (della Porta, 2000).

The literature on activists documented that activist participation varies by length of time. *Persisters* are dedicated to a movement for a lengthy period, *shifters* switch movements, *dropouts* return to private life (della Porta, 2000). Persisters are confident that their actions will make a difference over the long haul. They believe they will change the world through their specific strategic efforts or through their modeling a justice orientation (della Porta, 2000). Activists have an aptitude for activism, reflected in part by persistence through personal and social barriers (della Porta, 2000; Dutt & Grabe, 2014). They are educated, but their income may be low. Life may be structured around

part-time paid employment so as to give more time to activist activities (della Porta, 2000).

Activists are guided by ethical values. The ethical values can be absorbed through families, educational systems, and social movements (della Porta, 2000). Activist values are strengthened through participation. Activists participate in historically unique contexts. The governing values and codes of conduct of individual activists will vary according to the particular historical movement (della Porta, 2000). An internal relationship with activism may become so strong as to permeate inner life. Such a full connection of the individual's being with activism praxis may be seen through statements such as "This is what I was meant to do" (della Porta, 2000).

The age that a person's activism began can make a qualitative difference in activist experience (Savas & Stewart, 2018). First, youth born into an oppressive context might never remember a time in which activism seemed like a choice. Their inner experience might be such that their activism felt like the only natural response. Youthful activism served as an opportunity to experience independence, strength, and freedom from constant oppression (Savas & Stewart, 2018). Second, persons who experienced and responded to community distress for the first-time during adolescence remember a "before" time in which they were not responding to life with activism. Activism for the adolescent became incorporated as a consciously chosen part of identity. Adolescent activism served as an opportunity to form an identity and connect with support from a community who shared the new values. Third, persons who respond to community distress for the first time in adulthood have already developed their identity. Adult-initiated activism served as an opportunity to take responsibility and engage in actions

that were then incorporated into existing identity and values. Adults may bring years of internalized repression to their early activism. Positive early activist experiences served to help adult activists overcome any initial reticence (Savas & Stewart, 2018).

I commenced this study with the notion that intersex activists share characteristics in common with activists in other movements. I assumed that the participants would likely hold the positive belief that their advocacy would make a difference. At the study outset, intersex activism demonstrated the activist practice outlined in the literature of targeting a structural goal, namely working to ban medically unnecessary intersex infant sex-related surgeries. I also considered that intersex activists might reflect differences as compared with activists in other movements. For example, some social movements have local membership and hold meetings in person; intersex activism involves geographic dispersal and online activity given the relatively small intersex population.

### **Medical Literature Emphasis: Disorders/Differences of Sex Development Multidisciplinary Team Clinics and Parent Counseling**

Since the 2006 Consensus (the current medical protocol for intersex infant and youth care), greater attention is being paid to the role of parents, both in the literature and by activists. The reasons are twofold. First, parents have caregiver needs. Second, parents possess the legal right to consent to treatments for their minor. As previously noted, DSD MT clinics are where counseling for parents of intersex children is supposed to take place by virtue of the 2006 protocol.

Recent research has provided greater insights into parental experiences of intersex births and their engagement with the medical treatment processes recommended for their infants. Crissman (2011) documented four domains of concern in early parent experience. The domains include assigning the infant's gender, decision-making regarding infant

surgeries, disclosing information about their child's intersex/DSD to others, and interacting with health care providers.

Parents may have a period of shock and grief. They need time to shift away from long held assumptions about sex. Infant bonding may be difficult, especially during the diagnostic phase prior to assignment (Saunders et al., 2008). They may not be sufficiently informed about controversies surrounding infant genital surgeries. They may not know of options to the surgeries such as postponement (Sanders et al., 2008). Parents may understandably reach for surgery with some measure of magical thinking hoping that physicians have the power to “find” the “true sex” of either male or female in their infant and completely “fix” their baby (Gough et al., 2008). Time is needed to grieve the loss of what they expected for their child, learn about their child's intersex variation, love the child, and critically evaluate surgical options (Roen, 2009). Parents ideally receive therapy to cope with shock, adjust to the diagnosis, bond with their infant, communicate with relatives, cope with uncertainty during sex assignment, and prepare to make surgery decisions (Gough et al., 2008). Parents may benefit from psychosocial support to address stigma (Rolston et al., 2015).

There is a lack of evidence explicating the content and quality of the DSD MT counseling that parents receive (Liao & Simmonds, 2014). Psychological support programs in DSD MT clinics, though obligatory, have yet to be codified (Bennecke et al., 2015; Lee et al., 2016). A comprehensive plan of DSD MT psychosocial support for parents, and later with intersex youth, would involve addressing theoretical frameworks, evidenced-based methodology, and service priorities (Liao & Simmonds, 2014).



DSD MT clinics may not be achieving the vision of parent counseling in the 2006 Chicago Consensus (Liao & Roen, 2014). DSD MT clinics are often surgeon led. A values conflict between psychology and medicine may result in inner team conflict (Liao & Simmonds, 2014). Physicians and surgeons may verbally acknowledge the importance of the counseling part of the team. Yet, clinic leadership may fail to dedicate sufficient financial resources to satisfactorily address intersex families' ongoing psychosocial support needs. Thus, surgeons may believe, without foundation, that parents have been adequately counseled and are therefore capable of assuming the role of informed and independent members of a shared decision-making team (Liao & Simmonds, 2014).

In conclusion, the effects of any DSD MT team parent counseling ultimately pertain to an intersex individual's lifespan needs. During infancy, gender is assigned, and guardians consent to optional infant surgeries with permanent consequences (DuBois & Iltis, 2016; Harper, 2007; Holmes, 2008; Karkazis, 2008). Adult intersex individuals will be irreversibly impacted by the decisions their parents made for them in infancy with support from DSD MT counseling. Though DSD MT counseling is not termed "surgical facilitation" in medical literature, the experiences in DSD MT clinics may not be in accord with what professional counselors think of as appropriate professional counseling for irreversible decisions that will affect the lifespan.

### **Legal Role of Parents in Medically Unnecessary Intersex Infant Surgeries**

In the United States, intersex activists are concerned with the legal authority vested in parents to provide proxy consent for medically unnecessary infant sex-related surgeries. Several issues related to parental legal authority over their intersex infants are summarized in the following questions. Would parents stop agreeing to the optional surgeries if informed consent practices and counseling support were more thorough and

provided over several sessions to give time to process the information? Does the legal presumption that parents should have proxy consent based on a presumed overlap of parent and child interests factually apply in the case of intersex births? In other words, do parent and child interests uncharacteristically diverge with an intersex birth? (Parents may be more concerned about family stigma during the child's 1 to 18 years whereas an intersex youth who becomes a sexual adult lives with the consequences of optional sex-related surgeries for their lifespan.) Should enhanced parent-child bonding ever be a justification for violating a child's right to self-determination and bodily autonomy? Should a parent's right to give proxy consent be legislatively revoked because ashamed and fearful parents will continue giving proxy consent unless it is legally banned?

### **Arguments in Favor and Against Parental Proxy Consent**

Greenberg (2012) stated that the justifying claims for parental authority to consent to optional infant sex-related surgeries are on the basis that the surgeries are in the children's best interests. Proponents of parental authority state that the surgeries are no longer conducted in secrecy and parents are presumed thoroughly informed. The surgeries presumably prevent future psychological harm in the child. The harm prevented is considered greater than the surgery risks because supposedly surgery techniques have improved. Finally, the surgeries are believed to properly belong in the domain of parental authority because parent and child interests are one in the same.

Greenberg (2012) stated that those who dispute parental authority to consent to optional infant sex-related surgeries do so on the basis that the surgeries are harmful and not in the children's best interests. Opponents assert that the invasive and irreversible surgeries cause unnecessary scarring and pain. Surgeries actually create the stigma they supposedly avoid by the trauma that occurs from medically treating these children as

abnormal. The children will be psychologically scarred by medical efforts that were designed to prevent psychological distress. Multiple follow-up surgeries will be required to repair previous surgeries. The surgeries are primarily conducted to relieve the anxiety of others, which is unethical. Medically unnecessary infant surgeries that can be postponed violate a child's sense of autonomy leading to potentially lifelong psychological problems.

### **Potential Legal Challenges to Medically Unnecessary Intersex Infant Surgeries**

Greenberg (2012) detailed legal avenues that might result in banning optional sex-related intersex infant surgeries. The legal challenges could be legislative or judicial. The judicial possibilities include multiple lines of argument.

#### **Legislative Approach**

Intersex activists strategically engage in legislative efforts to halt medically unnecessary sex-related surgeries on intersex infants. In California, interACT and other human rights organizations successfully advocated for the first-ever state resolution to recognize the human rights violations faced by intersex people. The resolution encouraged stakeholders to refrain from intersex surgeries without the recipient's consent (interACT Advocates for Youth, 2019c). Efforts by interACT to move beyond resolutions toward laws banning the surgeries is underway (interACT Advocates for Youth, 2019b).

#### **Judicial Approach: Potential Claims**

The only high court to have considered optional infant intersex surgeries is in Columbia, South America (Greenberg, 2012). In the Columbia case, the court decided that infant genital surgeries should be treated differently from typical cases in which parents have unfettered authority to provide proxy informed consent for their minors

because parents are not usually informed about intersex variations; having an intersex variation is socially viewed as a disease; and the medical profession communicates an urgency about a surgery that can actually be postponed. The court stated that the evidence in favor of and opposed to a ban conflicted, therefore, evidence was indeterminate. The court aimed for a compromise position through a process of qualified and consistent informed consent. Informed consent was qualified and consistent if it was in writing, fully informed, and provided over a period of time and over several occasions so that parents had time to understand the situation. The composition of fully informed consent needed to include the dangers of current treatments, the existence of other nonsurgical paradigms, and the possibility of delaying surgeries. Adequate psychological support for the child should also be provided.

### ***An Informed Consent Violation***

The doctrine of informed consent is the most likely legal doctrine to successfully challenge optional infant sex-related surgeries (Greenberg, 2012). Informed consent has an especially strong potential due to its being founded on a recognized constitutional right (Greenberg, 2012). Americans have a constitutional right to liberty guaranteed by the 14th Amendment that protects self-determination and bodily autonomy. Physicians who surgically alter individuals must legally provide sufficient information for individuals to exercise choice over what will be done to their bodies (Ford, 2000). Violations of informed consent are brought in the form of civil torts of negligence or battery; however, negligence is more common (Greenberg, 2012).

The right of informed consent presumes adult capacity to weigh risks and benefits. Accordingly, parents generally serve as proxy consent providers for surgeries on

their minor children and/or developmentally disabled adult children. In most cases, the authority is granted because parents are presumed to be acting in their children's best interests. Nevertheless, in some situations parental right to provide consent for surgery on a minor child has been restricted when courts determined that parent and child interests were not equivalent (Greenberg, 2012).

An informed consent challenge on behalf of intersex minors would argue that an exception to parental authority applies to optional sex-related surgeries on intersex infants. One such recognized exception involves instances of forced sterilization. The courts have recognized that parents sometimes provide consent to sterilization of their child for their own interests, not the child's interests (Greenberg, 2012). Some sex-related surgeries in intersex minors, such as removing ovaries of a child assigned male or removing testes in a child assigned female, result in sterilization. Cases challenging the sterilization of intersex minors could be brought by (a) medical personnel or hospitals concerned to avoid legal liability, (b) persons who were sterilized without their consent, or (c) government agencies. A defense would likely state that the goal in removing gonads was to prevent cancer, not to sterilize. If the surgical procedure is described as medically recommended, then courts generally do not review medical practices.

Claimants pursuing an informed consent challenge might also state that due to the invasive and irreversible nature of the optional surgeries, the informed consent privilege provided to parents should be subjected to heightened scrutiny. The heightened scrutiny could be provided by the court or a committee such as a hospital ethics board. A challenge based on failure of heightened scrutiny would not be as strong as a

reproductive rights challenge given the latter's foundation in a constitutional right (Greenberg, 2012).

### ***Sex Discrimination***

Activists may use sex discrimination to challenge optional infant sex-related surgeries (Greenberg, 2012). Sex discrimination laws were originally conceived of as redress for women for the privileges accorded to men. Initially, courts were reluctant to apply protections to sexual minorities, but these protections are gradually expanding (Greenberg, 2012). Several U.S. circuit courts have ruled that employers discriminate when they hold employees to stereotypical performance standards based on gender role performance, gender behavior, or gender identity. Greenburg stated that several current intersex medical treatments may be in part based on sex or gender stereotypes, including (a) surgery to reduce the size of a clitoris, (b) administering dexamethasone in utero toward the goal of preventing masculinization of 46,XX fetuses with CAH, (c) surgery to create or deepen a vagina, and (d) surgery to move a male urethra opening so that it occurs at the tip of the penis.

Claimants could argue that clitoris reduction is based on the discriminating gender stereotype in which the medical profession cares more about genital appearance than genital sensation. Claimants could argue that dexamethasone in utero is administered to avoid physical masculinization, tomboy behavior, or lesbian sexual orientation. Thus, dexamethasone administration may occur under the discriminating gender stereotype that women should fulfill feminine stereotypes. Claimants could also argue that optional surgical treatments of hypospadias reflect the discriminating gender stereotype that men need to urinate standing. Claimants could also argue that vaginoplasty and dilation

procedures performed in infancy are based on the discriminating gender stereotype that all women want penetrative intercourse.

### ***Disability Discrimination***

The disabled have legal protections against discrimination based in large part on the Americans with Disabilities Act (Greenberg, 2012). A claim based in disability law would require evidence that the surgical procedure was performed under the erroneous assumption that intersex persons have a disability impairment. The claimant would argue that DSD children are inappropriately construed as disabled by current medical protocol. Intersex persons, unaltered by hormones or surgeries, are incorrectly assumed to be unable to engage in satisfactory sexual or romantic relationships and therefore in need of genital surgeries. They are falsely and without proof assumed to face inevitable emotional trauma due to being born intersex. (Greenberg, 2012).

## **Professional Counseling Resources and Competency Guidelines**

### **Intersex Client Categories**

Several categories of intersex clients may present for counseling. The categories discussed next are examples and not meant to be an exhaustive list. Overarching categories include parents, youth, adolescents, adults, and family members. At the hospital, parents of a newborn may be the first to receive counseling. Subsequently, as the child matures, parent and child may receive counseling on clinic days (Moran & Karkazis, 2012). Preadolescents may present to process their feelings about treatments that postpone or reduce physical sex change at puberty (Moran & Karkazis, 2012). Preadolescents, adolescents, and adults may come to counseling for relationship issues such as how to disclose an intersex variation to a partner.

Other clients may include adolescents who first learn of their diagnosis at puberty and/or are adjusting to intersex changes at puberty (Moran & Karkazis, 2012). For example, an intersex adolescent, gender identity girl/woman with CAIS may have just learned of her variation. She may be struggling with her long felt gender identity of girl/woman now knowing she has testes and her chromosomes are male 46,XY karyotype. She might have received contradictory information regarding testes removal and is seeking therapy to process that decision.

Adults who are processing what happened to them as minors might present for counseling (Consortium on the Management of Disorders of Sex Development, 2006b). Some may be unhappy with their assigned gender and seek emotional support to transition. Other intersex clients may present to counseling solely to obtain mental health fitness letters prior to hormone or surgical body modifications of physical sex.

### **Multicultural Texts**

There is a dearth of original intersex counseling research. The vacuum is even more pronounced when considering intersex issues in conjunction with other nondominant status areas such as race, rural life, and aging (Alderson, 2013). A few multicultural texts provide a general overview of intersex history and the psychological needs of intersex individuals (Alderson, 2013; Burnes & Richmond, 2012; Ginicola, 2017; Goodrich & Luke, 2015). The texts reference physical and psychological damage from the modern medicalized approach to intersex management. Issues highlighted include shame, hidden medical records, stigma, betrayal by authority, difficulty with trust, isolation, body image, and damage from parent and physician silence and/or lies. Other issues addressed include PTSD, depression, suicidality, anger, grief, sexual function, gender identity, parental shame and stress, and parental bonding (Alderson,



2013; Burnes & Richmond, 2012; Ginicola et al., 2017; Goodrich & Luke, 2015; Singh et al., 2010). Two authors discussed treatment modalities useful for addressing specific issues such as group therapy and Van Vliet's framework for understanding shame (Alderson, 2013; Goodrich & Luke, 2015).

As is necessary given the absence of counseling literature, these texts rely on research outside the field of counseling (Alderson, 2013; Burnes & Richmond, 2012; Ginicola et al., 2017; Goodrich & Luke, 2015; Singh et al., 2010). The counseling field lacks training curricula for intersex counseling (Alderson, 2013). Singh et al. (2010) observed both a growing demand for intersex mental health practitioners and a lack of practitioner competency with the issues.

Theoretical orientations have not been tested for efficacy. Burnes and Richmond (2012), however, outlined a case conceptualization specifically for a client with an intersex variation. The authors presented a hypothetical case history and diagnoses according to the *DSM*. In their case conceptualization, Burnes and Richmond used several theoretical counseling constructs including process based, patient centered, feminism, relational-cultural, and trauma therapy. The authors noted that their approach involved practicing under a medical model by virtue of using the *DSM* to diagnose. Burnes and Richmond observed that therapists who practice intersex counseling using the *DSM* might experience vicarious trauma for practicing in the same medically oriented treatment and diagnosis system that perpetuates physical and psychological damage in intersex people.

### **Useful Resources**

In addition to providing an overview of intersex counseling issues, Singh et al. (2010) discussed the distinctions between human physical sex, gender, and orientation.

The distinctions are salient to human identity development. As previously noted, the distinctions are vital to understand and keep separate in intersex counseling. Intersex individuals do not fit the binary understanding of human sexuality (Singh et al., 2010). Singh et al. also discussed transgender counseling issues in depth. As previously mentioned, intersex “trans” issues are not equivalent to transgender issues, yet transgender counseling issues are relevant for some intersex individuals who seek transition from their assigned sex/gender.

Alderson (2013) created a useful table by combining several sources that break down various intersex variations into categories of biological description, prevalence, karyotype, and common gender assignment. At a glance, the table reveals the wide variety among the intersex variations. Accordingly, the table provides awareness that counseling for intersex individuals who have different variations cannot be homogenized into one set of counseling needs. For example, a person with Klinefelter syndrome who is emotionally concerned about gynecomastia (breast enlargement in males) will likely present differently than a person with Turner syndrome who is emotionally concerned with heart complications. At a glance, the chart shows that some variations are associated with more gender consistency than others. Finally, the table makes clear that intersex variations have many different etiologies and the etiologies result in a variety of physical manifestations.

### **Competency Guidelines**

Singh et al. (2010) produced an intersex counseling competencies chart by supervisee developmental readiness level meant to apply to both intersex and transgender counseling. The levels are organized according to categories of knowledge, skill, and values/attitudinal competencies, and categories of practicum, internship, professional

practice, and advanced practice (Singh et al., 2010). The chart provides useful detail regarding general sexual minority multicultural competences.

The Association for Lesbian, Gay, Bisexual, and Transgender Issues in Counseling (ALGBTIC) Competencies Taskforce detailed general principles or categories focusing exclusively on intersex competencies (ALGBTIC LGBQQIA Competencies Taskforce, 2013). The principles hold that counselors should do the following:

- understand the biology of intersex and the history of medical treatment,
- provide support to the family when the child is born, including complete information about the child and any options, including referrals,
- be aware of all forms of oppression and stressors that intersex individuals experience, including marginalization within the sexual minority population,
- possess an understanding that (a) neither gender nor biological sex is binary and (b) gender and orientation are not tied to biological sex,
- know about the history of the intersex activist movement,
- be sensitive to language as a potential source of psychological harm such as pronouns that do not fit and/or binary only gender terminology,
- have a responsibility to advocate for medical care and encourage postponement of all optional treatments,
- be aware of the lack of research based specifically on intersex individuals, and
- keep current on the literature (ALGBTIC LGBQQIA Competencies Taskforce, 2013).

As noted, one of the ALGBTIC intersex competencies holds professional counselors responsible for knowing the variety of forms of intersex oppression and stressors. To date, multicultural counseling literature has emphasized two intersex categories of potential oppression and stress: harm encountered by all sexual minorities who are marginalized in Western society and harm encountered as minors who receive nonconsensual, optional sex-related medical treatments. Yet, intersex individuals also experience difficulties in families, schools, friendships, and romantic/sexual relationships (Alderson, 2013). The following content is intended as additional detail regarding knowledge, attitudes, and skills requirements first outlined by Singh et al. (2010) and the ALGBTIC Taskforce (ALGBTIC LGBQQIA Competencies Taskforce, 2013).

### **Additional Counseling Competency Detail**

#### **Parents and Guardians**

Parent and guardian decisions will affect the child for life (interACT Advocates for Youth, 2019f). Parents and guardians are assumed to be in the best position to protect their children from harm and to serve as advocates for optimal medical treatment. Professional counselors, however, maybe called on to help an intersex child who has been harmed by a well-meaning parent/guardian.

Parent and guardian priority should be for the intersex child's needs across the lifespan. However, these individuals may cause harm if they confuse whose needs are paramount and make medical and social decisions based on relieving their own stress and shame (Singh et al., 2010). Parents and guardians may harm when they place more weight on preventing childhood stigma than preserving their children's sexual sensations for the future. Concealing medical diagnoses, treatments, surgeries, and other acts of

secrecy leads to psychological harm (Singh et al., 2010). Giving too much information at one time is overwhelming (interACT Advocates for Youth, 2019f).

The child should not be used to process parent or guardian emotions. Parents and guardians benefit from their own support group or therapy. They may harm when they blame themselves and/or treat the diagnosis as a burden. Parents and guardians may create distress when they do not work together with their mate as a parenting team (interACT Advocates for Youth, 2019f).

Parents and guardians are tasked with providing for their child's emotional support. They may underestimate how serious an intersex variation is to their child's total identity. They may wrongfully assume that behavioral signs of apparent adjustment mean that the child has internally resolved having an intersex variation (interACT Advocates for Youth, 2019f). Parents and guardians benefit if they make the child feel special because of differences and not in spite of them. Psychological harm is created by pitying the child (interACT Advocates for Youth, 2019f). Parents and guardians should make clear that therapy is available and that attending counseling sessions does not mean the child has a mental illness. Therapy can also provide value by addressing a youth's need for adjustment and improving family communication (interACT Advocates for Youth, 2019f).

Distress can follow if parents and guardians are unprepared to act as proactive protectors. Parents and guardians should seek out consultation from a diverse team of professionals and community members who can help explain options and support healthy parental coping. Parents and guardians should proactively create opportunities for their children to talk about their intersex experiences. Parents and guardians should proactively

provide their children with access to other intersex individuals (interACT Advocates for Youth, 2019f). The child may be feeling stigma and/or guilt for impacting the family. Given these negative emotions, the child may not bring up intersex issues on their own without proactive effort by parents. Parents and guardians need to be prepared to answer questions knowledgably.

Parents and guardians should be aware of the high family stress related to a parent's decision to opt for unnecessary sex-related surgeries. Decisions made for the child in youth will impact family relationships for life (interACT Advocates for Youth, 2019f). Parents and guardians are the individual's protectors and advocates in the medical system. As children mature, they may judge their parents and guardians harshly if they did not resist pressure from medical personnel and gave their consent to unnecessary irreversible medical actions. Intersex adults may feel betrayed and harbor intense feelings of unforgiveness toward parents and guardians for not being better protectors (Karkazis, 2008).

Parents and guardians may harm if they do not protect their children from feeling like guinea pigs through such medical practices as allowing multiple physicians to conduct objectifying exams for their own learning or curiosity interests. They may harm if they talk to a doctor in the room rather than their child. Parents and guardians may harm if they do not try to explain such procedures as vaginal exams in advance and help the child feel as comfortable as possible (interACT Advocates for Youth, 2019f).

Intersex individuals may feel stress due to the sense that their parents or guardians tried to erase them. They may describe a sense of erasure even if their parents or guardians did not opt for surgery. Parent or guardian pressure to have their child perform

according to typical gender roles and behaviors of the assigned gender may feel like erasure. Parents and guardians harm if they are homophobic, transphobic, and/or queer phobic (A. Marquez, personal communication, March 23, 2019).

Parents and guardians benefit if they teach their children about patient rights (interACT Advocates for Youth, 2019f). They benefit if they empower their children to say no to uncomfortable medical experiences in advance. Parents and guardians should encourage their children to determine who should accompany them to medical exams. They should not respond with hurt if they are not invited to the exam and only a physician is desired (interACT Advocates for Youth, 2019f).

Parent and guardian communication in general is a particularly challenging area to navigate (interACT Advocates for Youth, 2019f). Parents and guardians harm if they compare their children to others who are less fortunate. They harm if they tell the children how they should feel. Parent and guardian references to “typical experiences” such as pregnancy can make the child feel left out. Parents and guardians should act with sensitivity and know that any discussions about their child’s intersex variation, publicly or within the family, can be highly triggering (interACT Advocates for Youth, 2019f).

The entire family will be affected by the birth and life experiences of their intersex child. Parents have an important role in guiding relatives. Relatives will need to learn about the impact of the particular intersex variation and of the importance of support and privacy. Parents and guardians benefit by keeping the family informed (interACT Advocates for Youth, 2019f).

Parents and guardians should be aware that their intersex child may feel jealous of their siblings’ “normalcy.” An intersex child may feel left out as their siblings go through

puberty. Siblings may resent and reject an intersex child for taking family time, energy, and financial resources (interACT Advocates for Youth, 2019f). Parents and guardians need to avoid any family rejection and/or scapegoating.

Parent communication regarding disclosing the intersex variation to others is especially sensitive. Whereas secrecy will create shame, honoring privacy will be important to the individual (Singh et al., 2010). Decisions about disclosure will have to be navigated in infancy and in youth with schools, family, friends, and caregivers (interACT Advocates for Youth, 2019f). Harm can come if the fact of an intersex variation gets into the hands of people who behave without sensitivity nor compassion.

Ideally, an intersex individual gets to decide when, how much, and to whom information about their intersex variation(s) is provided (interACT Advocates for Youth, 2019f). The individual benefits by being empowered to be the person who actually provides disclosures. The individual will feel the consequences of how disclosures to others were handled in infancy and youth.

In infancy, an intersex individual's agency regarding disclosures is clearly not possible. Unfortunately, initial guardian decisions about who to tell in the family happen at the time parents are likely overwhelmed. If parents have disclosed while the child was in infancy, the youth has a right to know who knows (interACT Advocates for Youth, 2019f).

When the child is no longer an infant, parents should inform their intersex child prior to their making any disclosures. Parents should not tell their intersex child to never disclose the fact of an intersex variation as secrecy fosters shame. The child should be helped to understand how to engage in selective disclosure and maintain appropriate



privacy. Parents can prepare their intersex child to disclose by discussing the advantages and disadvantages of a disclosure in advance (interACT Advocates for Youth, 2019f).

School will be an important place for parents to act as advocates and protectors, for textbooks will likely not have information about intersex variations and contain binary language (interACT Advocates for Youth, 2019g). Garnering proactive support for an intersex child in school will likely be an ongoing effort, not a one-off activity.

interACT educational pamphlets may help the school become more sensitive. Parents or guardians should consult with their children before sending pamphlets, anonymously or otherwise (interACT Advocates for Youth, 2019f).

### **Medical Personnel**

Professional counselors may be called on to help intersex persons process how they have been psychologically or physically harmed by medical professionals. Any member of the medical treatment team may be associated with emotional harm. Nurses and other attendants may be not be trained to create a sense of respect, dignity, and autonomy. As medical authority figures, physicians in general and surgeons in particular are in uniquely powerful positions to impair emotional well-being. (interACT Advocates for Youth, 2019c).

Physicians may foster lifelong distress in an intersex person if alternative options were not given to parents without pressure (interACT Advocates for Youth, 2019c).

Medically unnecessary intersex infant surgeries may harm by creating scars that generate shame during daily views in the mirror. Medically unnecessary intersex surgeries alter erotic tissue and may impair adult sexual function and sensation (Karkazis, 2008).

Medically unnecessary surgeries can wreck confidence in sexual and emotional

relationships (interACT Advocates for Youth, 2019c). Surgeries can harm when the wrong sex was assigned and thus the wrong surgical actions were taken.

Medical exams are particularly virulent sources of harm (interACT Advocates for Youth, 2019c). Medical professionals harm when they do not honor the fact that a vaginal exam is a time of vulnerability. Physicians harm by making the exam a medical training experience or a time to explore an intersex body for curiosity. Physicians harm by making medical encounters pertain to meaning in their own lives by stating things like, “This is exciting, you are my first intersex patient.” Physicians should treat an intersex person as the expert concerning their own body. For example, even at a very young age, an intersex person should be asked for their input on how the exam should proceed and who should be in the room.

Physicians and surgeons should not assume that children are unaffected by genital exams. A doctor harms by inserting his finger into a vagina when not absolutely necessary. Time should be taken to explain to the child the difference between an appropriate medical exam and molestation (interACT Advocates for Youth, 2019c). Physicians and surgeons create distress by taking pictures of genitalia. Doctors harm by asking questions during or right after a vaginal exam instead of being sensitive to the time that it takes the child to recover from shock. A pediatric-sized speculum should be used (interACT Advocates for Youth, 2019c).

Disclosure of an intersex variation should be handled with sensitivity but not secrecy. Physicians and surgeons harm by keeping secrets about diagnoses, the purpose of surgeries, and the results of surgeries due to assumed fragility. Withholding information and/or outright dishonesty harms by generating shame (interACT Advocates

for Youth, 2019c). Furthermore, hiding the truth is actually pointless because intersex individuals can do their own research on diagnoses and surgical procedures (interACT Advocates for Youth, 2019c). Distrust for the professions and the people who kept any secrets is likely. As a result of distrust, individuals who need medical support may be reluctant to seek care.

Even apart from disclosure of the variation, doctor–patient communication can be a source of psychological damage (interACT Advocates for Youth, 2019c). Regardless of positive intent, physicians and surgeons harm if they tell overt lies. They create shame when questions are dismissed or discouraged. Medical professionals should not talk to others in the room as if the individual is not present. Physicians and surgeons harm through faulty assumptions when they inappropriately speak in absolutes such as “You will never meet another person like yourself,” “Your vagina will never be sufficient for marital relations, or “Surgery is the only way for you to have ‘normal sex’” (interACT Advocates for Youth, 2019c). Medical terminology can be shame producing, for example, describing a penis or vagina as “inadequate.” Physicians and surgeons should not communicate an assumption that having a particular variation means that an intersex person has a particular gender identity or sexual orientation or that the person is confused about their identity or orientation (interACT Advocates for Youth, 2019c).

Physicians and surgeons may incorrectly assume that an intersex person is comfortable with DSD terminology. Terminology including pronoun preferences should be clarified (interACT Advocates for Youth, 2019c). Doctors should be informed and not ask their patient for information about an intersex variation. If doctors do need to be educated, they should listen carefully. If physicians and surgeons invite follow-up contact

for any further questions, they should honor their promise and provide answers (interACT Advocates for Youth, 2019c). Medical personnel may harm by asking meaningless questions. For example, if a period is impossible, intersex people should not be asked the date of their last period.

Medical professionals should understand that an intersex person is impacted emotionally by their intersex variation, not just physically. Physicians, surgeons and other personnel benefit when they encourage an intersex person to share their feelings. Medical professionals are in a unique position to be a conduit to supportive resources such as therapy and support groups for parents and intersex persons themselves (interACT Advocates for Youth, 2019c).

### **Friends**

Counselors have a role to play in processing ways that friends of an intersex person make mistakes and/or provide helpful support. Friends have a powerful role in creating a safe and supportive space (interACT Advocates for Youth, 2019d). They benefit by asking interested nonjudgmental questions. Friends provide support with ongoing check-in questions because an intersex youth's feelings of safety and support may change day to day (interACT Advocates for Youth, 2019d).

Friends may fail to understand how difficult sharing or self-acceptance may be given the individual's past shaming experiences about their body (interACT Advocates for Youth, 2019d). They may fail to take the time to ask questions in order to understand very complex information and may push too soon for information. Assumptions based on inadequate information about genitals or other aspects of intersex life can damage. Friends may think that all intersex persons have the same medical issues and experiences. They may not understand that some intersex persons are greatly affected by their

diagnosis, but others are not. Friends may create psychological damage by treating an intersex person as abnormal instead of as a unique person deserving dignity and respect (interACT Advocates for Youth, 2019d).

Friends can be especially harming if privacy is not respected and confidential disclosure is shared without permission. Hurt may be experienced if friends say minimizing things like, “Thankfully, you have so many other good things in your life.” Friends can harm by not understanding that sometimes hormone treatments cause increased moodiness. Accordingly, some intersex persons may need tolerance at times for emotional fluctuations. If infertility is involved, it is not helpful to say that adoption is an alternative (interACT Advocates for Youth, 2019d).

### **Schools and Educators**

Teachers should have basic knowledge competency about intersex biology. Competency includes knowing (a) the difference between gender, sexual orientation, and sex biology, (b) the diversity of intersex biology, (c) intersex terminology, and (d) the history of medical approaches to intersex. Attention to social needs is important. Intersex youth may struggle with feeling loveable because in contexts where relationships are discussed, intersex life is not included (interACT Advocates for Youth, 2019f).

Educators have an important role in fostering intersex student self-esteem by creating an informed, safe, and inclusive environment (interACT Advocates for Youth, 2019f). Educators should provide instruction in the school community via informed speakers. They should provide support proactively by educating students about gender and sex diversity in a way that makes intersex individuals feel supported. Educators provide support if they ask intersex youth about the terms they prefer and then use the

terms consistently. If sexual minority clubs are on campus, facilitating inclusion for intersex students is beneficial (interACT Advocates for Youth, 2019f).

Schools may be places of harm, especially in sex education classes and during nurse visits (interACT Advocates for Youth, 2019f). In classrooms, intersex students may feel erased if sex is discussed as only binary or if teachers conflate gender and/or orientation with biological sex. Teachers harm when they stereotype gender variations; for example, through statements such as “Males are the ones with deep voices and body hair.” It is harmful for teachers to state or imply that intersex is one thing and therefore intersex people are all the same (interACT Advocates for Youth, 2019f).

Teachers harm if they tokenize an intersex person as the representative of all intersex experience. Some intersex students may wish to share, but others may not. Teachers may harm if they act surprised or in awe about differences (interACT Advocates for Youth, 2019f). They should not use outdated terms like hermaphrodite. Teachers harm when they use the term “normal” when talking about typical male or female as doing so implies that intersex variations are abnormal (interACT Advocates for Youth, 2019f).

Schools can be harmful places if intersex people are told to stay out of certain bathrooms. Schools harm when bullying is allowed. School health centers can harm if assumptions are made that all feminine-looking people have periods. Health terminology should be specific and not summarized according to gender. For example, school health personnel should say “growing more hair” or “breast development” instead of “becoming a man” or “becoming a woman.” Instead of “feminine products,” school health personnel should use “menstrual products” as some intersex young men have periods.

## **Preves's Intersex Study Findings Using Cass's Sexual Minority Identity Development Model**

I conclude this chapter with a description of the work of sociologist Sharon Preves. Preves (2003) analyzed the data from over 20 intersex adult individuals using the structure of Cass's (1979) sexual minority identity model. I discuss Preves's work in detail because toward the end of my data analysis, when I compared Preves's results to mine, the intersex identity development model emerged. In other words, a unique model independent from the Cass model developed from comparing Preves's results with this study's results. I discuss the new identity development model in more detail in Chapter 5.

It is helpful and not surprising that Preves coordinated her intersex findings under the basic structure of Cass's sexual minority identity model. Cass's six-stage sexual identity model is a familiar model in counseling. The titles of the six stages in Cass's model are Stage 1. Identity confusion, Stage 2. Identity comparison, Stage 3. Identity tolerance, Stage 4. Identity acceptance, Stage 5. Identity pride, and Stage 6. Identity synthesis. Preves combines Cass's first two stages into Preves's first stage, otherwise the parallel is complete. The (summarized) titles of Preves's five stages are Stage 1. Recognizing one's nonconformity, Stage 2. Acknowledging one's difference, Stage 3. Validation of self, Stage 4. Pride in the marginal identity, and Stage 5. Identity synthesis and integration.

Table 1 compares Cass's model and Preves's model. It also shows the themes in each of Preves's stages. Sometimes I abbreviate the length of Preves's themes and/or add a few words in parentheses to clarify a theme. Table 2, at the end of this section, recaps Preves's stages and findings.

**Table 1***Comparison of Stages in Cass's and Preves's Sexual Minority Identity Models*

| Cass's model                 | Preves's model  |
|------------------------------|---|
| Stage 1. Identity confusion  | Stage 1. Recognizing one's nonconformity  |
| Stage 2. Identity comparison | Themes: <ul style="list-style-type: none"> <li>• Being an object of study (shame, stigma, and isolation)</li> <li>• Fearing the unknown (monstrosity)</li> <li>• Erasing difference</li> <li>• Performing (fit in/ease stress/please)</li> <li>• Doing gender (empowered performance)</li> </ul>  |
| Stage 3. Identity tolerance  | Stage 2. Acknowledging one's difference<br>Themes: <ul style="list-style-type: none"> <li>• Putting an end to secrecy (rejecting stigma)</li> <li>• Personal archaeology (locating personal history)</li> <li>• Reclaiming the (destroyed) self</li> <li>• Self according to biological logic (privileging new information)</li> <li>• From shame to anger to empowerment</li> <li>• Telling others (breaking secrecy and isolation)</li> </ul> |
| Stage 4. Identity acceptance | Stage 3. Validation of self   |
| Stage 5. Identity pride      | Stage 4. Pride in the marginal identity<br>Themes: <ul style="list-style-type: none"> <li>• Humor to transform stigma</li> </ul>  |
| Stage 6. Identity synthesis  | Stage 5. Identity synthesis and integration   |



## **Preves's Stage 1. Recognizing One's Nonconformity**

In Stage 1, Recognizing one's nonconformity, Preves (2003) noted that sex is fundamental to how society organizes. It is therefore hard to negotiate self-identity when one's sex is challenged. Writing about intersex treatment under the first medical protocol, Preves explained that intersex individuals are born into a medicalized culture that speaks three main harmful messages: intersex people are (a) medical objects (which produces shame), (b) not to know the truth about their biology (treated with secrecy), and (c) such secrecy is in their best interest (isolated). While the medical goal under Money's protocol was to decrease stigma and promote clear identity, the reverse occurred through medicalized treatment that followed the protocol. To move beyond the pathologizing medicalized context, the intersex person faces a long-term process of renegotiating a stigmatized identity (Preves, 2003). Preves cited the following themes in Stage 1.

### ***Being an Object of Study (Shame, Stigma, and Isolation)***

An intersex individual experiences identity assault due to being treated as a medical object (Preves, 2003). Objectification and consequent distress occur during overly invasive, unwanted, repeated, and highly public medical exams and through surgeries causing shame, stigma, and isolation. As a consequence, individuals feel humiliated, demeaned, ashamed, freakish, and alone (Preves, 2003). The degree of shame and stigma is associated with the degree of medical intervention the person experiences. The messages received include that the person and their body are unacceptable, and the person is not allowed to have autonomy over their body (Preves, 2003). Persons struggle with the contradiction of being told that they are normal but yet they need finishing surgeries. Psychological effects include internalized shame and stigma, isolation, loneliness, undermined ability to form a positive identity and engage in sexual

relationships, difficulty setting appropriate boundaries, and extension of body misfit status to misfit status in other areas of identity. With their body in question, the individual may turn to question their gender and/or orientation and engage in excessive self-monitoring (Preves, 2003).

### ***Fearing the Unknown (Monstrosity)***

Secrecy, intended as a strategy to prevent social stigma and cement a gender identity, actually makes life worse (Preves, 2003). Lies are used by those in authority to prevent the person from knowing the truth about themselves, but the practice backfires (Preves, 2003). The person may imagine that authorities are keeping something monstrous and/or life-threatening from them. In fact, authorities often use threat of cancer to justify removal of gonads. The seeds of monstrous possibilities are planted in an intersex mind by medical lies. The person lives in isolation. In isolation, imagination runs wild.

### ***Erasing Difference***

Preves (2003) detailed that intersex reality involves noticing the efforts of others to physically erase their difference. The message received by those “fixed” is that intersex people are unacceptable as born. Society must surgically remove parts of intersex people so other people can bear looking at them. The necessity of erasing intersex people is so imperative that it must occur in spite of harmful physical effects to the intersex person. The physical effects that must be born by intersex people so others can stand to look at them include nerve damage, scarring related to the surgery, scarring related to skin grafts for the surgeries, mutilated appearance, and loss or diminished orgasm.

### ***Performing (Fit in/Ease Stress/Please)***

The intersex person monitors others' behaviors for how to act "normal" and have a positive social experience (Preves, 2003). The shamed intersex person may have developed a network of lies and engaged in other proving or hiding behaviors to avoid being outed as a fake "normal" person. Possibilities include promiscuity, excessive gender monitoring, and lying with cover stories about possessing "normal" sexual characteristics, such as a period (Preves, 2003).

Intersex people notice that others are stressed by their intersex aspects that seem out of character for their assigned gender (Preves, 2003). The intersex person may internalize a message that they have a responsibility to change their body to make others feel comfortable. For example, some may pluck facial hair, not because they want to but because family members are upset if they do not. Young women may be talked to about the importance of an adequately sized vagina to "please their husbands" (Preves, 2003).

### ***Doing Gender (Empowered Performance)***

Intersex individuals may feel an empowered version of performing to fit in as normal (Preves, 2003). Over time, the intersex individual may study and master gender expression for a particular gender and know how to produce the performance at will. An intersex person may feel satisfaction for possessing control over the gender expectations and perceptions of others.

### **Preves's Stage 2. Acknowledging One's Difference**

In Preves's Stage 2, the individual comes to recognize the probability of self-membership in the new status but is not yet fully self-accepting. Preves's Stage 2 articulates the long and arduous process of an intersex person breaking out of the pathologized identity and coming into the possibility of a new, nonpathologized one. The

self must develop the agency to search for knowledge leading to a different view of self (or discover new information by accident that prompts reevaluation). The new knowledge must be processed in light of the pathologized model. The search for new information in this stage often involved persistence in the face of medical and parental roadblocks.

Relationships are impacted by the new knowledge.

Preves (2003) noted that revelations leading to new identity possibilities occur in a context of social awareness that develops in a particular historical place and time. Consciously or unconsciously, new identity possibilities build from the conceptual and economic resources of their time. Some of the valuable conceptual resources that led to a nonpathologized intersex identity are the women's and LGBTQ+ social movements. They helped discredit Money's first treatment protocol known variously as the optimal gender of rearing model, the concealment model, or the genitals make gender model.

Preves (2003) further observed that intersex people are geographically dispersed. The new identity development movement grew in part out of knowledge resources and support that were shared with others who lived far away. An intersex individual's ability to arrive at a new nonpathologized identity depended in some measure on the economic resources of education and access to a new phenomenon, Internet-connected computers.

The new nonpathologizing framework conceptually relied on one or more counterarguments to the first medical protocol. The counterarguments faulted Money's protocol due to flaws in assumptions about biology, exaggerated claims of medical success, and social constructivism. The biology counterargument relates to the assertion that gender development is in fact largely influenced by hormones, not primarily the environment, as Money alleged. The counterclaim about exaggerated medical claims

relates to the fact the medicine is not delivering the social and medical benefit it promises. In other words, contrary to medical claims of healing the person and preventing shame and stigma, medical results actually impair the individual, both physically and psychologically. The social constructivism counterclaim holds that the notion of biology as only male and female is a social created definition that is false; sexual biology should not be conceptualized as a situation of male and female polar opposites but instead accurately described as a spectrum.

Preves (2003) developed the following themes in her Stage 2. The intersex individual (a) puts an end to secrecy to find their authentic self, (b) investigates medical records in spite of encountering roadblocks to access, (c) persists despite shocking revelations, and (d) grapples with the present and future social and biological repercussions of living with their personal intersex variation. Pathology gets moved outside of the self into the social/political context. Psychological effects in Stage 2 include shock, fury, and relief. Themes in Preves's Stage 2 are described next.

### ***Putting an End to Secrecy (Rejecting Stigma)***

Preves (2003) described a commonly observed, circular reinforcing pattern in which stigmatized persons act from internalized negative self-judgments. Their internalized negative framework perpetuates the stigma. Preves observed that not all intersex persons seem able to leave their stigmatized self-concept behind. However, over time, some intersex individuals in Stage 2 do develop the ability to move away from their stigmatized model of self.

Reasons why some intersex people possess this ability may vary. One reason is that personal growth is a skill and some intersex people may have already possessed that

skill. Social support plays an important role. Furthermore, some may have a strong desire for a more authentic self. Some may possess religious beliefs that override a pathological model of self.

### ***Personal Archeology (Locating Personal History)***

Medical records were not easily obtained under the first protocol and its secrecy orientation. Some intersex individuals went to great lengths to try to access their personal medical history and to understand more about their biology, even resorting to legal recourse. The behavioral action in doing so demonstrated personalities who were determined to wrest back autonomy and control over their own bodies. In other words, on a spectrum with utter helplessness, hopelessness, and actionless depression on one side and optimistic agency at the other, personal archeology demonstrates optimistic agency. Personal archeology demonstrates a degree of empowerment and willingness to judge for self what had been done.

Hopeful agency should not be confused with happiness during investigation. The process may be performed while feeling desperate and furious. Finding records might entail shock and anger at having been lied to and/or reading information known by others but not shared. The individual likely encounters unfamiliar and pathologizing medical terms such as “failed” and “inadequate.” Medical knowledge has to be acquired to understand the records. Sometimes, individuals are able to diagnose their own variation from partial information. Violent thoughts may be directed toward the physicians. Suicidal thoughts may be directed toward one’s self. Furthermore, all of this investigation happens before the individual arrives at the stage of pride in marginal self when the individual would have a well-developed social network. Thus, the experiences of digging

for information and then mentally and emotionally processing content are accomplished in some degree of aloneness (Preves, 2003).

### ***Reclaiming the (Destroyed) Self***

Preves (2003) described a self that experiences destruction and reconstruction in adulthood. Through the process of investigating and uncovering new knowledge, the individual's previous sense of themselves under the pathologized model may have been shattered. The seismic shake-up of self may involve intense identity confusion and self-doubt. The individual may feel completely overwhelmed by the revealed high degree of oppression and by the fear of needing to start over. Suicide ideation might arise in face of the psychological tsunami.

### ***Self According to Biological Logic (Privileging New Information)***

During personal archeology, the person learns more about their biology (Preves, 2003). This may result for a time in confusion due to privileging the new biological information about their intersex variation over what they have felt about themselves their whole life. The individual may feel that their former life was fraudulent. For example, a teen who learns she has XY chromosomes may wonder if this means she was a boy all along.

Preves (2003) noted that, importantly, the psychological shake up may reveal to the individual which parts of culture receive shame and which parts do not. Cultural preferences and prejudices are therefore processed as well. Not all processing results in distress. The person may feel relieved to discover a biological explanation for all their differences. Biology may be considered a card dealt by fate and therefore not shameful. Conversely, new knowledge may bring sexual minority distress. Sometimes new

knowledge may raise for the first-time issues of homosexuality and “trans” identity that are often considered chosen and shameful. Individuals might struggle with what is similar and what is different between typical trans and intersex “trans.” Finally, not all people will report struggling with their reorganization of self in adulthood. Some may cite that, for example, coming out as gay was much harder than coming out as intersex. Intersex involves hidden difference whereas being gay is more observable and therefore draws more public attention.

### ***From Shame to Anger to Empowerment***

Preves (2003) noticed that a strong shift in emotion happens during Stage 2. Preves compared it to moving through grief stages. Personal archeology leads to shock, sometimes denial and initial depression, then anger, and then grief for the lost self that will now never be known. The moving through of emotions might entail identifying the people or institutions who deserve blame (Preves, 2003).

### ***Telling Others (Breaking Secrecy and Isolation)***

Preves (2003) noted that the effect of the secrecy mandate under the Money’s protocol may prevent individuals from developing a stable sense of self. Conversely, sharing with other intersex people reverses that effect and is cathartic. Preves found that telling others leads to intimacy and trust, and the process gets easier over time. Some may tell others for the political motive of halting the harm.

### **Preves’s Stage 3. Validation of Self**

In Preves’s Stage 3. Validation of self, and Cass’s Stage 4. Identity acceptance, the individual has moved beyond mere tolerance and is engaging with self-acceptance as a member of their new community. The individual deals with all that participating in their new group involves. The prospect of meeting similar others may have seemed unnerving



at first but connecting beneficially ends isolation. Breaking the bonds of social isolation leads to deep social connections, perhaps for the first time, as individuals share the knowledge that the horrors “happened to me too.” The acts of revealing self verbally, and even showing genitals to each other to see the full extent of medical harm, can trigger strong emotion and enhance solidarity. Grief and anger may be felt on behalf of those who were irreparably surgically harmed by loss of orgasm or sexual sensation. Survivor guilt may occur for being lucky and not surgically harmed like others. Finding similar others is experienced as proof of another world, their own world. The individual has a new sense of belonging by finally meeting fellow “aliens.” Former self-blame at having had a difficult time may give way to self-forgiveness by realizing that others have struggled to value themselves as well. Talking with others may help place the medicalized approach in social context. The individual comes to realize that their difficulties do not reflect internal failings. They represent instead the failure of society, psychologists, medical doctors, and parents to protect innocent infants. Greater self-efficacy and political empowerment likely follows.

#### **Preves’s Stage 4. Pride in the Marginal Identity**

In Preves’s Stage 4. Pride in the marginal identity and in Cass’s Stage 5. Identity pride, the individual is active in coming out and is less willing to blend. Tasks may include supporting social movements and coping with anger and defensiveness. Collective action is taken toward redefining intersex in positive ways. The new group is actively promoted and the group(s) that produced the stigma are judged negatively. Support groups provide meaning, structure, and role models. Self-worth may be defined positively as a direct result of intersex difference. Difference may be politicized by insisting on public names even in situations that might normally be anonymous. Others

may purposefully engage in being out by name for its strategic value in psychological healing. Difference may be viewed as having led to an advanced, heroic ability to view the world from many perspectives. A sexual awakening may occur as a new positive identity opens up positive possibilities of physical experiences. Intersex bodies, no longer objects of internal shame, may be treated with greater care and respect. In defiance, some may wish to accentuate gender-variant expressions of hair, makeup, or dress since norms according to the binary have been eschewed and diversity embraced. Gratitude for difference may be expressed.

### ***Humor to Transform Stigma***

This stage involves humor to transform stigma (Preves, 2003). Differences may be treated with humor to draw political attention to the pathologizing viewpoint, for example, by appropriating the term hermaphrodites. Gender humor in the form of playfully highlighting the Y in XY, karyotype CAIS persons who identify as women may lessen stress about a formerly sensitive topic. Humor signals ease with the new, nonpathologized identity (Preves, 2003).

### **Preves's Stage 5. Identity Synthesis and Integration**

In Preves's Stage 5. Identity synthesis and integration and in Cass's Stage 6. Identity synthesis, the individual's marginalized sexual identity has been incorporated into other identities. The new identity may no longer occupy the same degree of attention. Tasks may include moving away from actively promoting the intersex community to focusing on other identities. Individuals may no longer participate in chat groups. The individual will maintain pride in marginality even if periods of depression and doubt periodically surface. Preves noted that another identity theorist, Goffman, was pessimistic

by referring to a “spoiled identity,” but Preves maintained the optimistic belief that identity synthesis can be fully achieved (Preves 2003).

**Table 2***Preves's Intersex Findings Using Cass's Sexual Minority Identity Model*

| Stage                                 | Findings  |
|---------------------------------------|---|
| 1. Recognizing one's nonconformity    | Being an object of study (shame, stigma and isolation)<br>Fearing the unknown (monstrosity)<br>Easing difference<br>Performing (fit in/ease stress/please)<br>Doing gender (empowered performance)  |
| 2. Acknowledging one's difference     | Putting an end to secrecy (rejecting stigma)<br>Personal archeology (locating personal history)<br>Reclaiming the (destroyed) self<br>Self according to biological logic (privileging new information)<br>From shame to anger to empowerment<br>Telling others (breaking secrecy and isolation) |
| 3. Validation of self                 |   |
| 4. Pride in the marginal identity     | Humor to transform stigma   |
| 5. Identity synthesis and integration |   |

### **Conclusion**

Intersex variation is an umbrella term used to describe a variety of different forms of congenital atypical sex development involving chromosomal, hormonal, or other causes. Intersex infants are currently assessed in DSD MT clinics and assigned a gender. Optional sex-related, medically unnecessary surgeries may be offered as options to parents. Counseling is supposedly being provided in DSD MT clinics but the nature of counseling being provided across DSD MT clinics has not been researched.

Optional sex-related surgeries are currently legal in the United States because the law recognizes a parental proxy right to consent to surgeries on behalf of their children. Three conditions would stop medically unnecessary surgeries on intersex minors. First, parents would stop consenting. Under the new 2006 Chicago Consensus protocol, however, parents continue to opt for medically unnecessary surgeries despite more involved processes involving shared decision-making, counseling support, and greater informed consent than were operant under Money's 1950s optimal gender of rearing model. Second, medically unnecessary surgeries would stop if they were made illegal by law. Third, judicial challenges might prevail on the claims that they are violations of laws related to informed consent, sex discrimination, and/or disability discrimination.

Intersex people have a variety of sexual orientations and gender identities as is the case with the human population as a whole. However, intersex people are included as a group within the larger group of sexual minorities based upon their atypical biology. The intersex community shares shame and discrimination experiences with sexual minority groups marginalized by sexual and romantic orientations and with groups marginalized by gender identity and gender expression. Intersex people, however, are uniquely subject to explicit erasure of personhood—first in binary sex development theory and second without their consent, hormonally and on the surgery table. Physical erasure for having an intersex body can be experienced as psychic annihilation as well.

To date, professional counseling has addressed general competency categories for intersex counseling. Counseling literature will benefit from additional specificity through this study regarding how intersex people experience psychological harm and how they

have learned to cope and engage in life from a vantage of positive identity and positive relationships.

I concluded this chapter with an in-depth discussion of the intersex identity stages and themes depicted by Preves. Preves (2003) organized her data according to the structure of Cass's sexual identity model. Looking ahead to the findings, my comparing Preves's stages and themes with the present study's findings resulted in the development of this study's unique intersex identity development model.

## **CHAPTER 3: METHODOLOGY**

In this chapter, I describe the methodology used to conduct this study. I first present the lessons learned before this study was approved. I spent several years preparing to conduct an intersex-related dissertation. By the time I proposed this study, the many lessons I learned influenced my selecting interpretative phenomenological analysis (IPA) as the research approach. I explain my rationale for selecting IPA in detail. I also describe IPA's philosophical foundations as they explain IPA's orientation to small sample sizes and IPA's researcher data collection and analysis practices. In addition to IPA methodology, I looked to Corbin and Strauss for guidance regarding social context and derivative human processes. The social contexts in which human beings interact help to illuminate human processes, for these processes make sense in light of the contexts in which they occur. I then describe the procedures I used for data collection and analysis. I also set forth in detail IPA's six data analysis steps.

### **Lessons Learned During Study Prehistory, 2014–2019**

I provide the following discussion on this study's prehistory as preliminary information to this study's methodology. The 2014 to 2019 prehistory of this study yielded insights into the challenges of researching a relatively new and sensitive subject for the field of counseling, namely intersex experiences. My decision to focus on the experiences of intersex activists in this study followed years of discarding alternative approaches. The abandoned approaches also led to my choosing IPA for its idiographic emphasis. The abandoned approaches illustrate the challenges in conducting a counseling study on intersex issues.

I learned of intersex people and their medicalized treatment in a sexual issues class as a master's degree student. I was appalled that I had no idea surgical harm was

happening to intersex infants without their consent. This class was life changing. I realized that my ignorance pertained to the fact that an entire group of people were hiding out of sight of the public sphere. The attack and shame that must be behind that invisibility seemed enormous. From that moment, I decided to dedicate my career to supporting the counseling needs of intersex people.

Choosing the right university at which to pursue my doctoral degree came first. Given that intersex counseling was my focus, as a cisgender, straight, endosex female, I knew I had a steep learning curve ahead. I specifically looked for a doctoral program based on its strength to support an intersex-focused dissertation. I sought admission to the University of Missouri–St. Louis (UMSL) specifically for its scholarship in LGBTQ+ issues, social constructivism, and counseling paradigms. The UMSL faculty informed me that they would help with those topics, but the specific topic of intersex counseling was undeveloped.

The main corpus of literature would have to be found outside of counseling. I addressed intersex issues in all my major doctoral papers. Research threads led me to medicine, nursing, bioethics, science history, sociology, feminism, and gender studies. By the time of my dissertation proposal acceptance in spring 2019, I had formed first-hand impressions of the challenges in intersex research.

My first vision for a dissertation design targeted a quantitative approach to researching intersex trauma. I viewed this approach as strategically desirable because the medical field is anchored in quantitative research. I reasoned that physicians might stop performing nonconsensual surgeries if convincing quantitative findings on the trauma related to these surgeries were demonstrated. I located sources that documented



significant qualitative findings on trauma among intersex adults (Lev, 2006; Preves, 2003). However, quantitative studies on intersex trauma are few and contradict qualitative findings on trauma. Quantitative findings have documented low presence of posttraumatic stress (PTS) symptoms (i.e., low present experience of hyperarousal, dissociation, and memory intrusions) in intersex adults (Brinkmann et al., 2007). Confused about the low findings, I investigated PTS measures and realized that these measures emphasize present symptomatology. I concluded that PTS measures might not be the best for assessing the impact of past intersex trauma that may have resolved over time with growth and support.

Were there were other types of trauma conceptualizations that fit intersex disturbance better than PTS? That question led me to developmental trauma disorder (DTD). The conceptualization behind DTD is that repeated inflictions of distress throughout one's early years (i.e., the foundational stages for healthy relationship formation) impact the person's ability to trust authority (or anyone). Youth's relationship with authority is adversely impacted because authority failed its responsibility for providing protection (D'Andrea et al., 2012; van der Kolk & d'Andrea, 2010).

I observed that the DTD trauma conceptualization seemed similar to intersex distress. Intersex distress occurs over developmental stages in youth and adolescence by repeated unwanted medical exams and surgical procedures. I had already noticed trust issues in intersex stories. First-person narratives described strong anxiety in the presence of physicians and feelings of betrayal about parents as they were perceived to be colluding with physicians (Karkazis, 2008; Preves, 2003).

The treatment approach for DTD also seemed to resonate with intersex stories. According to some DTD proponents, DTD's validity is evidenced by variance from PTS in terms of what is efficacious in treatment approach (van der Kolk & d'Andrea, 2010). PTS treatments often involve exposure therapies to lower anxiety. In contrast, exposure treatments are actually likely to trigger PTS in youth who have DTD if their destroyed capacity for trust is not addressed first (van der Kolk & d'Andrea, 2010).

Unfortunately, in the process of searching for a validated DTD measure, I learned that DTD is not recognized in the *DSM-5*. As mentioned, the goal behind a quantitative approach to the present study was to achieve credibility in the medical field by collecting numerical, measurable data on intersex trauma. There seemed no point in my implementing a quantitative study that would be discounted based on using DTD, a controversial and unrecognized disorder. I abandoned a DTD approach to the dissertation.

I next considered parents as quantitative subjects. Surgeons conduct the surgeries, but parents provide the consent. Preves (2003) had noted that literature on parents was virtually nonexistent. By 2015 to 2018, however, both qualitative and quantitative research had been conducted on some aspects of the parental experience. Still, obtaining data from parents remained an intriguing prospect especially since parents might be more accessible than intersex adults.

I imagined that if better informed consent was provided to parents, perhaps surgeries would lessen. I hoped that more parents might decrease their willingness to provide consent based on a more thorough informed consent procedure. However, I was disappointed somewhat by findings in Dayner et al.'s 2004 study on parental thought

processes in consenting to intersex infant surgeries. The study indicated that parents were willing to give consent for their infant's genital-altering surgeries even knowing the potential loss of their child's genital sensation. I decided against putting my research efforts toward a more thorough informed consent process if parents could opt for irreversible harming surgeries already knowing they harm.

During the same prehistory years of 2014 to 2018, I attempted via cold call to begin connecting with the intersex community. I was rejected by the first person I reached out to for "not getting it" due to using the term "intersex condition." I later learned that the term is offensive as it implies that having an intersex variation is a pathology instead of a naturally occurring bodily variation.

After some time passed, I ventured out again and joined a few intersex online support groups. I did not post due to feeling insufficiently educated and likely to make another inadvertent error. I read comments online that discouraged intersex members from cooperating with researchers as doing so might result in the researchers somehow claiming to find data that supported continuing the surgeries. In other words, my early outreach made clear that counseling research was by no means an automatic positive calling card in the intersex community. The situation was worrisome given my need to find intersex people willing to trust me and be a part of my study. The situation was emotionally frustrating for me given my goal of wanting to improve counseling services. The situation was totally understandable as the protocol that initiated medical harm was designed by Money, a psychologist.

The treatment protocol for intersex infant surgeries had changed from the 1950s protocol Money designed to a second protocol initiated in 2006. The second protocol

involved assessing and treating the infant in newly formed DSD MT clinics. The secrecy regarding diagnosis and treatment in the first protocol had been jettisoned in favor of open, multidisciplinary decision-making. For the first time in intersex history, counseling was supposed to be included as a part of the treatment process. Starting in 2016, I attended Androgen Insensitivity Syndrome-Difference of Sex Development (AIS-DSD) conferences for 3 years hoping to connect with DSD MT clinic professionals. I attended conferences at Denver's Children's Hospital in 2016, Phoenix's Children's Hospital in 2017, and Chicago's Children's Hospital in 2018. In particular, my goal was to network with psychologists or social workers who worked in DSD multidisciplinary clinics associated with major children's hospitals and hopefully gain research access to the clinics.

From connections made at AIS-DSD conferences, for approximately a year between 2016 and 2017, I attempted to gain research access to two different DSD MT clinics to qualitatively understand the nature and scope of counseling being provided under the second protocol. Though the idea involved giving up on the hope of quantitative study, a DSD MT counseling study seemed on point for the field of counseling. I abandoned that idea after a clear refusal from one clinic and months of poor email responses from the other. In the interest of time, I jettisoned both of my goals of investigating counseling in DSD MT clinics and performing a quantitative study. By late 2017, without being clear yet on a precise subject for my intersex study, I decided to pursue a qualitative study of intersex adult subjects. Yet, even meeting the challenge of a lower sample size for a qualitative study seemed precarious.

The prospect of gaining access to the intersex community changed from risky to hopeful when I reached out to a highly visible activist late in 2017. The activist ultimately decided to endorse my goal of improving intersex counseling and took on the job of mentoring me. The activist's decision to support my work did not occur overnight. For about a year, weekly conversations occurred that were rewarding but sometimes uncomfortable.

The consequences of my failing activist testing seemed dire, and I felt under the mentor's spotlight with his repeated testing of my intentions. I wondered about what might happen if a highly public activist decided that I was not worth supporting and then shared that opinion with other activists. The activist community is small. Being blackballed by even one activist was a danger. Conversely, an insider relationship would help me deepen the study.

Discussions about activist payment and acknowledgment were ongoing and difficult. The activist expressed concern that I stood in position to profit financially and develop notoriety from the activist's pain and expertise. My reality was very different: I self-funded this study. I was concerned about the impact on the study if our relationship involved payment. The weekly talks would certainly stop for financial reasons.

A major low point in building the relationship occurred when the activist became angry over my repeated pronoun misgendering. Gendering infractions are not equally felt among people. Misgendering a person whose very existence had been in peril throughout his lifespan due to misgendering by physicians, society, and parents was viewed by the activist as a grave insult.

I searched myself for why I kept making the offensive errors. My mistakes revealed flawed assumptions and undesired, reverse prejudice. First, I was affected by the absence of visual cues and relied on tone as the relationship involved only phone and email. Second, I realized, with embarrassment, that some of the misgendering reflected my own failing in the very area in which I was working to improve/support in others. I had my own difficulty understanding that female body parts do not necessarily match girl/woman gender. The activist and I had talked about the activist (who now identified as man) nursing his children. In my prejudiced, erroneous mind, only females with the gender of a woman nurse. Finally, I had not realized I held a reverse prejudice in favor of women (over men or those with nonbinary genders) and had ascribed a woman gender to the activist as an unconscious compliment. I had placed the activist as an example of very high human evolution in the image of Wonder Woman, a woman possessing a ferocious fighting spirit and at the same time a loving, nurturing, gentle spirit. In my prejudiced mind, the dual combination of fighter and nurturer was in a woman, not in a man. Unfortunately, my prejudiced error in misgendering was not received as a compliment and actually greatly disrespected the man activist who happened to have been able to give birth and nurse. Our activist–researcher relationship survived that time due to the activist’s willingness to forgive me for misgendering errors.

Another difficult part of relationship negotiation pertained to the issue of “What skin do you have in our relationship if I bear my soul to you? Will you use or dishonor me?” Intersex people have been gravely wounded by therapists and psychiatrists. I wondered how vulnerable a counselor researcher needs to be so that an intersex activist will feel safe and not like a bug under a microscope, to be analyzed and then tossed away.

At what point would a researcher's failure to be vulnerable adversely impact depth of research and opportunity to be of service? Conversely, was getting too close going to create an unhelpful bias? A literal quid pro quo never occurred of "If I talk about my genitals, therefore you talk about yours." However, I did have a palpable sense that the relationship quality and commitment over time would depend on whether the activist and I were both willing to share at deep levels, entailing human feelings of vulnerability.

Our activist mentor–researcher relationship finally did achieve the relaxed balance of trusted professional friendship based on a common goal of supporting intersex counseling needs. The sharing between us was vulnerable and deep, but the topics were different. For example, I shared my personal fear of Alzheimer's disease and how my sense of having only a limited amount of time drove my single-minded dedication to one topic, intersex counseling. In turn, the activist mentor shared all things about his being intersex and activist. The study benefited. For example, I developed a heightened sensitivity about the importance of understanding emotional experiences related to intersex variation differences and about issues related to intersex "trans."

The precise reasons I finally gained the trust of the activist were apparent over time. The reasons may benefit other counselor researchers and, therefore, are shared as follows. I gained trust because I (a) was paying for dissertation expenses and thus not making money while the activist made none, (b) had learned the complex basics of intersex biology and history on my own and thus I was not wasting the activist's time, (c) had demonstrated long-term commitment through several prior years of learning and attending conferences, (d) agreed with the goal of preserving the right of self-determination for intersex minors, (e) was willing to be trained to use nonpathologizing

language, (f) understood and could articulate how the mental health professional community had harmed intersex people in the past, (g) would credit the activist by name for his mentoring role when the study was over and I was allowed to do so, and (h) did not confuse the public voice of a counselor with that of an intersex activist. In other words, the lane of counselors is to support but not speak for the intersex community.

In early summer of 2018, the activist suggested I consider interviewing other activists. The merits of doing so were clear and strong. Activists occupy ground zero in intersex community conflicts. They are highly informed about intersex issues. They are public figures and not likely to be emotionally disturbed by sexually oriented research. The approach would be a valuable strategy for transferring activist knowledge into the counseling literature. Finally, activists have stress in their own right and deserve specialized counseling understanding and support.

### **Introduction to Interpretative Phenomenological Analysis Study Design**

I conducted this study using IPA as explicated by Smith et al. (2013). IPA focuses on interpreting the individual nuances of conscious human experience according to the perceiver's own terms and not as defined by preexisting categories or theories. Humans are envisioned as unique meaning-making perceivers, who are existentially bound by their own physical bodies and born into a preexisting world of language and culture. Humans create their own meaning in the daily process of dynamically interacting with the world of objects and other people through intentional pursuits (Smith et al., 2013).

Not all meaning making is relevant for IPA research. IPA targets memorable experiences; in other words, comprehensive units of conscious experience. Comprehensive units are defined as an individual having to work through the experience; in other words, be reflective about them (Smith et al., 2013). Comprehensive units thus



stand hierarchically superior to the majority of experiences that pass by without consciousness. Comprehensive units may possess a variety of properties. For example, they may be proactive or unexpected, negative or positive, or composed of subunits that are contiguous or separated in time (Smith et al., 2013). In the present study, the comprehensive units were the internal, conscious experiences of intersex activists regarding their intersex variation, intersex activism, and contact with professional counseling.

### **Rationale for IPA**

IPA is an appropriate qualitative research strategy for a relatively unexplored psychological topic. According to Smith et al. (2013), IPA is increasingly used in social and health sciences, particularly in psychology, medicine, and nursing. In psychology, IPA studies have been conducted to make sense of inner human experiences in topics of sexuality, health and illness, psychological distress, life transitions, and identity (Smith et al., 2013). The experiences of intersex activists overlap with these topics because intersex activism pertains to psychological and medical practices.

IPA has a heuristic phenomenological emphasis that aligned well with studying intersex activists. IPA is sensitive to the intentional, dynamic, and interactive aspects associated with human meaning making. First, intersex activists must work intentionally through comprehensive units of experience, namely the internal debates about the meaning of having an intersex variation and whether to go public about their intersex status by getting involved politically. Second, the consideration activists bring to their ongoing decision-making is influenced by their dynamic engagement with the language, culture, and time in which they were born. Third, in the process of their meaning making, activists are involved in dynamic, interactive relationships with intersex individuals, other

activists, and medical professionals. I especially valued IPA over other types of phenomenology design for its interest in idiographic differences given my sense that intersex variation differences needed exploring. IPA is based on three philosophies addressed next: philosophical phenomenology, hermeneutics, and idiographic pursuit of knowledge (Smith et al., 2013).

### **IPA's Philosophical Foundations**

IPA's roots in philosophical phenomenology derive from the work of four phenomenological philosophers —Husserl, Heidegger, Merleau-Ponty, and Sartre (Smith et al., 2013).

#### ***Husserl***

IPA is indebted to Husserl for his pioneering role in breaking with objectivist research by adding credibility to scientific focus on the perceiver's self-described experience (Smith et al., 2013). Second, IPA is indebted to Husserl for the view that phenomenology is essentially an interpretive endeavor because the researcher must interpret the meaning maker's experience. Third, IPA is indebted to Husserl for the methodological approach of setting aside or *bracketing* the researcher's perceptions or outside theories to look at things freshly according to the perceiver's particular perceptions (Smith et al., 2013).

IPA departs from Husserl's philosophical interest in determining the abstracted essences of things. IPA is a psychological research endeavor interested in richly described unique experiences of actual people. By extension, IPA also departs from Husserl's pursuit of a transcendental phenomenology capable of defining the abstracted essence of consciousness itself (Smith et al., 2013).

### ***Heidegger***

IPA is indebted to Heidegger for his existential delineation of the contextualized, temporal, and intersubjective nature of psychological realities. From an IPA research standpoint, this means practical focus on people who are not lone entities. People are viewed as embedded entities for they are situated in their language, culture, relationships, and concerns (Smith et al., 2013).

### ***Merleau-Ponty***

Merleau-Ponty's legacy for IPA researchers pertains to a nuanced meaning of physical embodiment. Humans look out on the world from a body that is a unique lens never fully shared with another. The recognition that humans are inescapably subjective due to living in unique bodies gives IPA its principle of the validity of small samples. Only through small samples can the particularized variations between individuals be fully developed (Smith et al., 2013). According to IPA, even with the best interpretive research, the unique lived experience of others can never be fully captured (Smith et al., 2013). An IPA researcher will not assume, for example, that one person's use of empathy is exactly the same as another's.

### ***Sartre***

Sartre's legacy for IPA researchers is to see people as goal-seeking beings operating within an evolving context of personal and social relationships. Humans are ever forming by intentionally engaging in the world. Sartre emphasized humans as dynamic, purposeful beings. IPA researchers notice dynamic human intentionality (Smith et al., 2013).

## **Hermeneutics**

The formal study of interpreting human meaning making evolved through academic interpretation of biblical text. Over time, hermeneutic scholars developed different beliefs about how to conduct text interpretation. Nevertheless, hermeneutic scholars share in common a sensitivity that challenges are presented by the goal of interpreting meaning from people who wrote in a different time, culture, and/or language.

IPA is hermeneutic; in other words, interpretive. The researcher is required to make the perceiver's meaning about a phenomenon come alive through interpretation (Smith et al., 2013). The analysis aim is to explicate participant meaning and the variables that make up the situatedness of both speaker and researcher such as language, culture, temporal, and physical realities.

Though the emphasis is on the perceiver's meaning, the final product of an IPA study is always a combined interpretive study about both participant and researcher (Smith et al., 2013). The IPA data analysis arrives at interpreted meaning via a dynamic, cyclical process called the *hermeneutic circle*. The activity goes back and forth between the text as written and the interview in its entirety, between up-close meanings and meanings revealed from wider vantage. Going small into the data may be referred to as the *hermeneutics of empathy*. Going back and forth between the speaker's meaning and researcher's fore conceptions or theories may be referred to as the *hermeneutics of questioning* (Smith et al., 2013). Interpreting text is sometimes termed a *double hermeneutic* process of the researcher trying to make sense of the perceiver trying to make sense (Smith et al., 2013). The practical value of the hermeneutic circle in IPA data analysis is that the process checks the researcher from imagining meaning not in the text and thereby reveals only meaning grounded in the data (Smith et al., 2013).

The IPA hermeneutic researcher also engages in ongoing process of bracketing (Smith et al., 2013). Bracketing recognizes and sets aside the researcher's fore conclusions, preconceptions, and/or theories that may bias. The cyclical process of bracketing continues until the up-close potential meanings coalesce with potential wider vantage meanings. A cyclical approach to bracketing is also necessary as a researcher's bias may only become apparent after repeated readings.

IPA is broad regarding use of interpretation tools if and only if they are defensible in the data and not due to unbracketed researcher bias (Smith et al., 2013). In other words, defensible theories, fore conclusions, and/or interpretation claims are permissible in IPA (Smith et al., 2013). IPA researchers may also properly provide interpretation different from the speaker's explicit personal interpretations. The speaker may be unaware that a psychological interpretation explains their experience, perhaps due to being an insider or lacking psychological training.

An IPA interpretation may even provide conjecture about the speaker's unspoken mind. In contrast to hermeneutic scholars who focus on words written centuries past, IPA is typically focused on present day text created in the presence of researchers specifically at their direction. The IPA researcher may credibly offer grounded claims about speaker mind since the researcher was in the room at the time. The IPA approach thus stands in contrast with a more restrictive approach by some hermeneutic scholars who claim that interpretation must be restricted to literal text-only. In their historically focused research, the speaker lived in a different era and reasonable interpretation about that speaker's mind was irretrievably lost in history (Smith et al., 2013).

As data analysis proceeds in IPA and the hermeneutic circling continues, deeper interpretation levels should follow. For example, the first level might focus on the speaker's explicit meaning, the second on the speaker's use of metaphors, and the third on the link between the speaker's explicit and metaphorical levels of meaning combined with relevant psychological theory (Smith et al., 2013).

IPA interpretation may lead far away from the participant's explicit statements into theory as long as findings are grounded. Smith et al. (2013) used an example of a dream with a horse. IPA is not entitled to say the horse is a phallic symbol based solely on Freudian theory. Specific text would have to contain sexual content for Freudian theory to be considered.

Following analysis, IPA interpretations of speaker meaning are offered cautiously. IPA is philosophically circumspect about claims of interpretation certainty because of the time lags between an event and a perceiver's reflection about it, and between the perceiver's reflection and the researcher's interpretation. IPA prefers to describe well-grounded interpretation as *experientially close*. In summary, the central hermeneutic issue in IPA is whether experientially close interpretations reveal defensible meaning gathered from participant text rather than meaning gathered from the researcher's ungrounded prior categorizations or theory.

### **Idiography**

IPA is idiographic; in other words, focused on particularized human experiences. In practical terms, an IPA study will liberally provide quotations revealing nuanced variation among participants. By focusing on nuanced detail, IPA claims to do justice to human psychological complexity via dealing in "real world" findings about real people (Smith et al., 2013). By focusing on actual cases, IPA claims the potential to reveal real-

world flaws in existing theories that only appear real through quantitative aggregation (Smith et al., 2013). In other words, use of idiographic data in analysis is a response to problems with quantitative nomothetic data. Use of quantitative, nomothetic data is considered problematic because by aggregating, no actual experience is described (Smith et al., 2013). IPA does not go so far as to make an ontological claim that distilled essences of human experience are unknowable. Rather, discerning essences is not the IPA aim (Smith et al., 2013). Nevertheless, according to Smith et al. (2013), IPA may be used in theory creation if several IPA research studies are linked to create grounded psychological theory.

To summarize IPA theoretical underpinnings, IPA is a research approach designed to capture human internal experience in full complexity by knitting together scholarship in phenomenology, heuristics, and idiography. The researcher endeavors to get phenomenologically close to participant experiences by hermeneutic, idiographic interpretation. In the process, perceivers are revealed as (a) unique, embodied, thinking, and feeling beings who are (b) existentially situated in their time, relationships, and culture, and who, (c) live their lives in an ongoing dynamic process of enacting meaningful intentions (Smith et al., 2013).

### **Introduction to Data Collection and Data Analysis**

#### **IPA Methodology According to Smith et al. (2013)**

IPA data collection and analysis processes are to be organized, systematic, sensitive, and flexible (Smith et al., 2013). In the present study, I provided safeguards for all four qualities but also provided particular constraints regarding flexibility out of concern that the flexibility espoused by Smith et al. (2013) might be a liability. On the one hand, IPA methodological flexibility creates space to tailor research processes. On

the other hand, too much flexibility might lead to lax practices and questionable results. I adapted context and process considerations from Corbin and Strauss (2015) to tighten IPA's flexibility. I also added constraints to the Smith et al. (2013) model by capturing Smith et al.'s (2013) analysis suggestions and codifying them into tasks to be followed. I followed Smith et al.'s (2006) overarching criteria for data analysis—the IPA six stages of data analysis.

### **Context and Process Adapted From Corbin and Strauss (2015)**

Smith et al. (2013) discussed human contexts and processes that individuals go through as relevant to idiographic meaning making and therefore important in data analysis; however, the IPA authors did not provide detailed instruction about how to analyze for context and process. In view of this void, I borrowed instruction from Corbin and Strauss (2015) but for an alternate purpose than their grounded theory development goal and hence to a different degree of attention. I intended to use Corbin and Strauss's context and process guidelines only for the purpose of illuminating any social contexts and individual processes important in activist's idiographic meaning making. Explicating context and process to the degree required for a grounded theory level of prediction was not considered relevant. As intersex activism is a relatively new and evolving phenomenon, grounded theory development may never be relevant.

I next discuss context and process in more detail. I discuss the majority of the study's data analysis work on context and process at this point rather than later during the IPA six steps of analysis. My reasoning is related to continuity. It may be more helpful to have the majority of explanatory material related to analyzing for context and process located in one place.



I anticipated contextual conditions as potentially important in this study; for example, at the societal level in norms regarding biological sex as male or female only. During data analysis, I did notice contextual conditions involved in the participants' subjective meaning about the phenomenon. I was sensitive to contextual conditions such as "personal ability, motivation, knowledge level, environmental factors, cultural practices, and taboos, economic and political factors and so on" (Corbin & Strauss, 2015, p. 217). Contextual conditions noticed were also at micro levels (individual, family, or group) and at macro levels (subinstitutional, organizational, community, city, and so on). Clues noticed included "because" and "since," followed by an action–interaction. I prepared a memo titled "Context" for each participant. The identified conditions answered the questions of why and when.

In addition to context, I focused on processes involved in each participant's subjective meaning about activism. Process refers to the adaptive changes people make in their action–interactions in response to changing conditions (Corbin & Strauss, 2015). Process explains fluidity in life. Conditions and priorities are constantly changing, and so people are constantly adjusting so as to achieve their goals or solve problems. As Corbin and Strauss (2015) wrote, "When analyzing data for process, researchers should aim at capturing the ability of human beings to think through and adjust their action and interaction to solve problems and reach goals whether acting alone or in conjunction with others" (Corbin & Strauss, 2015, p. 185). Processes can be organized as variable, routine, contingency, linear, dynamic, strategic, automatic, random, and/or novel.

To analyze for processes, I looked for how the activists handled their main problems associated with their intersex experience. As a major clue to processes in this

study, I noticed the gerund ending to verbs—“-ing.” For example, I observed the activists engaging in processes of “realizing” and “connecting” and those processes were ultimately raised to themes in this study.

Corbin and Strauss (2015), in their goal to produce grounded theory, looked for processes toward the end of data analysis. As stated, I was not looking for a grounded theory in this study. My interest in processes was not so strict as to be looking for universality or predictability of process among all participants. I was interested in human process because it is a feature of human meaning making. I therefore analyzed process comparatively early, at the same time as all of the other initial coding, during the data analysis time of late Step 1 and early Step 2. I prepared a memo titled “Process” for each participant.

Use of Corbin and Strauss’s (2015) guidelines as I adapted them would not lead to a grounded theory level of abstraction about predictable action–interaction. Yet looking ahead in this study, my emphasis on context and process for methodological strength ultimately was a factor in the unexpected development of an intersex identity development model. Toward the end of this study, I looked at the main social contexts I had observed and saw stages of an intersex identity development model. These social contexts or stages are as follows:

- Stage 1. Binary-only framework: intersex as a disorder.
- Stage 2. Breaking the binary-only framework.
- Stage 3. Beyond the binary-only framework: intersex as a natural bodily variation.

One final observation at this point about context and process. Historically, identity models have tended to list either an individual's state of being or an individual's process at their highest level as a stage. Cass listed an individual's state of being, identity tolerance, as one of her stages. On the other hand, Preves listed a process, acknowledging one's difference, at her model's highest level of stages. I did not use individual states of being and/or processes at the highest level of the intersex identity development model because individual states of being and processes make sense within contexts. I therefore placed social contexts as the new model's highest level. In summary, both context and process turned out to be very important in this study as factors in an intersex person's identity development as the individual undertakes a major personal evolution from a pathologizing social context to a nonpathologizing one.

### **Additional Methodological Adaptations**

This study's quality rubric followed the Smith et al. (2013) interpretation of Yardley's (2000) study quality criteria (see Appendix C). I also analyzed participant handouts in three dissertations with psychological frameworks (Griffiths, 2009; Hind, 2014; Williamson, 2013) in which IPA methodology was used and then wrote participant forms specific to the present study's content needs.

### **Data Collection**

#### **Institutional Review Board Approval**

I followed institutional review board (IRB) protocols. I first obtained IRB approval by outlining the study's investigation purpose, procedures, anticipated risks and benefits to the participants, steps taken to protect the participants, and manner of obtaining participants. To protect participant integrity, I stated in the IRB application that participants were free to raise topics of importance to them.

## **Researcher Roles and Research Questions**

As the sole researcher, I conducted all tasks, including study set up, conducting and coding interviews, verifying transcription accuracy, writing journals and memos, and compiling the final report. In accordance with IPA protocols, the research questions were open and exploratory. The questions emphasized experiences, their meanings, and the participant process of developing meaning. In keeping with Smith et al.'s (2013) guidance, they did not emphasize outcomes. The following were the overarching primary questions asked of participants in this study:

1. What has it been like having an intersex variation?
2. What led to becoming an intersex activist?
3. What is your life like now as an intersex activist?
4. How has the 2006 change in medical protocol impacted intersex people?
5. What has any personal experience with intersex counseling been like?
6. What would improve counseling for intersex individuals and families?

## **Target Population, Participant Criteria, Sample, and Recruitment**

Smith et al. (2013) stated a personal preference for case study in IPA studies as this approach reveals full detail about a single subject's perspective. IPA holds to the principle that large sample sizes are counterproductive to detailed idiographic IPA analysis. Smith et al. acknowledged, however, that IPA sample sizes of two or more are more common.

Intersex activists were the target population for this study. I interviewed four activists for idiographic nuance as well as common themes. A major study goal was to demonstrate variation differences in intersex experiences. The life stories of the activists

were presented in detail as they reveal idiographic nuance of four different intersex variations.

IPA samples are purposive. Purposive sampling involves using predetermined factors that ideally elicit the desired information (Patton, 2002). Potential participants who do not meet the criteria are not included (Merriam, 2016). I used the following criteria in this study: (a) self-identification as having a form of intersex, (b) intentionally and publicly engaging for more than 1 year in activities designed to affect change for other intersex individuals, and (c) a political stance of opposing unnecessary medical surgeries and other medical treatments performed without the consent of the intersex recipient. The sample criteria were validated in each of the participants through collecting demographic information as well as through obtaining publicly available information from the participants' online public content.

Given the small population of intersex activists, no warrant of maximum variation sampling was made. Nevertheless, effort was made to collect data that could reveal idiographic difference by sampling activists with different variations, different genitalia, different medical experiences, different orientations, and different experiences with intersex "transitioning." Several types of intersex variations were represented. One participant was born with atypical genitals and the variations of congenital adrenal hyperplasia and polycystic ovaries; one participant never received conclusive variation diagnosis to explain his atypical genitals; one was born with female typical genitals and variation of complete androgen insensitivity syndrome; and one was born with atypical genitals, partial androgen insensitivity syndrome, and hypospadias.

The sample also demonstrated idiographic variation in medical “fixing” of intersex features to normalize the individuals as either male or female. One participant was “fixed” with hormonal and mental health treatments designed to reinforce assignment as girl. One was “fixed” with measures designed to determine whether he was more boy or girl so that surgeons could then conduct “fixing” surgeries, but the surgeries never happened. One was “fixed” by gonad surgeries designed to reinforce her as a girl, and one was “fixed” with both therapy and surgeries designed to reinforce him as boy.

Idiographic variation regarding gender and intersex “transitioning” was also represented. One participant was misassigned girl and in his 40s had an intersex “trans” experience that he called “gender emancipation.” One remained boy/man as assigned at birth. One remained girl/woman as assigned at birth. One reported three sex or gender transitions, once at birth from X on birth certificate to girl gender, then girl to boy at 8 months, then male to female on legal documents at 47 years of age.

Idiographic variation regarding orientation was represented. One participant knew all along he was gay boy, yet he lived most of his life as a heterosexual girl and became gay by virtue of his “transition”/emancipation to man in his 40s. One was a gay man. One was a heterosexual woman. One lived most of his life as a heterosexual man but with transition in his 40s, now lives some days as a woman and some days as a man.

I hoped for but did not warrant in the study criteria the ideal of obtaining highly visible activists. After the interviews were completed, I asked two of the activists to provide the names of U.S. intersex activists, subdivided further into most active and less active. The two activists consulted with each other and provided a list of 13 highly active activists and 26 lesser active ones. I did not recognize all of the names. Of the highly

active names that I did recognize, one was eliminated according to study criteria because I knew that person was endosex trans and not intersex. I then estimated that about 10 from the total list had been very active from 1996 to 2006 but were now less active. In summary, I interviewed two of the 12 highly active activists and two from the less active list of 26. In total, by interviewing four out of 38, I interviewed approximately one tenth of the total population of the first wave of U.S. intersex activists and a higher percentage of the those who are currently active.

Three participants were obtained through my contacts, and one was referred by the mentor activist. All of the activists had prior knowledge of my interest in working toward improving intersex counseling experiences. I was not very active on Facebook, but all the participants and I had been linked for over a year. In other words, no requests for participation were made to total strangers. Prior recognition of my name by the participants perhaps explains in some measure the level of graphic honesty achieved in this study.

Though the focus of this study was not on intersectionality, I made two unsuccessful efforts to include a person of color whose marginality of race factored significantly in their intersex story. After a month with no responses, I abandoned this goal. Nevertheless, ethnicity and religious differences did receive some degree of attention. Two of the four study participants described the impact of their ethnicity (Spanish and French Canadian) and religion (Catholicism). The participant with Spanish heritage, however, volunteered that their most salient intersex experiences were not related to their ethnic heritage. In other words, issues of intersectionality and intersex activism remain to be explored.

## **Participant Protections and Procedures**

I implemented the ethical values in IPA research through participant protections and procedures. I acted with appropriate IPA fidelity toward subjects by reflecting Smith et al.'s (2013) guidance to be open minded, flexible, patient, empathetic, persistent, and curious. I did not expect to find a single version of truth. Instead, I worked to understand and mirror each participant's unique perspective faithfully.

In this study, ethical practice was dynamic as it was managed with an ongoing focus of avoiding harm. Informed consent, anonymity, safety, privacy, and confidentiality were honored throughout the study as per Smith et al. (2013). To ethically address a historic intersex community concern that clinical professionals produce harmful research by not listening to intersex voices, the participants confirmed their narratives. All four participants reviewed the document and provided editorial suggestions, primarily on content pertaining to them. No participant corrected the intersex identity development model. One participant valued the model so much that he asked permission to use it to organize his autobiography.

### ***Informed Consent***

Participants received written and verbal explanation regarding the full nature of participation, including the subjects to be discussed (see Appendix D for the written explanation). They were informed that anonymous but verbatim content and the outcomes of data analysis might be used in publications. They were further informed that the data would be managed with systematic care, security, and sensitivity. All participants received two copies of the written consent form with my contact information at the beginning of the interview. The participants and I reviewed the forms together and then signed both copies of the consent form (see Appendix E). One copy was given to the



participant. Participants were informed of the right to withdraw at any time during the study. I offered to turn off the recorder at any time, but no one requested to end their interview. During one session, one of the participants briefly sobbed through his words describing the abandonment and mutilation happening to intersex children throughout the world. I offered to stop, but the participant requested that we continue.

Three 1.5 hr sessions were offered to give participants ample time to tell their stories. Two participants chose three sessions and two chose two sessions. Each taping session lasted about 1 hr 40 min. In other words, two participants talked approximately 5 hr, and two others talked for approximately 3 hr. I provided referrals to crisis hotlines, but none of the participants reported using them. The first participant suggested modifications to the debrief form as he knew of better hotline numbers. I adapted the debrief form for the remaining participants per his recommendation (see Appendix F for the original debrief form and Appendix G for the modified form).

Appropriate time was dedicated for data analysis in order to provide justice to participants' right to be faithfully and accurately represented. Data analysis spanned 5 full-time months for 16 hr of oral testimony. Each activist received a \$25 Amazon gift certificate as a token of appreciation for their study participation.

### ***Anonymity, Safety, Privacy, and Confidentiality***

Ethical principles of data collection and analysis followed in this study included steps taken to ensure participant anonymity, safety, privacy, and confidentiality. The informed consent document stated that anything said or done was anonymous within legal and ethical limitations. Interviews were conducted with safety and privacy at a location of the participant's choosing. Three interviews were conducted in the living

areas of private residences. One was conducted privately in a reserved library conference room.

Anonymity assurance in this study was feasible and provided. Steps taken to protect participant identity included assigning a number and pseudonym to each participant and not identifying their geographic locations. Following approval of this dissertation, the participants were offered a copy of their audio recordings, and my copies were destroyed. Transcripts contained no identifying information. Anonymous transcriptions were only on my computer, and the digital files were destroyed after dissertation approval. Every effort was made to disguise identifying information in quotations and in the findings. Confidentiality was warranted and maintained, even though three of the activists expressed disappointment for not being represented in the dissertation by their real names.

### **Interviews**

In keeping with IPA methodology, I collected detailed, reflective, first-person accounts. Content included stories, thoughts, feelings, processes, and contexts that influenced participant meaning (Smith et al., 2013). Particularized data were collected through semistructured interviews conducted to maximize authentic gathering of participant perspective (Smith et al., 2013).

Merriam (2016) recommended that researchers spend time preparing for participant interviews to promote rapport and neutrality so as to elicit natural reactions. I prepared a flexible interview schedule in advance (see Appendix H), which I used during all of the interviews. The purpose of the schedule was to identify the range of topics, devise sensitively worded questions, remove bias, anticipate challenges, and ensure that research questions were answered. I reviewed the schedule with the activist mentor and

then memorized it to promote rapport. However, I did refer to the written schedule several times to help me keep the research questions in mind. The participants sometimes took the interviews in unanticipated directions, which I pursued. Human unpredictability was welcome during the interviews. Often, what seemed like a confusing tangent at first later turned out to be a highly relevant direction. The interview schedule provided a balance of structure and flexibility.

Smith et al. (2013) suggested a variety of query types such as descriptive, narrative, structural, contrast, evaluative, third-person perspective, comparative, prompts, and probes. Query types I attempted to avoid included leading, yes/no, judging, rapid paced, manipulative, or multiple issues in a single question. To put participants at ease, I attempted to move the interview questions from descriptive or narrative in the beginning toward more analytic and evaluative toward the end, from general to specific, and from less to most sensitive. In practice, the initial general question of “What was it like to have an intersex variation?” produced answers that were immediately specific and sensitive.

I encouraged the study participants to select comfortable locations for their interviews so as to encourage open disclosure and hence greater trustworthiness of content (Marshall, 1996). At the interview, I informed the participants of my genuine interest in their perspectives and told them that there were no wrong answers. I shared that the interview might sometimes seem like a one-sided conversation given my goal to thoroughly understand their meaning. I let them know that some of the questions might seem obvious in terms of response, but that this was because I wanted to check my understanding. I also advised the participants that I might take some notes during the interviews.

I assumed that the activists would be proficient with sexual and emotional content but not necessarily comfortable. I used a measure of “small talk” at the beginning of the interviews to put the participants at ease. Merriam (2016) noted that the insider–outsider stance might impact the fullness of disclosed information. To achieve a measure of insider status, I shared my motivation to have no child feel body shame and have no parent feel unsupported during a time of difficult family decision-making. However, I endeavored to not build rapport so overly reassuring as to create bias. I endeavored to be patient with silence and responsive to the rhythm of interaction. I monitored the interview’s effect on each participant. I made corrections to the interview schedule and my interviewing technique after the first transcription.

A neutral researcher stance during the interview requires setting aside some measure of the empathetic and affirming counselor stance (Smith et al., 2013). Professional counselor habits that I sidelined in data collection included being therapeutic in the interview, providing clinical judgement, and steering the participants’ perspectives toward positive appraisals. At the end of the interviews, participants received and sign a debrief form that reminded them that there was still time to withdraw (see Appendix G). Referral phone numbers were provided in case the participants needed further processing.

### **Transcripts**

The medium of audio is considered unobtrusive (Merriam, 2016). Reflecting guidance from Easton et al. (2000), I audio recorded the interviews with three data recorders in case of malfunction. The transcription protocol in this study addressed (a) text formatting and line numbering to aid coding and retrieval processes, (b) source label formatting designed to facilitate retrieval and protect privacy, (c) document headers that organized information consistently, (d) verbatim transcription for accurate

reproduction, and (e) a protocol for preserving and/or destroying data (McLellan et al., 2003). Notable nonverbal utterances were transcribed, sometimes verbatim, sometimes with transcript notation for significant pause and/or brackets for explanatory material such as “[laughter].” I used a transcription service to transcribe the recordings and verified transcription accuracy by reading each document and listening to the recording at the same time.

Two printed copies of the interview transcripts were produced, but I only used one as computer text highlighting replaced the need for the second. The transcript had wide margins and several blank columns, which I used for coding. Text was in the first column. Typed notes and codes were placed in the second column, and themes were later noted in a third column. Key quotes were highlighted in bold. Although IPA allows using coding software, I manually coded all data.

### **Memos, Journals, and Other Data**

IPA permits contextualizing interview data with other data types (Smith et al., 2013). My observations, notes, memos, and journals were included as data. I used memos prepared during study prehistory and throughout data analysis to keep track of my progress while opening up data and developing emerging themes. Without the use of memos, it would have been impossible to keep track of all the issues explored over time (Corbin & Strauss, 2015). Each memo had a header with the date and title of the idea, process, or theme under consideration.

Later in the analysis phase, I prepared participant memos that contained themes and key quotes from each participant. To develop organization and hierarchy, I cut the pages with the quotes into pieces and then sorted them on two large tables by theme and

category. I then prepared summary descriptions of the grouped quotes. The themes and quotes are included in the Results section.

Journals are tools for self-awareness that enable researchers to observe the evolving and reciprocal interaction between the researcher and the study (Corbin & Strauss, 2015). In the present study, journaling recorded “appointments, summaries of discussions, decisions made over the course of the research, and notes following data collection” (Corbin & Strauss, 2015, p. 37). The interviews themselves, however, were the primary data sources for the present study because the research pertained to the inner world of intersex activists.

### **Data Analysis**

An IPA analysis process is deemed adequate if six analysis steps are conducted (Smith et al., 2013). The IPA data analysis process, however, allows for innovation, and therefore is not expected to be perfectly linear. The six analytic steps flow generally from the particular within an individual to the shared among individuals and from the descriptive to the interpretive.

#### **Step 1: Reading and Rereading**

In Step 1, I offloaded initial thoughts onto a copy of the transcript in a process designed to keep researcher “noise” from interfering with the participant’s story. I conducted two uninterrupted times of listening to the recordings while reading the transcript. Afterward, I produced an overall impression of the transcript in a memo titled “Reading 1—Researcher Bird’s Eye Impressions of Interview and Transcript.” Observations were general about my overall researcher experience such as depth of rapport, participant willingness, and ease of communication. A third uninterrupted listening to the transcript shifted toward the participant’s account. I made observations on

the chronology and major topics and then produced a memo titled “Reading 2—General Impressions of Participant Content.” My actions in Step 1 were designed to reduce the quantity of random impressions that might distract from getting into the data as presented and to begin bracketing any fore conceptions or bias.

### **Step 2: Exploratory Commenting/Initial Noting**

In Step 2, I conducted close, line-by-line commenting on the meaning in the participant’s statements. Comments were descriptive, linguistic, and conceptual about the content. Step 2 was the most time-consuming work with the transcript as it involved examining the interview content and the language used line by line to identify the specific, idiographic ways the participant talked, thought, and understood the phenomenon (Smith et al., 2013). The goal was to produce a detailed set of notes on the data and avoid superficial analysis. Initially, I worked to understand the participant’s intended descriptive claims and understandings. Then I went deeper into participant meanings.

My initial idea of using various text formatting styles to distinguish descriptive, linguistic, conceptual, and personal dialogue was attempted but then discarded as distracting and inefficient. Instead, I used Word’s color highlighting feature to visually distinguish the types of content. For example, words that seemed especially powerful were highlighted in red. Other key concepts, quotes, and metaphors were highlighted in bold-faced black type. Topic changes were highlighted by turquoise for later retrieval.

I placed strong emphasis on descriptive content by virtue of wanting to introduce new descriptive detail about intersex life narratives and activist opinions into the counseling literature. Descriptive comments involved participant content taken at face value. The description was close to the participant’s words about items of concern such

as events, experiences, relationships, places, processes, values, and principles. Evidence for the description was observed in the forms of overt description, assumptions, phrasing, idiosyncratic speech, and emotional responses.

Linguistic comments were also noted, for example, in the forms of comparisons, contrasts, amplifications, pronoun use, laughter, pauses, repetition, tone, fluency, and especially metaphor. Certain phrases such as “genital exposure trauma,” “freak,” “annihilation,” “erasure,” and “eugenics” seemed to jump off the page. I later used these terms as in vivo codes.

I was trained to bracket, and I expected to engage in frequent notations of personal dialogue by first noticing and then questioning commonalities of experience between the participants and myself in a search to find and remove my bias. In fact, the participants’ stories were so different from my experience as a heterosexual, endosex female woman that I did not often feel sensations of “Is this them or me, for something just like that happened to me?” Instead, my general internal process could be more accurately described as stress trying to comprehend content from another world. Even with the previous year of activist mentoring and several years of reading narratives from other fields about intersex experiences, I, who had grown up under binary privilege, felt deeply challenged by the data. I struggled to find words to describe unrelenting ubiquitous pressures I was hearing that happened from birth onward due to social forces that had tried to make the participants disappear as exceptions to all that is supposed to exist, namely males and females. The questions most often in my mind were not “Have I over identified? and “How can I bracket myself out?” Instead, my most frequent internal questions were “Do I have the capacity to really capture the horror I am hearing and find



the words that do that horror justice? “What words can I use?” and “I cannot use typical words like shame, isolation, or family rejection without watering down what I am hearing.”

Conceptual comments opened up potential participant meanings beyond the purely descriptive level. These comments were sometimes one or a few words. Sometimes conceptual comments were questions such as “Why am I hearing details about rock stars and performance art? Connection or coincidence?” Some conceptual notations over time were raised to higher levels of conceptualization. For example, two participants discussed their involvement or interest in performance art. For one, the concept was raised to the level of affirming experience. For the other, the concept was elevated to a harm—force fitting.

Step 2 analysis for the first participant lasted over 1 month. It was arguably a tactical error to work on the most complicated story first. The only intentionality behind my starting with the first participant was to analyze according to the order in which the interviews were conducted. In other words, there was no reason that the shorter and less complicated interviews could not have been analyzed first. By the end of the month, the quantity of generated notations that came out of hermeneutics of empathy were unmanageable, and I felt no movement in the analysis phase. Coding the less complicated interviews first might have been a better idea. I might have made progress faster, felt less overwhelmed by the mass of codes, and been bothered less by no sense of tangible progress toward the next step.

### **Step 3: Developing Emerging Themes**

As I did not feel ready to enter Step 3 despite 1 month of work on the first activist’s transcript, I knew something had to change. Progress was not discernable

despite coding, rereading, listening to the transcript in audio several times, recoding, and rereading. In hermeneutics of questioning, I stepped back and asked what was really happening in the data. The resounding answers were “harm” and “overcoming harm.” This perception was the first approach or tactic that added order to the complexity of the data.

Data analysis began to take shape with that question. I went back to the data and documented all of the harms and any affirming experiences. I then organized the list of harms by their source—family, medical professionals, or mental health professionals. Some harms seemed so ubiquitous that they belonged to a more general category. At that point, I raised family harms a level to become a component of social harms in general. For example, the harm of pity, in which others mistakenly assume intersex people feel bad about having atypical genitals (and/or atypical gender identity and expression) may come from a sister, a physician, or a therapist. In other words, pity is a ubiquitous harm intersex people experience throughout life from a variety of sources. Objectification of an intersex person as a medical thing, on the other hand, is a harm that comes into the intersex person’s life specifically from the medical system.

Next, I realized that another way to make genuine progress was to extract all of the relevant descriptive data needed to answer the research questions. I extracted the descriptive part of the participant’s life narrative to partially answer Research Question 1: What has it been like having an intersex variation? A key context, namely the binary-only framework, (BOF), began to take shape in the process of documenting the descriptive part of the first activist’s life narrative. I then focused on answering the descriptive part of the three research questions pertaining to activism (Research Questions 2, 3, and 4):

What led to becoming an intersex activist? What is your life like now as an intersex activist? and How has the 2006 change in medical protocol impacted intersex people? I then focused on the descriptive part necessary to answer Research Questions 5 and 6: What has any personal experience with intersex counseling been like? and What would improve counseling for intersex individuals and families? Once the volume of descriptive content was extracted for all of the research questions, I found it much easier to focus on more abstract issues such as context and process.

Given this study's psychological framework, the extracted descriptive content emphasized psychological elements. Themes emerged from the descriptive comments that captured the psychological essence of an identifiable section of activist text; for example, "defensive lying." The themes extracted were an amalgam of participant meaning and researcher interpretation. For example, the theme of "emotional disturbance" did not appear as actual participant words. Smith et al. (2013) cited this step as an example of the hermeneutic circle in which the original lines of the text are taken apart and reordered into a new whole.

In summary, during Step 3, I shifted into a more interpretive phase by developing emerging patterns using techniques to identify patterns. Smith et al. suggested that IPA researchers use one or more techniques to take a fresh look at the data from the participant's vantage. I used techniques of looking for the overarching narrative (i.e., characters, setting, plot, conflict, and resolution), and subtracting out the description part of research questions. All four activists' storylines were stories of harm fostered by a way of thinking, namely a BOF in which intersex is only a disorder to be fixed. I detailed the participants' stories and opinions (i.e., descriptions), the list of harms, harming sources,

and affirming experiences in a document titled “List of Draft Emergent Themes.” I sent this list to the first activist I interviewed, and he validated it.

#### **Step 4: Searching for Connections Across Emergent Themes**

In Step 4, I searched for patterns among the themes. At this point, I decided to go back to the data and take a fresh look. I extracted all bolded quotes in the transcript in chronological order and placed them in a separate document. I recoded the quotes to verify themes, search for connections, and check for a relationship between context and process. In terms of process, I paid particular attention to the significant number of gerunds in the data as they indicate that a process is happening to someone or something. “Realizing,” for example, seemed to jump off the pages because of the emotional shock that seemed to follow. Once I noticed the gerunds, I evaluated them in relationship to a possible context in which the “-ing” process occurred. For example, the theme of toxic labeling occurred during a social context in which authority figures, including parents, mental health professionals, and medical professionals, labored to enforce the BOF.

Most themes held, but some needed reworking. For example, I looked at several individual harmed reactions and found a general category of harmed responses. As another example, alien/superhero was divided to become both a harmed reaction and an adaptive reaction. In this step, I prepared a document titled “Participant Table of Superordinate and Subordinate Quotes and Themes” for each participant, which included page numbers, line numbers, and key quotes.

#### **Step 5: Moving to the Next Case**

Step 5 involved completing Steps 1 through 4 for each participant before moving on to Step 6. The process was a check to prevent me from automatically seeing in a

subsequent participant's transcript the same themes as in the prior one. The process reflected the idiographic emphasis of IPA by being alert to difference, not just similarity.

### **Step 6: Looking for Patterns Across Cases**

In the final step, I printed the documents titled "Participant Table of Superordinate, Subordinate Themes and Quotes," each in a different color. Activist 1's document was printed in pink, Activist 2's in green, and so forth. I then used scissors to turn each of the themed quotes into separate little pieces of paper. I wrote all of the themes on yellow stickies and spread them out on two large tables. I then matched each quote to the yellow stickie with the same title.

Some themes seemed to be piled with quotes in four colors; some themes had quotes of only one or two colors. This allowed me to reorder the data using techniques such as numeration, subsumption, and function in a tactile and visual way. I asked myself question such as "Do themes from one help explain others?" and "Is an even higher level of abstraction possible?"

Once all the data were analyzed, I conducted a review of Preves's findings to evaluate the relevance of her findings to my study's findings. The data findings in Preves' work and in my study did not conflict. Findings from my study, however, added activism, counseling, and variation-specific content. Intersex "trans" experiences were also new data. I attempted to organize the new information so as to be especially useful for counselors. Data were organized in easy-to-scan categories, including harms, sources of harms, harmed responses, and adaptive responses.

In the process of comparing the Preves/Cass model with the organization of data in my study, a new, more succinct intersex identity development model surfaced. In the process, two contexts/stages were added to the BOF. I solicited input from one of the

study participants to audit the new model's coherence and plausibility. As mentioned earlier, the activist validated the model and asked permission to use the model to organize his autobiography, which was in progress at the time of this study. I concluded data analysis by documenting my self-reflection on my perceptions, conceptions, and research processes (Smith et al., 2013).

## **Presenting Results**

### **Criteria for Evaluating Study Quality**

Smith et al. (2013) stated that conducting Steps 1 through 6 constitute an adequate study. Furthermore, the steps also provide evidence of a quality study. However, Smith et al. went deeper in their discussion of study quality. Among previous researchers who have addressed quality standards for qualitative research, Smith et al. reported a preference for Yardley's 2000 criteria. To follow suit, I performed a study quality audit using the Yardley criteria. Evidence for quality compliance came from the suggestions made by Smith et al. I placed Smith et al.'s summary of the Yardley criteria and Smith et al.'s evidence considered relevant toward meeting the Yardley criteria into a rubric for this study (see Appendix C). At the conclusion of my work, I graded the study using this rubric and prepared a quality report (see Appendix I). In summary, this study properly evidenced sensitivity to context, commitment and rigor, transparency and coherence, and importance and impact.

### **Researcher Bias**

I identify as a straight, endosex (female typical), cisgender, married, late middle-aged White woman. Apart from 3 middle school years in Venezuela, I grew up in affluent suburbs in the United States. I am the mother of two adult, endosex, cisgender children. I had no knowledge of the intersex community prior to learning about intersex medicalized

treatment in my master's degree program in counseling. My overall interest in addressing human need traces to daily commutes to middle school through dirt barrios in Maracaibo, Venezuela. Third-world poverty left an indelible impression. The sights of those years provided long-term fuel for my persistent interest in alleviating human suffering through activism.

A bias I possess is my agreement with the ACA's Resolution To Protect Intersex Children From Unwanted Surgery, Secrecy, and Shame. In other words, I am opposed to medically unnecessary intersex infant surgeries. The importance of the ban was the starting point of my research.

My agreement or bias regarding the importance of banning intersex infant sex-related surgeries developed out of personal childhood trauma. My father physically abused me during my preschool years for my self-pleasuring behavior, which was an action he considered a Catholic mortal sin. His well-meaning intention was to stop the behavior so as to save my soul from hell. The destructive effect of his punishment was to make me somewhat uncomfortable in personality as well as in body. My journey through the trauma involved initial trust in parent and church authority and internalized shame and self-distrust. Subsequently, I developed sufficiently so as to have the personal power to resist parent and church authorities in regard to their teachings that resulted in body shame. In this study, I was alert to a similar growth trajectory in the activists. I recognized a similar path in the activists from their initial shame to their developing a perspective that allowed harmful authority to be validated as well-meaning but nevertheless deserving of rejection given the effects of their damaging beliefs and behaviors.

As mentioned earlier, the first time I learned about unnecessary medical surgeries performed on infants was in 2011 during my sexual issues course required for my master's degree in clinical mental health counseling at Fairleigh Dickinson University in New Jersey. The stories of a hidden population and the physical and psychological pain due to medically unnecessary surgeries were deeply disturbing. The moment I first learned about intersex medicalized treatment was life changing. I recognized a degree of similarity with my own past. Intersex people had been deeply shamed about their bodies, presumably by well-meaning parents and medical authorities. My connection to the intersex trauma I learned about in connection with intersex medicalized treatment was so deep that I dedicated my professional counseling career to improving counseling support for intersex individuals and their families. I moved for 2.5 years from New Jersey to Missouri to study at UMSL. I sought UMSL specifically for its expertise forte in two areas deemed essential for this study—social constructivism/paradigms of counseling and sexual minority scholarship. In other words, since first learning of intersex medicalized treatment, I have been deeply committed to intersex counseling needs and the cessation of medically unnecessary surgeries on intersex infants.

By referencing the Hays cultural complexity model to evaluate my cultural awareness and bias, I was aware of other potential bias due to my privilege as a member of almost all dominant groups, including being White, middle aged, able bodied, Christian-reared, European American, upper class, educated, heterosexual, and U.S. born (Hays, 2001). I was also privileged by virtue of having a female-typical anatomy; in other words, I was not born with an intersex biological variation. I was privileged as cisgender by identifying with the gender of girl assigned at birth.



I addressed potential researcher bias by rigorously following the IPA analysis steps previously discussed. The steps are purposefully designed to anchor observations in participant meaning and to avoid researcher bias. The intersex activists who participated in this study also provided a check on researcher bias. They reviewed and commented on my findings to prevent any unrecognized harm or bias.

### **Conclusion**

IPA's philosophical foundations are phenomenological, heuristic, and idiographic (Smith et al. 2013). I used IPA to evaluate the internal experiences of intersex activists regarding their intersex variations, activism, and any counseling received. As the researcher, my task was to faithfully represent the inner world of unique, embodied individuals who are pursuing meaningful goals and interacting dynamically with other unique individuals at a unique time in history. I followed Smith et al.'s (2013) IPA analysis steps with added safeguards for methodological rigor. Advance preparation for the interviews was designed to openly and accurately capture participant responses to the research questions. Data collection protections followed all ethical guidelines and addressed the participants' right to participate voluntarily, safely, anonymously, and confidentially. Guidelines to endure study quality and to protect findings from researcher bias were faithfully and systematically addressed.

## CHAPTER 4: RESULTS

This chapter details the experiences of four intersex activists: Angelo, Mitt, Marsha, and Val/Valerie. I first present the demographic information collected from the activists (see Table 3). Individual biographical narratives of the intersex activists are presented next. Each narrative has four parts: overview, intersex biology, physical health, and psychological health.

In the second part of this chapter, I present the context-oriented stages and their themes that emerged during the data analysis phase of this study. The themes can be understood as an intersex person's processes, experiences, or states of awareness in that stage, and additional components of that stage such as its ideas and harms. The themes are organized under three social contexts at the highest level as these contexts explain why the themes organized under them occurred. The combination of the three social contexts and their respective themes are then presented as an intersex-specific identity model.

**Table 3***Participant Demographics*

| Characteristic                           | Angelo (formerly Angela)                                | Mitt                                     | Marsha                                   | Val/Valerie (formerly Val)  |
|--|---|--|--|---|
| Chromosomes                              | 46,XX   | Inconsistent tests                       | 46,XY                                    | 46,XY   |
| Variation                                | Congenital adrenal hyperplasia, polycystic ovaries      | Hypogonadism (low hormone production)    | Complete androgen insensitivity syndrome | Partial androgen insensitivity syndrome, hypospadias                |
| Pronouns now                             | He/him/they/them  | He/him/his                               | She/her/hers                             | Herm/herm/herms   |
| Gender now                               | Man   | Man                                      | Woman                                    | Man and woman, fluid  |
| Gender at assigned at birth              | Girl  | Boy                                      | Girl                                     | Girl  |
| Gender change: “trans” (or emancipation) | From woman to man in his 40s                            | No                                       | No                                       | Girl to boy at 8 months, boy to female (on documents) in herms 40s  |
| Gender expression                        | Androgynous   | Man typical                              | Woman typical                            | Man some days, woman some days                                      |
| Body in mirror                           | Nonconforming: no testicles, small penis, small breasts | Nonconforming: no testicles, small penis | Conforming: typical female               | Nonconforming at birth, no testicles, penis amputation in herms 40s |
| Age range (in years)                     | 50–59   | 60+                                      | 50–59                                    | 60+   |
| Economic level                           | \$80,000–\$89,000                                       | \$20,000–\$30,000                        | \$100,000+                               | \$10,000–\$20,000   |
| Race/ethnicity                           | Spanish/German  | White                                    | White                                    | White/American Native or Alaskan                                    |

| Characteristic  | Angelo<br>(formerly<br>Angela)    | Mitt   | Marsha                                    | Val/Valerie (formerly<br>Val)  |
|---|-----------------------------------|--|---|--|
| Biology   | Intersex                          | Intersex   | Intersex                                  | Intersex   |
| Gender at<br>time of study  | Man                               | Man  | Woman                                     | Fluid  |
| Sexual<br>orientation   | Gay                               | Gay  | Heterosexual                              | Sapiosexual (brain<br>attraction)  |
| Marital status  | Married                           | Widowed  | Married                                   | Widowed  |
| Citizenship   | U.S.                              | U.S.   | U.S.                                      | U.S.   |
| Employed  | Contract work,<br>1–40 hr/week    | Disabled   | Employed > 40<br>hr/week                  | Employed 1–39<br>hr/week   |
| Education   | Bachelor of arts<br>degree        | Associate of arts<br>degree, some<br>additional<br>education | Graduate degree                           | Associate of arts<br>degree  |
| Years as an<br>activist   | 4                                 | 21   | 7+  | 17   |
| Weekly time<br>for activism<br>(in hours)   | 1–10 paid, more<br>than 40 unpaid | 0–10 paid, 10–<br>20 unpaid                                  | > 40 paid                                 | 0–10 paid, 20–30<br>unpaid   |
| Received<br>medically<br>necessary<br>intersex<br>surgeries                                 | No                                | No   | No  | No   |
| Received<br>harmful<br>genital/gonad<br>“fixing”<br>surgeries<br>(unnecessary<br>surgeries) | No                                | No   | Yes: one for<br>gonad removal<br>(testes) | Yes: 14 for<br>hypospadias repair<br>and finally penis<br>amputation due to<br>surgically caused<br>urinary blockage |

| Characteristic                                      | Angelo (formerly Angela) | Mitt | Marsha                  | Val/Valerie (formerly Val)                                   |
|---|--------------------------|------|-------------------------|--|
| Received harmful hormonal “fixing”                  | Yes                      | No   | Yes (surgically caused) | Short time only; discontinued due to iatrogenic harm effects |
| Affiliated with one or more intersex support groups | Yes                      | Yes  | Yes                     | Yes  |
| Affiliated with an intersex activist group          | No                       | No   | Yes                     | Yes  |

### Intersex Activists’ Experiences

#### Intersex Experiences of Activist Angelo (formerly Angela)<sup>1</sup>

##### *Overview*

Angelo’s story involved no surgeries but did involve hormone treatments to enforce female characteristics. Angelo was assumed at birth to be a female and named Angela. Angelo lived as Angela for 4 decades. Angelo struggled greatly with his girl

---

<sup>1</sup> All participants approved of their own pseudonyms. The naming convention for the first activist—Angela/Angelo during pretransition and Angelo posttransition—was the subject of much discussion and debate. Keeping Angela’s name during pretransition is intended to honor Angela’s life and emotional pain. Using only Angelo seemed to erase Angela. Second, the pseudonym convention for the first activist is also intended to depict an intersex “trans” story in contrast to an endosex trans one. The proper naming convention for an endosex trans person is to use the preferred gender both posttransition and pretransition. However, at no point in life was there ever a sense in Angela or Angelo of being in the wrong body. Angela enjoyed her breast, vagina, and penis, and Angelo feels the same now. Third, the difference between the first and third activists’ naming conventions highlights their different intersex “trans” experiences. The third activist, Val/Valerie, uses Val/Valerie throughout the study. Val/Valerie has always felt gender always. Conversely, Angelo feels best described by a masculine name posttransition. Finally, the pseudonym naming conventions are meant to describe internal experience. In other words, what is not being described is how others perceive the activists’ gender. Prior to transition, the world presumably perceived Angela/Angelo as Angela. After transition, the world perceives Angelo. Prior to transition, the world perceived Val. After transition, the world perceives Val some days and Valerie other days.

assignment during youth and adolescence. By his 20s, however, Angelo had adjusted to living as a woman. Two decades later, Angela/Angelo's ill health due to feminizing treatments of testosterone blocking and adding estrogen forced a reconsideration of maintaining a girl/woman appearance and gender.

Angelo's story is a "trans"/emancipation intersex story. At puberty, Angela/Angelo had consented to hormonal feminization. However, the "consent" followed years of extreme medical and psychiatric efforts to ensure that Angela/Angelo maintained her/his girl gender. At age 40, Angela/Angelo was married, living in the role of mother of two biological children and one adopted child, and was deathly ill. Angela/Angelo took charge of her/his own health needs and found a trans-friendly physician who would work with an intersex body in a treatment approach tailor made for an *N* of one. The approach involved letting unusually high levels of testosterone return and then adding more testosterone. The approach successfully restored the body to health. Given the masculinizing effects of testosterone, Angela/Angelo "transitioned" to Angelo. Angelo does not look back with internal rejection of his life as Angela. Angela provided many personal gifts that Angelo continues to treasure such as children and the joys of being a beautiful woman.

Angelo stated he now preferred the term "emancipation" over "transition" because he always knew he was a boy. When Angelo emancipated in his 40s for health reasons, he became precisely who he said he wanted to be at age 3 years: a gay man, married to a man, and a gestational father; that is, a man who gave birth to his own babies. Angelo believes that all of the mental health, medical, and social "fixing" was a

destructive waste, almost ending in his extermination at the hands of physicians, psychiatrists, therapists, and self.

### ***Angelo's Biology***

Angela/Angelo was born with chromosomes typical for a female body, 46,XX karyotype. The body, however, masculinized in utero due to high levels of testosterone production. Two intersex variations, polycystic ovaries and congenital adrenal hyperplasia (CAH), were involved in the overproduction of testosterone. Angela/Angelo was born with a smaller and differently shaped vagina and female reproductive organs. Angela/Angelo possessed female fertility, was assigned female, and was assumed to have the gender of a girl. There was no intersex option on birth certificates at the time in Angela's/Angelo's home state.

Angelo's genital organ has been variously called by medical professionals as an oversized clitoris (as Angela), and a phallosclit, phallus or penis (as Angelo). Since Angelo's time of emancipation in his 40s to gender man, he has preferred either phallus or penis. Angelo reported that his penis is tied down with skin that is part of his vaginal folds. Angelo's penis, like a typical uncircumcised penis or clitoris, is hooded clear to the tip. His penis is somewhat buried when flaccid and becomes three times larger when erect. In its erect state, Angelo's penis assumes a straight-out position and emerges from its foreskin hood. He reported having a penis at a Prader Scale 2 that grew to Prader Scale 3 with testosterone supplementation. (The Prader Scale measures the path of sexual differentiation.) Angelo reported that his scrotal labia are fleshy to a degree that testicles might logically seem to be present, but the area splits into a vaginal opening instead. Hormone replacement therapy (HRT) with testosterone put Angelo through a second

adolescence in his 40s. With the testosterone addition, Angelo developed secondary sex characteristics of a man, and his hands, feet, and phallus grew.

Angelo stated that some intersex people with a hooded penis seek surgery to remove the skin that ties their penis down to enable a straight-up erection so they can penetrate their partner. Angelo was informed that he could have his penis released from the skin that tied it down, then circumcised, and then surgically built up to create a 3-in length. Vaginectomy and complete hysterectomy were suggested to build up his penis and release it. Angelo was warned, however, that the surgery could interfere with his orgasm trigger. He refused it as the procedure would result in loss of his vagina and its sensation.

Angelo's urethra is positioned differently from an endosex (not intersex) person. His urethra is located at the base of his penis, in between his penis and the higher portion of his labia. Angelo reported that he sits to urinate. His urethra location is akin to, but not exactly like, the intersex trait of hypospadias. Hypospadias applies if the scrotum is closed and the phallus is Prader 4 or 5 with no obvious vagina.

Angelo stated that he does not know if he has something similar to seminal vesicles or not. He ejaculates via his Skene's gland (the prostate in males) and his urethra. One medical theory is that Angela's/Angelo's Skene's gland developed more like a male prostate than a female Skene's gland. The result was that Angela was, and now Angelo is, able to ejaculate semen liquid, but without male fertilizing capability. The quantity is the same as an adult male, not the tiny amount that may occur in female-typical individuals. Some of the ejaculate can regurgitate into the bladder. The regurgitation used to cause chronic bladder infections until Angela/Angelo learned to



urinate after ejaculation to clear out the bladder. Angela/Angelo was pregnant six times and gave live birth two times. Both babies had to be born by caesarean section due to Angela's/Angelo's cervix not dilating and her/his pelvis not accommodating the infants.

### ***Angelo's Physical Health***

Throughout his life, Angela's/Angelo's natural development tended toward masculinization. As an infant assigned female and named Angela, any of Angela's/Angelo's features that were masculinizing were treated as independent disorders to be fixed through feminizing therapies. The physical "fixing" of Angela/Angelo involved hormone treatments but not surgeries.

In route to his decision to transition/emancipate his gender, Angela/Angelo realized she/he had been overtreated psychiatrically and undertreated medically. Angelo stated that many of Angela's/Angelo's medical issues in youth were often treated as psychosomatic symptoms and medicated with psychiatric drugs. Preceding transition, Angela/Angelo learned that she/he is afflicted with Ehlers-Danlos (a connective tissue disorder), a mitochondrial disorder called Complex I dysfunction with oxidative phosphorylation disorder (an energy processing disorder), and intersex variations of CAH and polycystic ovaries. In combination, these diagnoses explain many of her/his improperly diagnosed health issues involving loose joints and bruising, autonomic dysfunction, emotional dysregulation, inadequate energy production, and sleep problems, namely myopathy, neuropathy, chronic fatigue, narcolepsy, and cataplexy.

In her/his 40s and very ill, Angela/Angelo moved with her/his husband and children across country to seek treatment from one of five physicians in the nation capable of treating mitochondrial needs. Via online communications, Angela/Angelo led

many others suffering from mitochondrial disease to the same doctor and then unified everyone in a Facebook group.

Over time, Angela/Angelo became wheelchair bound under the mitochondrial specialist's care. Angela/Angelo observed that many others in the Facebook group also ended up in a wheelchair due to severe autonomic dysfunction. Through online research, Angela/Angelo discovered that the physician's mitochondrial approach, in combination with Angela/Angelo's existing formulaic drug regimen to keep an intersex person feminized, (namely zero testosterone level, statins, and testosterone blockers), was toxic. The physicians were overmedicalizing, and the side effects of the medications were making people sicker. Angela/Angelo realized that the medical profession had engaged in iatrogenic harm. The overall treatment approach had been formulaic. In other words, the treatment approach was not individualized to an intersex person who manufactures their own high testosterone from both CAH and polycystic ovaries and who also had mitochondrial disease. Furthermore, the mitochondrial physician added many other drugs that made Angela/Angelo sicker.

Angela/Angelo was determined to stop the feminizing drugs and the drugs given for autonomic dysfunction and hormone imbalance. When Angela/Angelo informed the doctor of her/his intent, the physician fired Angela/Angelo as a patient. The physician sent a certified letter declaring "patient noncompliance." Angelo later came to the conclusion that Angela's/Angelo's medical records were shared in the physician's medical system in violation of privacy rights as no other doctor in that system was willing to provide treatment.

Angela/Angelo knew that withdrawal from feminizing and other drugs was dangerous but decided to embark on slow tapering regardless. She/he remembered feeling like there was nothing to lose because death felt close anyway. Angela's/Angelo's body began masculinizing under its own natural level of testosterone. She/he also made dietary changes for mitochondrial support. Physical health slowly returned. The mitochondrial specialist physician was reported to the hospital board and later removed from practice as a penalty for his formulaic medical treatment.

Angela's/Angelo's continuing research led her/him to suspect that adding more testosterone via injection might be beneficial for the mitochondrial disease. Angela/Angelo had learned that some people with muscular dystrophy (which is related to mitochondrial disease) were injecting testosterone to get out of wheelchairs. The Muscular Dystrophy Association shared such stories online. Angela/Angelo found one transgender-friendly reproductive endocrinologist willing to take her/him as a patient and develop an individualized approach to testosterone injections.

In the medical system, adding testosterone is assumed to be desired for the reason of gender dysphoria, not for physical needs related to health, in this case mitochondrial (biological energy) processing. The medical procedures for adding hormones to change gender require a counselor's letter stating the importance of the drugs for mental health. Angela/Angelo was told that to get medical insurance to cover her/his hormones, or to be able to see the reproductive endocrinologist, a counselor would have to diagnose her/him with gender dysphoria. This situation greatly upset Angela/Angelo for she/he knew there was no internal experience of gender dysphoria. Angela/Angelo had always known she/he was a man even though she/he had finally adjusted to living as Angela.

Angelo explained that what Angela/Angelo went through during the transitioning procedure was pursuant to state law, which followed guidance from the trans organization WPATH. He stated that the WPATH process was problematic for an intersex person seeking to “transition” because it forced the person to be involved in a system that required a lie. The lie was that Angela/Angelo had to admit to gender disturbance as such was required of anyone making a request to receive hormones different from their birth assignment. Yet, Angela/Angelo would not have been in the predicament of needing a counselor letter warranting gender disturbance but for the social, medical, and mental health professional forces that tried to turn Angelo into someone he never was, namely a female/girl. Angelo stated that the WPATH process for an intersex “trans” person can be one in which an intersex victim feels once again victimized by the original erroneous gender assignment made by a physician. Angelo remains upset about having had to endure a process that was not designed for an intersex “trans” person.

Angela’s/Angelo’s new physician added testosterone to her/his naturally high levels of testosterone. The physician then monitored bloodwork and adjusted levels according to Angela’s/Angelo’s verbal reports of health improvement. Looking back, Angelo reported that Angela/Angelo felt a bit scared at that time as she/he had to sign a release waiver absolving the physician of any potential harm since the treatments were experimental.

Angela/Angelo considered the new physician a life saver, but not perfect. The doctor was not sensitive and used the term DSD instead of intersex variation. Furthermore, with the new doctor, Angela/Angelo felt obligated to tolerate offensive

medical practices. For example, Angela/Angelo felt obligated to include many of the physician's associates in the examinations. The excess medical personnel came into the consultation, announced that they had never met an intersex person before, and asked if it would be all right if they stayed to learn. Angela/Angelo agreed to their requests only out of fear of patient abandonment. By that time, Angela/Angelo had already been adversely labeled as patient noncompliant two times—once when stopping addictive psychiatric drugs and once when refusing to continue mitochondrial treatment. To obtain testosterone, Angela/Angelo felt that there was no choice but to acquiesce to medical practices that were objectifying and humiliating.

Angela's/Angelo's additive testosterone treatment caused a second adolescence, which is a common transition experience. Changes included male body changes, for example, breast size reduction, penis size increase, and heightened libido. Under the addition of testosterone, Angela/Angelo improved to the point of no longer needing a wheelchair. Autonomic dysfunction and low blood pressure vanished. Blood pressure normalized. Incontinence disappeared. Erections and orgasms returned after an absence of 10 years.

Given the masculinized changes under the new hormone treatment, the “transition”/emancipation from Angela (woman) to Angelo (man) became appropriate. Angelo reported a strengthened sense of self as finally being able to live publicly in the gender of a man. He had enjoyed his time as a “beautiful woman” but now felt more at home and authentic with the gender of a man.

Angelo reported being very happy with all of his body parts, some of which are thought of as male and some of which are thought as female. Angelo considers himself

very fortunate at having escaped surgical strategies designed to make him look like a girl for they would have reduced or removed his penis. Angelo credits his parents' Catholicism to having escaped the surgeries. Angelo describes his transition as more of an emancipation than a transition because he was reclaiming all of his bodily functions. Angelo reported ongoing collaboration with his physician to address his unique intersex health needs.

Angelo, relatively rare as a CAH man, expressed concern that the CAH women he hears from are among the sickest intersex people. Angelo fears that they are experiencing what he went through, namely iatrogenic harm from feminizing hormonal treatments. Angelo reported feeling sad for them. Whereas (after a brief period of coping with her/his own internalized transphobia), Angela/Angelo was content to masculinize, the majority of CAH women might not be willing to masculinize. These CAH women forgo the possibility of improving their physical health because they identify as women. Some very sick CAH women have told Angelo that they would rather die than allow their body to return to its own natural level of testosterone and/or take additional testosterone for health improvement.

### ***Angelo's Psychological Health***

Angelo reported growing up with significant stress as during her/his time as Angela/Angelo largely caused by society's response to how Angela/Angelo manifested gender. At age 3 years, Angela/Angelo reported to her/his family that she/he was a boy who wanted to give birth as a father married to a man (i.e., gestational father). Angela's/Angelo's family, however, could not comprehend their girl being a gay boy without either testicles or a large penis wanting to be a gestational father. The family

labored diligently to keep Angela/Angelo as a female/girl/heterosexual through a variety of treatments including gender conversion therapy, other talk therapy, behavior modification, psychiatric drugs, and hormone feminizing treatments.

Angela/Angelo was diagnosed and considered mentally ill due to her/his alleged delusion. At age 4 years, Angela/Angelo was sent to a gender conversion therapy program staffed by counselors and psychiatrists. Girl gender roles and girl gender expression were stressed. Angela/Angelo was showed dolls that had penises and testicles and told that large penises are what makes a boy. For a time, she/he stopped speaking.

Three times while in high school, Angela/Angelo reasserted her/his alleged “delusion” that she/he was a boy who wanted to be a pregnant man married to a man. Each time, she/he was committed for a month of psychiatric hospitalization. Psychiatrists used various psychiatric labels that then allowed them to prescribe over 14 damaging and addictive medications per day, which had to be taken all of the time, not just during hospital stays.

Psychiatrists observed increased emotional distress in Angela/Angelo following psychiatric treatment and assumed the distress was more emotional disorder as opposed to a natural traumatic response to having one’s existence and emotions denied. More drugs were prescribed. Psychiatrists observed Angela’s/Angelo’s many undiagnosed somatic symptoms, labeled them as mental illness, and then also medicated them with psychiatric drugs. In the hospitalizations, Angela/Angelo was threatened with shock treatment if she/he did not agree to being a girl who liked boys.

From all the years of psychiatric medications, Angelo reported that Angela/Angelo became one of the “living dead” and lost her/his exceptional giftedness in

art and music. Angela/Angelo was placed on disability status due to the psychiatric diagnoses and medications. Ultimately, a new psychiatrist decided that the psychiatric diagnoses and medications were incorrect. Angela/Angelo successfully weaned off of psychiatric medications through personal tapering and using Narcotics Anonymous recovery methods.

Overall, Angela's/Angelo's interaction with the medical community in youth and adulthood involved 19 surgeries and countless hospitalizations for a variety of medical needs. The experiences were traumatic. Angela/Angelo experienced examinations by unnecessary personnel. Angela's/Angelo's genitals were touched without medical justification. Angela's/Angelo's genitals were overmanipulated to the point of arousal. Medical personnel made inappropriate comments such as "I wish I had one."

Twice, Angela/Angelo was partially paralyzed and could not provide her/his own personal care when in the hospital, so she/he went without cleansing. Angelo reported that the poor care Angela/Angelo received in hospitals was due to lack of willingness in caregivers to touch Angela's/Angelo's genitals. Angelo stated that improper hygiene created negative synergy. Unclean genitals created smell resulting in less care from nurses. Angelo attributed Angela's/Angelo's inability to get a proper bed bath in the hospitals to transphobia and intersex phobia.

Angela/Angelo experienced intense family gender policing and abuse around her/his androgynous gender expression. Significant family attention was paid to gender lines that could not be crossed. Angela/Angelo felt shamed by her/his sister's ongoing efforts to feminize her/his body through clothes and make up.



Angela/Angelo was abused physically and emotionally by her/his father. Angelo recalled that Angela's/Angelo's father "went for the head." Her/his father blamed Angela/Angelo for family problems due to not accepting her/his girl birth assignment. Tax time was especially stressful. Yearly, Angela/Angelo was blamed for bringing the family to the brink of bankruptcy due to her/his high medical and psychiatric expenses and hospitalizations. At night, Angela/Angelo practiced how to escape her/his home in case the father did try to murder her/him and the rest of the family as he promised to do. Angela's/Angelo's older sister committed suicide at age 11 years following one of the father's abusive rages she received.

Growing up, Angela/Angelo was confused as to why she/he was treated so harshly. She/he had to learn that being a boy was off limits because her/his phalloslit was not of a certain size and gender was supposedly "all about the genitals." She/he also had to learn that man things were taboo for a girl. Angela/Angelo felt like life was about learning lessons as to where the gender lines were and then developing the skills to force fit into that framework. Later, in his 50s, emancipated Angelo realized that the social difficulty he experienced all of his life related to transphobia since he looked neither like a typical girl nor a typical boy.

Angelo reported profound social and psychological isolation in youth and being a social outcast in school. Angela's/Angelo's parents moved so that in grammar school, Angela/Angelo could walk home during lunch time since no one would play with her/him. Frequent hospitalizations in youth reinforced her/his feelings of abandonment.

By junior high school, Angela's/Angelo's body was sending new signals that she/he was not a typical girl. Angela/Angelo felt betrayed by "her" body since it did not

act like the female body described in sex education. For example, Angela/Angelo ejaculated in the quantity of a normal man. When Angela/Angelo saw the genitals of a typical female/girl for the first time, she/he realized that “real” girls look very undersized in comparison. The sense of shame and disconnect about how her/his body was supposed to behave as a girl and what it was actually doing was so confusing that Angela/Angelo imagined being an alien from another planet. Multiple times in her/his life, she/he came to the conclusion that she/he had to be an alien given how divergent her/his experience was from what was supposed to happen on planet Earth.

Angela/Angelo dated a first boyfriend for 6 years. The relationship ended with a rape, a severe beating, and a court case. Angela’s/Angelo’s first boyfriend had always turned her/him around during sex to avoid looking at his genitals. Angela/Angelo increasingly felt frustrated with the boyfriend for his prioritizing his sexual pleasure at the expense of Angela’s/Angelo’s. Angela/Angelo asked the boyfriend to focus on Angela’s/Angelo’s genitals instead of hiding them by turning her/him around. Angela/Angelo told the boyfriend that she/he wanted a “blow job” and to be sexed like a man. Angela/Angelo recalled that the boyfriend flew into a fury, anally raped her/him, and beat her/him severely. Angelo described the situation as the boyfriend performing a homophobic “corrective rape” on her/him designed to “batter the gay out” and thereby prove to himself that he was not gay. In the court case, the boyfriend testified about Angela’s/Angelo’s genitals and her/his wanting to be sexed like a boy. The judge provided a mutual restraining order but did not find for the rape charge, leaving Angela/Angelo feeling invisible about the extreme trauma.

Until marriage, Angela/Angelo experienced heterosexual lovers as not knowing how to be good lovers and using Angela/Angelo only as a “cum receptacle.” Angelo reported that during dating Angela/Angelo was very inhibited and felt ashamed to be seen naked. Angelo called the trauma associated with being naked “genital exposure trauma.” Angelo attributed the trauma to objectifying medical exams and the first boyfriend’s disgust about Angelo’s enlarged organ. Until marriage, Angela/Angelo could not orgasm in the presence of a lover. Angela/Angelo felt shame about being a woman who ejaculated in a quantity comparable to an adult male.

In marriage, Angela/Angelo grew out of genital exposure trauma and fear of ejaculation. Angela/Angelo did so by insisting that her/his husband treat Angela’s/Angelo’s sex organ like that of a gay man. Furthermore, Angela/Angelo insisted that everyone’s needs be met. Angelo stated that Angela’s husband was not threatened by the request and regarded it as an adventure.

By 2014, Angela/Angelo was 46 and had been married as a woman to a man for 15 years. Angela/Angelo had given birth two times. Angela/Angelo had evolved into a beautiful woman under the effects of testosterone blockers and feminizing hormones, and relished the attention received. However, as previously noted, the effects of the feminizing medical treatments, in combination with Angela’s/Angelo’s mitochondrial disorder treatments, were making Angela/Angelo deathly ill.

The process of Angela’s/Angelo’s comprehending that feminizing and mitochondrial treatments were the cause of her/his health decline involved a graduated series of insights including new knowledge about phenomenon called trans and intersex. Angelo described ultimately having to break mentally with the binary-only framework

(BOF) that his family and physicians had been pursuing, namely female/woman/heterosexual. In hindsight, Angelo could see that his breaking the BOF involved a series of sequential steps. First, in 2014 through online relationships, Angela/Angelo learned for the first time that there was such a thing as “transitioning” in which people changed their birth assignment. Second, Angela/Angelo learned that Angela/Angelo did not exactly match this thing called “trans” because Angela/Angelo was not female or male typical. Third, Angela/Angelo learned that not all trans people want to have top and bottom surgeries. Some trans men keep their breasts and vagina just as some trans women keep their penises. This was encouraging as Angela/Angelo wanted to keep all of the female parts given their capacity for pleasure. Fourth, through the Internet, Angela/Angelo began learning about something called intersex. Angela/Angelo began to realize that she/he too had some intersex physical characteristics. As Angela/Angelo investigated more, she/he realized the whole truth. Angela/Angelo learned that she/he was an intersex person with two variations, CAH and polycystic ovaries. In other words, Angela/Angelo had two excess testosterone producing hormone variations that had virilized her/his genitals and reproductive system. The final realization came when Angela/Angelo discovered that even though most CAH 46,XX persons identify as girl, a small group of CAH individuals do identify as men. Some of them are gay, and some of them have given birth to children.

Angelo observed that the idea of a CAH man is controversial given that the CARES Foundation, the main support group for CAH, does not recognize the small group of CAH individuals who identify as men. Angelo believes that the reasons the foundation’s parent organization, CARES, does not recognize men are that CARES is

transphobic and in favor of clitoris reduction surgeries. Clitoris surgeries are disastrous for CAH men because if they transition from girl/woman to boy/men, they have actually received penis reduction surgeries, a very inconvenient truth for CARES to admit.

When Angela/Angelo fully realized that she/he was an intersex person, she/he encountered a landslide of new knowledge that shattered Angelo's/Angela's previous binary-only framework. Angela/Angelo learned that Angela's/Angelo's psychological and medical experiences had been similar to those of other intersex people. Many intersex individuals had their various intersex characteristics treated as independent disorders without ever hearing unifying and nonpathologizing terms like intersex or natural bodily variation.

Angelo stated that the net effect of being described as having a disorder of sex development rather than described as having an intersex variation meant existence in a pathologizing framework. Disorders require fixes. In contrast, intersex has a history of activist people who labor against hormonal or surgically "fixing" alterations with their affirming understanding that sex biology exists along a continuum.

A new intersex-positive framework developed in Angela/Angelo in place of the old BOF. A supportive community helped establish the positive framework. Angelo explained that, with support from an embracing intersex community, intersex children can be raised with emotional support instead of being altered through hormones and surgeries. Profound isolation need not be the intersex experience.

Angelo describes himself now as having the gender of man, a nonconforming intersex body (i.e., visibly different from typical male or female), being gay in

orientation, and androgynous in expression. Angelo stated that as he is a man, all of his body parts are man parts. His man parts include penis, breasts, uterus, and vagina.

Angelo reported that Angela/Angelo had internalized transphobia at the time of transitioning. When it became clear that transitioning would help Angela's/Angelo's health, Angela/Angelo initially resisted doing so for it would result in a relabeling of self and husband as gay. In other words, Angela/Angelo experienced internal disturbance at the time of the transition.

Angelo reported that despite reassurance from his husband, he still has trouble seeing his own genitals as desirable due to society's rejection. He nevertheless reported having an active and versatile sex life as a "transitioned"/emancipated man. Angelo stated that he and his husband each engage in activities commonly understood to be both woman and man enjoyments, sometimes as frequently as three times per day. He described their love making as hermaphroditic sex. Angelo reported an ability to orgasm in three ways: phallic, anal, and vaginal. He expressed relief that he escaped infant genital surgeries as all of his sensation remains intact. He hypothesized that he may have been protected as a consequence of his parents' Catholicism as Catholicism is against sex assignment surgeries. As an adult, Angelo has consistently refused any genital surgery to avoid any loss of sensation. He expressed survivor guilt because so many of his intersex associates are not so fortunate.

Angelo reported developing strong sensitivity to labels over the years. He wishes he had been allowed to select his own labels because the ones that were given harmed him. The false labels included all the psychiatric labels, lesbian (because he was a boy), and patient noncompliant. Angelo reported realizing that his past labels provided a

window into intersex phobia, homophobia, and transphobia. Angelo was misdiagnosed with labels such as cyclic bipolar with hypomania, dissociative personality disorder, and borderline personality disorder. He stated that these diagnoses were bogus and that a new psychiatrist disputed all of them. Angelo has been free from 14 pills of psychotropic drugs per day since 2000 and reported that he will never go back to a psychiatrist again. The only psychiatric label that was valid was complex posttraumatic stress. The heartache of labeling aside, Angelo still needed medical support. Angelo was frustrated by his ongoing difficulty finding medical doctors. The problem was particularly difficult when he had to find cooperative clinicians in order to transition.

Angelo credited his ability to be a stage artist to the faking/lying that he learned in order to defend himself from the medical and mental health professional communities. Among the many untruths Angela/Angelo learned to tell to be safe was the lie that she/he was a female/girl/heterosexual. Doing so was required to avoid electric shock treatment and get out of the hospitals.

Angelo expressed deep hurt and anger about all the loss he experienced as a result of being treated as an abnormal disorder to be “fixed.” He stated that growing up had involved utter erasure of his emotional needs. He termed his social, medical, and mental health treatment experiences variously as “emotional castration,” “psychic mutilation,” and “eugenics.” Angelo learned from another activist that he had been forced by society to engage in “gender performance.” That concept really helped Angelo process his loss.

Angelo felt grief at not knowing how physically masculine he could have been without all the feminizing hormones he was given from puberty until his 40s. For example, he will never know his true height, foot size, hand size, facial structure, genital

size, or genital appearance. He was also sad that he would never know his full beard as Angela/Angelo plucked her/his facial hair for years to appear female.

Angelo is still angry at his father for the abuse, scapegoating, treating him as mentally ill, and denying his existence as a gay boy who wanted his vagina and uterus. Angelo feels angry at society for coming up with the notion that sex is binary only. He feels robbed by parents, physicians, and the mental health communities who reinforced the BOF. Angelo is tremendously angry that years of psychiatric medications robbed him of his exceptional artistic gifts, his potential for college life, and a career. He reported ongoing issues with brain damage from the psychiatric drugs. Angelo feels especially robbed by Money and all those who invented the notion of binary-only sex for their role in creating gender conversion therapy. Angelo wishes for restitution but knows none will be forthcoming because intersex people are not yet protected.

Looking back now, Angelo described the oppression he experienced as more than rejection. His very existence was denied and then exterminated. Angelo felt exterminated under the BOF as the framework did not acknowledge the existence of intersex bodies, only “disorders” of male or female. Social forces implementing the BOF tried to exterminate Angelo by medical treatments (hormones) and by mental health treatments (psychiatric drugs, talk therapy, and hospitalizations). He spent decades of his life being exterminated by social, medical, and mental health treatments designed to ensure that he remained female (not intersex), girl (not boy), and heterosexual (not gay). Angelo wishes that instead of all the “fixing” and exterminating treatments, his parents had just used the money to send him to the Julliard School of Music.



## **Intersex Experiences of Activist Mitt**

### ***Overview***

Mitt's story involved the least medical "fixing." Mitt did, however, receive severe psychological "fixing" treatment related to his intersex variation at the sex development clinic of one of Money's primary collaborators, psychologist Anke Ehrhardt. Mitt's story did not involve transition. He grew up as boy and later developed as a gay man.

### ***Mitt's Biology***

Mitt described being undifferentiated and "right in between" male and female. He reported having a small penis and not having differentiated gonads (no ovaries or testicles). He said it made no sense to talk about whether he had a "big clit" or a "small penis" because it is all the same thing at his undifferentiated level of sex development. He reported always being "way too small" in stature. Mitt has never had a full medical workup but reported that three chromosome tests produced different findings. One test stated 46,XY karyotype and two stated 46,XX karyotype.

### ***Mitt's Physical Health***

Mitt reported that he escaped surgery in part because when he was born in the 1950s, babies were not yet given anesthesia. Mitt's childhood physical health was relatively normal until it took a decline at puberty. His friends were maturing, but he looked 10 at age 14. Mitt felt like he was getting sicker, weaker, and shrinking. He developed anemia, osteopenia, immune system collapse, and connective tissue disorders. He constantly injured his joints and bled. He reported being very underweight.

Mitt was placed on HRT at age 15 years and he has been on it ever since. With HRT, he had normal sexual development. He reported being late but having normal sexual feelings in common with other teen boys. He developed "every 5 minutes" libido

and nocturnal emissions, though without great quantities of liquid. Mitt has a small penis that functions like a typical male phallus. He also reported discovering he had a vagina during his 40s, but it closed over not long after his discovery. Both features, his phallus and his vagina, provided sexual satisfaction.

### ***Mitt's Psychological Health***

At his birth, Mitt's parents were told to provide him with a gender-neutral name and wait to see which gender emerged. His parents were also told that when he reached puberty, they might have to find treatment for him because his body might not make sufficient hormones. Mitt reported that his gender as boy was clear by age 3 years and it remained stable throughout his life. He stated that everyone always saw him as a boy.

Mitt was not curious about his physical difference at first. He had two endosex (typical male) younger brothers and thought they were the odd ones for looking like Dad already. His mother had been a premed student and never lied about anything related to Mitt's body. When Mitt was 4 years old, she told him that he would need to adopt children since he did not have testicles. Mitt was not shamed at that time, only horrified at the thought that some children did not have parents. Mitt determined to adopt, which he later did.

Mitt felt empowered by his father and grandmother. His grandmother told him that only a few people are awake in this life and that he was one of them. From what his grandmother said and from his unique body, Mitt thought he might indeed be an empowered alien. Mitt told the neighborhood kids that he was a superhero from another planet and he could prove it. He dropped his pants. His friends were amazed by his small penis and no testicles, so they believed him.

Mitt's family had hidden family secrets. He reported that "every type of queer" was on his mother's side of the family. His mother, though straight, had been perceived in adolescence by others as a lesbian. His mother's side were nonobservant Jews. Both of those socially shunned factors apparently oriented his mother toward not speaking the truth about the family's background even among themselves for fear of death (for being Jewish) or being locked up in an insane asylum (for being gay).

Mitt's parents responded differently to his bodily difference. His mother turned his care over to his father. Mitt reported extreme family friction and scapegoating. He said his parents fought about him and it was awful.

Mitt's father thought he was wonderful and unique. His father was extremely protective of him. His father would not tolerate bullying. Every year, Mitt's father went to school and let the new teacher know that he would hold that teacher accountable if any bullying occurred. Mitt's father taught him how to disrobe and make his way around in the locker room without revealing his genitals. Mitt reported that there was not a single thing that he could not discuss with his father. He stated that his father believed his son could be happy just the same as anyone else. His father already knew a happy couple where one of the partners had an intersex variation.

Early in life, Mitt knew he was gay, and the fact was celebrated by Mitt, his father, and Mitt's robust gay social network in high school. Mitt was popular at school because the school catered to the art and LGBTQ+ groups. As a gay boy among gay boys, Mitt never suffered due to failing to fit in socially.

At puberty, Mitt was not developing and was increasingly ill. His parents received two referrals, one to a "Money style" sex development clinic (optimum gender of

rearing/concealment model) and the other to an endocrinologist. Mitt's mother chose the sex development clinic first, and Mitt was treated there for over a year. The clinic was run by Anke Ehrhardt, a primary collaborator with Money. Even though Mitt was physically sick, Ehrhardt never had medical tests performed. Instead, Mitt was given 6 months of psychological testing and analysis. He stated that the goal was to determine whether his brain was more masculine or feminine. He believed Ehrhardt was trying to decide which half (male or female) was more dominant (binary model conceptualization) in order to recommend surgery accordingly. Mitt stated that the testing and therapy failed since he experiences his intersex self as not dividable; his female and male selves are intertwined.

Mitt said that his not having a clear dominant side made Ehrhardt mad at the family as supposedly only males or female existed. Mitt said that the few times his mother was alone with Ehrhardt, she came out of the room hysterical and near suicidal, crying that "They always blame the mother." Thereafter, Mitt's father would not let Mitt's mother be alone with Ehrhardt.

Mitt said that Ehrhardt told him the clinic intended to cut all of the penises off the children who were born with "too small" penises and tell them that they were female. Children were supposedly all blank slates, so if the parents lied well enough, the gender assigned would become reality. Mitt explained that Ehrhardt wanted to do a hypospadias repair instead of removing his penis because he was too old for the lies about being a girl to work. Mitt observed that people now know that Money's theory and therapy never worked.

Mitt recalled the traumatizing last meeting at Ehrhardt's clinic. In front of Mitt, his mother, and his father, Ehrhardt stated that in this society there is room only for males and females and Mitt was "nothing." Mitt reported being 14 years old and completely devastated by being literally told by his treating psychologist that "he was nothing." Mitt stated that Ehrhardt went on to outline that if his parents would not agree to hypospadias surgery, they would have to leave since the clinic could not allow Mitt to grow up to be a man because supposedly real men must stand to urinate. Mitt reported that his father bellowed at Ehrhardt that she had no idea what made a man or a woman and she was not going to touch Mitt or play guinea pig with his son any longer. Mitt reported suicidal ideation following the experience of Ehrhardt telling him he was nothing.

Though Mitt's failure to physically thrive had been the original reason for going to the clinic, no medical workups had been performed during that time. Mitt stated that only as the family was leaving down the hall did Ehrhardt finally address anything medically useful. Ehrhardt called after them to have Mitt tested to see if his sweat was salty. By the question, Mitt later realized that Ehrhardt had suspected but not verified that Mitt had the intersex variation CAH, which sometimes involves very dangerous wasting of bodily salt. Salt wasting must be supported by ongoing hormonal treatment.

Mitt's father sent him to the second referral, the endocrinologist. The physician was kind, patient, and ran many medical tests. The doctor said that from what he could tell, Mitt could be a girl or a boy and asked Mitt who he wanted to be. In other words, the physician gave Mitt the right of his own self-determination. As Mitt knew he was a boy, the endocrinologist put Mitt on male-oriented HRT, which he has been on ever since. The inclination to kill himself dissolved with male-affirming hormone treatment.

Mitt reported that his father is why he “made it” and his mother is why he almost did not. There was never nurturing by his mother, only rejection. His mother’s verbal abuse was profound. For example, when Mitt told his mother that a televangelist just said God loved him, Mitt’s mother told Mitt to go back to God because there was no room on earth for him.

Mitt’s mother’s verbal abuse became worse after puberty. After Mitt grew out of youthful androgyny, his mother became hostile about his gay orientation. She called all of Mitt’s friends and told them to stay away from Mitt because he was a sexual freak. Mitt reported absorbing the notion that he was a freak. His experiences in college, however, convinced him he could succeed, and his success countered suicidal inclinations. There was no family sexual or physical abuse.

Mitt attributed a significant portion of his mother’s disturbances to guilt that surfaced after she interacted with Ehrhardt. He reported that his mother absorbed Ehrhardt’s concept of mother guilt because she already had gender issues for appearing lesbian. Mitt observed that intersex parents in general tend to falsely assume they control their children’s sexual orientation outcomes. He recalled hearing other intersex parents say, “What are we going to raise this child as?” This statement demonstrates to Mitt an embedded false assumption that how a parent raises the child will be decisive about gender or orientation.

Mitt reported a very active sex life that began with early curiosity. He wanted to know everything about male and female anatomy. Though Mitt knew he was gay, he experimented with women to see if he could satisfy them too. By 18 years of age, Mitt had learned that he could make both men and women orgasm. Ehrhardt had told Mitt that

if he could not make love missionary style, he was not a man. Mitt learned he could make women feel great in other ways by repeatedly asking them what felt good.

Mitt went to college and met a woman who became his best friend. He married her because she was kicked out of her house. Mitt and his wife believed that they could make marriage work because they had sex together and they thought that made them bisexual. The relationship devolved without romantic or sexual attraction. In other words, the relationship dissolved because of orientation incompatibility, not due to Mitt's intersex characteristics.

Mitt reported a 12-year abusive second marriage to a deeply Christian man. He stated that his husband was never able to fully accept himself as gay and took it out on Mitt with verbal and physical abuse. The couple raised two disabled children together.

Mitt's Christian husband was conflicted about wanting extramarital experiences, and so the two partners went to a counselor. The counselor proved to be a remarkable counselor, a gay sex therapist, who learned everything he could about intersex and supported Mitt for 12 years. The counselor helped undo the years of shame, fear, secrecy, and lies that Mitt had experienced as an intersex person. Mitt had internalized shame for being intersex and assumed that, if he publicly revealed himself as intersex, he would be stoned or murdered. Mitt only revealed himself as intersex at the last minute with new lovers. He did not even tell his physicians that he had an intersex variation. The counselor encouraged Mitt to go to a nudist camp to get over his genital shame. At the camp, Mitt discovered he was desired as exotic and met the love of his life. Mitt had 15 wonderful years before his third husband died of illness.

Looking back on his life, Mitt said that the process of coming out gay in high school was like the *Wizard of Oz*, moving out of a black-and-white world to one that turned colorful. There was so much gay sexual opportunity and so little time. By contrast, coming out in his middle age as intersex was a dark experience. The first intersex people Mitt met were the ISNA activists, many of whom seemed mutilated beyond repair and rabid with fantasies of vengeance on the genital anatomy of their surgeons. Mitt was grief stricken for them because his anatomy was intact, and he had a great sex life. Mitt was further upset that physicians were not responding with compassion to the wounded activists. Physicians and surgeons were justifying themselves by saying that intersex people would be much worse off without surgical “fixing.”

Mitt believed that Ehrhardt’s approach was diabolical. Ehrhardt did not address Mitt’s obvious physical illness for the entire year Mitt was at the clinic. Instead, Ehrhardt tried to sell him and his parents on surgeries to make his body conform to a male appearance. Mitt expressed being grateful that his parents refused the surgeries as hypospadias surgeries are now known to be failures that leave men as “hypospadias cripples” with scarring and pain.

Mitt described himself as happily promiscuous. He reported having had more sex than most people he knew and that he orgasmed with every man. Mitt instructed them by telling them that he liked everything they liked, and what he had was just in miniature. Mitt stated that his sex experiences were clearly gay. In other words, to his partners he looked, smelled, and acted like a man.

Mitt reported knowing that he would never have some love-making experiences. Conversely, he had wonderful experiences due to his own unique anatomy. For example,



Mitt is happy he never lost his erection ability with age, nor felt embarrassment because an erection tented his clothes, nor had testicles that sweat, smelled, and hurt when he ran, nor had anything drip or ooze.

Mitt now believes that the fears intersex people have been taught are overblown. Society is not ready with pitchforks to murder at an intersex birth. Most people are not paying attention to the next bathroom stall. Mitt believes that parents are brainwashed into believing that atrocities will happen if they do not consent to surgeries by the surgeons who want to make money from the work.

Mitt reflected that people may not be hard-wired for gender, but they are not blank slates either. The proper approach is to help children grow into who they say they are. Mitt stated that Money's approach was sick and twisted. Only intersex children are treated with such diabolical treatments to change who they are without addressing their real health needs.

Physicians and surgeons are wrong about everything. Money and Ehrhardt were con artists with surgeries to sell. Physicians do not have the ability to make boys or girls. Physicians only have the power to create terror, shame, isolation, and feelings of being a freak and an alien. Physicians deliver "horseshit" with the notion that intersex people will be confused and not know who they are without surgeries.

Intersex people do not have to have forced gender assignments with surgeries and hormones to live a full life. Mitt found meaning as an activist by framing himself as the exception to the medical argument that surgery is better than leaving intersex people alone. Mitt feels he is far better off for having been left "unfixed."

Over time, Mitt developed the perspective that his physical difference was not so abnormal after all. After attending a gay men’s therapy group that included men who had “up to 8 inches,” Mitt realized that all men have penis size issues. Every single man in the group said his penis was too small, and yet not one said he would refuse another man for having a penis that is “too small” or even knew what “too small” meant. Through study of science, Mitt developed full understanding that an intersex person is not a freak of nature to be exterminated. Intersex variations are simply part of the natural and beautiful diversity of life.

### **Intersex Experiences of Activist Marsha**

#### ***Overview***

Marsha’s story involves nonconsensual surgical feminization to “normalize” her body at puberty as female. The feminization involved removing a body part, namely testes, that supposedly did not align with Marsha’s identity as a girl/woman. Neither Marsha nor her family had any idea that they were consenting to removal of her testes. The surgeon lied and said the surgery was a hysterectomy intended prevent cancer. Marsha did not discover the lie or that she had 46,XY chromosomes until she obtained her medical records in her 40s. As an outcome of the surgery, healthy gonad removal meant sterility and a life on HRT. As an unintended consequence of the cancer lie, Marsha developed posttraumatic stress (PTS) over the potential that she might develop cancer.

#### ***Marsha’s Biology***

Marsha’s external appearance at birth was female typical. Marsha had no sense of having anything other than a female typical body until her period did not start by age 15

years. As an adult, Marsha's body also appears female typical with the exception of no pubic hair.

Medical investigation at puberty revealed that Marsha had a smaller than normal vagina. Her surgeon told her that she needed hysterectomy surgery for a rare, precancerous disease and that she would be infertile after surgery. Marsha and her parents consented to the surgery, but what they thought they were consenting to was not what happened. There was no hysterectomy since Marsha did not have female reproductive parts. Instead, the surgeon removed healthy testes.

Marsha was told another lie that her cancer disease was so rare that there was only one other in another country. (In fact, complete androgen insensitivity syndrome [CAIS] is one of the more common intersex variations.) The lie was to keep Marsha from learning the truth. If Marsha knew she had XY chromosomes and had testes at one time, supposedly she would not be able to think of herself as a woman. Marsha reported that in the 1980s it was common for surgeons to intentionally withhold specific information about intersex variations. The secrecy and lies she experienced were an outcome of Money's work in which children with secure gender adjustment were not told the truth of having so-called "opposite sex" chromosomes and gonads. Marsha learned only in her 40s that she possessed the intersex variation now known as CAIS. She did not know until then that she had been born with male typical chromosomes and testes. She did not hear the word intersex until decades after her testes were removed.

### ***Marsha's Physical Health***

Marsha's testes removal surgery occurred between her sophomore and junior year of high school. The physician recommended a second surgery to enlarge her vagina for

penetrative sex, but her parents did not think that was necessary and refused. Marsha is grateful for never having had the “horrific” surgery, especially since her vagina resized on its own through her sexual activity.

After her healthy testes were removed, Marsha needed HRT for life because the so called “sex hormones” of estrogen and testosterone are vital for health needs in general, not just sex development. Marsha was prescribed estrogen in the form of birth control pills and reported being on female hormones of one type or another since then. Later, through support from the AIS-DSD support group, Marsha learned that she had other options besides pills and switched to a transdermal patch.

Marsha received mixed messages about the importance of her “hysterectomy.” The procedure seemed important as Marsha’s family provided a private room for her in the hospital and hormone pills were required every day. On the other hand, Marsha was told not to pay attention to what had happened as “others have it so much worse.” Marsha stated that the effect of her parents thwarting any discussion was to leave the experience unprocessed.

Marsha had a variety of experiences that left her feeling like an oddity. Her surgeon wanted her to use a plastic test tube as a makeshift dildo to stretch her vagina for her future partners. The request left her feeling dirty, so she did not comply. So many physicians coming into the room to examine her also made her feel uncomfortable. During medical examinations, she would put on headphones to tune out residents at the teaching hospital. Marsha reported no self-harm, suicides, psychiatric hospitalizations, or addictions. She did not obtain counseling until her parents’ divorce, which happened a few years before she learned of her intersex variation.

In her 40s, Marsha felt symptoms in her abdomen that triggered a PTS episode about cancer, the original diagnosis that was actually a lie. Marsha's primary care physician noticed that her emotional reaction did not seem proportionate to her relatively mild abdominal symptoms and suggested ordering her past records for more information. Marsha realized later that the primary care physician probably knew all along that Marsha had an intersex variation. The oncologist had referred Marsha to that primary care physician, so Marsha's intersex surgery records probably followed her to the primary care doctor.

The primary care physician left Marsha's medical records on her desk and left Marsha to read her records on her own. Marsha read the older term for CAIS, male pseudohermaphrodite testicular feminization. She realized she and her family had been lied to and an organ had been removed without her consent.

Marsha received positive counseling support when she discovered the truth. She was already in counseling, so she added the new issue to the ongoing trusted relationship she had with her therapist. Marsha feels angry about the removal of her healthy testes. She feels robbed because without the benefit of her own hormones, a life with HRT resulted in lowered sex drive and struggles with weight and moods. Marsha also struggles with uncertainty about HRT's effects. How much of her feelings and mood swings have been artificial due to the HRT and could have been avoided with her own testes is not something she will ever know.

Since then, Marsha has received medical care only from a primary care physician as there are not many doctors who understand intersex hormonal needs. She receives her HRT prescription from her primary care physician. Without the reproductive organs of a

typical female, Marsha reported not needing female internal care from a gynecologist, but she follows regular mammogram care protocol. She reported uncertainty approaching the average age for menopause for she wonders when she should scale down HRT. She stated that there are no best intersex health practices because the research does not exist regarding how to take care of intersex medical needs.

Marsha reported being a different kind of patient than she used to be. She is no longer the compliant girl of the past. She is skeptical and does not like medical intervention. She feels empowered by the knowledge that physicians are human and not all are good.

### ***Marsha's Psychological Health***

Marsha reported mainly positive experiences in her family of origin. Her family was "well off," White, Anglo-Saxon, and Protestant. The family was not communicative, especially about feelings. Her family was loving to a point, but not physically demonstrative. Every physical need "was addressed and more was provided."

Marsha reported no abuse of any sort, only emotional neglect. She noted that the emotional neglect around intersex processing was not noticeably different than the family's overall pattern of low communication regarding emotions. Marsha was a more successful student than her sister, so she received preferential treatment in the family and no scapegoating.

Regarding gender identity, Marsha described the common (but not universal) CAIS situation in which the gender identity of girl/woman persists throughout the lifespan. She always knew she was a girl. In other words, contrary to the reason surgeons have hidden information from CAIS patients, her learning that she had XY chromosomes

and internal testes at one time never altered her gender identity as a woman. She reported always having the heteronormative pattern of female, gender girl/woman, and heterosexual orientation. She never received feminine gender coaching. She never felt oppression for her gender or orientation.

Marsha reported no problems developing friendships. She developed, nevertheless, an underlying feeling of not really fitting in with either women or men. For example, if her girlfriends asked to borrow tampons, she felt estranged. She also reported feeling shame as a “freak” due to having a rare disease, not having a period, being recommended for a vaginoplasty, and being told to use dildos to stretch her vagina.

Marsha described dating as normal. As she did not know she had an intersex variation, disclosing that information to a partner was not an issue. Dating disclosure did involve telling partners of infertility due to her supposed hysterectomy. She was sexually active in high school but later realized that she disassociated to some degree with intimacy.

Marsha’s heterosexual marriage has been good, with ups and downs. She realized over time that she had difficulties with communicating and feeling comfortable with her body. She observed an absurdity, albeit a dangerous legal one. She and her husband are completely heterosexual, however, in a state that banned gay marriage and based its determination of sex on chromosomes, hers would be considered a gay marriage.

Marsha reported long-lasting impact of the cancer lie. She developed a preoccupation with the idea that she would develop cancer. For years, Marsha’s yearly checkups were in the cancer wing and she had to walk through the cancer ward to get to her appointments. She developed PTS triggers of bodily sensations, intense emotions, and

contacts with medical personnel. She reported no memory of some of the most intense emotional experiences of her life, such as being proposed to or the adoption of her children. Her PTS produced blackouts at those times.

The day that Marsha learned what had happened to her, she went home and went on the Internet to learn more about her variation. In 2007, the information was still limited; the term intersex was not yet used. Marsha was able to locate information under the terms AIS and testicular feminization. She also located an AIS-DSD support group.

About 6 months after Marsha learned the truth, there was a conference of AIS people. She described the experience of connecting with similar others as life changing. Marsha said her adjustment to her intersex variation dates to that time, but it remains an ongoing process. When she gained access to her medical records and finally met other intersex people, she realized she was not alone or “a freak.” Remarkably, Marsha reported that she no longer experiences blackouts after the date she discovered her intersex variation and went online to learn more about it.

Marsha felt profoundly invalidated by her family when the truth came out about the nonconsensual surgery. Her family minimized her experience by saying that the nonconsensual surgery and the lies did not matter as Marsha was still the same person. Marsha wanted her family to act with fury. In time, her family understood her emotional need for their validation of her anger.

Marsha reported having the perspective that, while there is no contest regarding human suffering, she believes she had a relatively easier intersex experience than others. She observed that the intersex “trans” experience seemed much worse. Always feeling like a girl and being treated like one was very different from the “trans” intersex



experience. Marsha realized that she had not had to go through gender conversion training to act like a girl. Furthermore, she had one surgery to remove testes, not multiple ones to sculpt her genitals to appear like a girl.

Marsha attempted to receive an apology from the hospital. She wrote a letter documenting the harm that came from the hospital's keeping her true diagnosis from her and removing her testes under the cover of a cancer threat. She asked to know that the hospital no longer had the policy of hiding the truth. The hospital responded dismissively.

Marsha stated that she still feels emotionally stunted. When someone asks her what she is feeling, she struggles. She wonders about the unknowable, namely had she been better off not knowing during her teen years that she had XY chromosomes and testes. She recognizes that she was not impacted by the burden of knowing she was a girl with male parts during teen years. Nevertheless, Marsha reported that she allows herself to give that thought only fleeting attention. She knows without doubt the painful, long-term damage that the cancer lie did to her. Her damage from the cancer lie taught her how important truth is to mental health. Marsha concluded that the preferable approach would have been age-appropriate disclosure with psychosocial support. Marsha observed that unfortunately affirming intersex counseling was not around in the 1980s.

## **Intersex Experiences of Activist Val/Valerie**

### ***Overview***

Val's/Valerie's personal pronouns are herm/herms/herms. In other words, Val/Valerie uses herm (for the same speech function as she or he), herms (for the same speech function as her or his), and herms (for the same speech function as hers or his). The personal pronouns were coined by Val/Valerie as a portmanteau of her and him. (The pronouns are not intended as an appropriation of the term hermaphrodite.) Val's/Valerie's

story involves failed, nonconsensual surgical masculinization beginning in infancy to normalize herms body as male. The surgeries did not work. Val/Valerie spent years in pain due to failed penis surgeries. In herms 40s, after another episode of a clogged urethra due to the failed surgeries, herm went to the famous trans physician, Marcia Bowers, for another repair. The damage was so pervasive that Bowers performed emergency castration of Val's/Valerie's small penis to save herms life. Except for the last one, none of Val's/Valerie's masculinizing surgeries were medically necessary. All of the surgical "fixing" was implemented for a social reason, namely standing to urinate as a masculine style. As an unintended consequence of the social surgeries, Val/Valerie developed PTS in response to stimuli involving medical staff and medical procedures. Val/Valerie represents an example of intersex "trans" experience. Herm lived most of herms life trying to be only a boy and now lives life gender fluid, as both man and woman.

### ***Val's/Valerie's Biology***

Val/Valerie was born with partial androgen insensitivity syndrome (PAIS), 46,XY karyotype, which resulted in atypical genitals visible at birth. The atypicality included hypospadias in a middle stage between male and female. Val/Valerie elaborated that herm hypospadias location of the urethra is right below herms penis head. Val/Valerie believes there may be an iatrogenic link to herm intersex biology for herm mother took an estrogen drug, diethylstilbestrol (DES), during pregnancy to prevent miscarriages. In addition to hypospadias, Val/Valerie was born with the bottom half of a vagina and two streak gonads (gonad tissue improperly formed and functionless). After herms last surgery, herm woke up to find herms penis was amputated. Val/Valerie now has two

vaginas. One vagina is behind the other, separated by a longitudinal membrane. The longer neovagina is 10 cm with normal access and a two-finger width. Herms natural vagina is 5 cm long. Val/Valerie reported being short and having small hands and feet. Herm also reported 38B-sized breasts, no body hair, no beard or mustache, osteopenia, and androgenic alopecia.

### ***Val's/Valerie's Physical Health***

Even though most U.S. birth certificates state M for male or F for female, Val's/Valerie's birth certificate states X. Val/Valerie was given a girl's name, Valerie. Herms first hypospadias repair surgery was performed when herm was 8 months old. The surgery goal was to relocate the metes of the urethra (i.e., a hypospadias repair). At that point, herm was given a boy's name, Val. Thirteen more surgeries followed that involved closing the existing urethra hole on the penis shaft, rerouting a new pathway to the penis tip, and harvesting skin from other parts of herms body for the tissue needed for the urine pathway. Val/Valerie endured pain and scarring at all of the sites, namely at the locations of skin grafts and the locations on and in herms penis.

The first surgery was unnecessary to address any health need. The purpose was purely social; namely, to make urine exit in a socially acceptable fashion that allows a man to urinate from a standing instead of a sitting position. A seated urinating position was deemed "unmanly" enough by surgeons to warrant the surgeries. As mentioned, the process was repeated 13 more times for the same purpose throughout Val/Valerie's life. All 14 surgeries failed. The newly created pathway would dry up and the original opening would reappear.

The net effect of the 14 surgeries was that Val's/Valerie's penis was so "clogged up" that herm could not eliminate without having to "roto-rooter" herms self. Herm could not afford medical equipment to self-catheterize. Given the necessity to find an affordable substitute, Val/Valerie used coffee stirrer plastic straws or a tool used for self-dilatation of distal urethral strictures found at a Fetish Fair Fleamarket conference.

Val/Valerie's own measures as self-catheterization were not always successful, which necessitated emergency hospital treatments to unblock the urine. Val/Valerie knew that too long of a delay after an unrelieved blockage meant herms kidneys would shut down and death would follow. Hospital staff, however, often did not understand the problem or how to cope with the medical emergency. Herm would be given the instruction by medical staff to go to the bathroom to relieve herms self as if herm had not already performed extraordinary methods to do so. Val/Valerie reached a point where herm could no longer tolerate the pain and trauma of daily self-catheterization. Herm elected in 2005, at 47 years of age, to amputate herms penis.

Val/Valerie reported that herms experience is not unique. Herm attended a 2019 hypospadias conference and had discussions with 20+ men who had as many as 40 surgeries related to the "manly" social purpose of standing to urinate. Val/Valerie stated that surgeries are continuing for the physicians' financial gain. In terms of the quality of the surgeries, herm reported that they are not much better than decades ago.

Val/Valerie went through a short period of unsuccessful hormonal therapy to reduce some feminization that began in puberty. At 12 or 13 years of age, herm was taken to an endocrinologist for testosterone treatments to thwart herms natural feminizing (e.g., breast development) and promote masculinization. The treatment did not last longer than

3 or 4 months. By virtue of Val/Valerie's variation of PAIS, (a variation involving a testosterone absorption problem not a testosterone production one) herms body was not able to absorb the normal level of testosterone it was already producing, much less the higher amount administered by the physician. The undesired effect of adding more testosterone to an already normal level was iatrogenic harm as the testosterone converted in the opposite direction to feminizing estrogen and began causing organ failure. To repair the iatrogenic effects, Val/Valerie was given a diuretic for months to rid herms body of the harmful testosterone prescription.

Now in late middle age, Val/Valerie reported taking small amounts of estrogen, calcium, and vitamin D3 and performing weight-bearing exercises to address bone thinning (osteopenia). Herm reported that ongoing hormonal management for hypospadias is not required but hormonal management is required for other aspects of PAIS such as bone thinning. Herm stated that if persons with either CAIS or PAIS are not given some female hormones beginning at puberty, they will develop osteoporosis as young as age 14 years.

### ***Val's/Valerie's Psychological Health***

As mentioned, after 8 months and herms first hypospadias surgery, herm was renamed Val and raised as a boy. Val/Valerie remained Val until the time of herms castration at age 47 years. Without a penis, Val/Valerie decided to revert to using Valerie on some legal documents. (Activist travel frequently. Carrying a legal document that said herm was a male but herms having no penis might cause problems related to air travel security.)

Val's/Valerie's parents were both abusive and loving. The abuse involved being very strict that gender expression must be only boyish. Anything feminine was punished by beatings with a belt. Cross-dressing clothes were destroyed or thrown out.

Val/Valerie's parents wanted herm "to man up" and "fight like a man." Herm was taught some self-defense techniques.

Val/Valerie's parents' physical abuse of herm was severe. Herm was beaten with a belt as often as every other week. The forbidden nature of feminine expression actually increased Val's/Valerie's desire to engage in cross dressing. Herm traveled miles to go to a new mall to dress as a girl for a few hours in order to express the unacceptable part of herms self for an hour or two.

Val/Valerie never felt like a girl trapped in a boy's body (i.e., endosex trans person) or like a heterosexual boy who liked to dress as a girl (i.e., cross dresser). Herm always felt both boy and girl. In herms youngest years, herm thought this duality was normal and that herm was a dual representation of both herms mother and father. Herm had seen herms parents naked. Val/Valerie assumed herm was like herms father in that he had a "stick" too and that herm was like herms mother in that she had a "channel" too.

Peer relationships were very painful. Val/Valerie was bullied and beaten for expressing herms "girl side." Herm endured peer beatings so severe that bones were broken. Val/Valerie believes that the peer beatings occurred because of herms effeminate appearance and behavior.

Val's/Valerie's only sibling, a brother, was not viewed as ever having been close or supportive after herm came out. More recently, herms brother seems to understand that Val/Valerie was not trying to be a "sissy pants" when they were younger. Val/Valerie

speculated that the slight improvement in the sibling relationship may be due to herms recent notoriety as an activist.

Val/Valerie described pervasive feelings of loneliness. In youth, Val/Valerie saw herms self as a kind of Christopher Robin going out into the woods alone to feel safe from family and peers. Val/Valerie tried to drown out the pain with beer, so some memories remain fuzzy.

Val/Valerie reported that there was a great deal of secrecy in herms life. Herm did not learn for a long time that for 8 months in infancy herm had been assigned girl. Herm reported that shame and secrecy are big issues for the intersex community. For Val/Valerie, the shame and secrecy commenced around seventh grade.

Val/Valerie stated that “doctors were there to harm, not help.” Surgeons harmed by performing 14 surgeries when none were needed. No benefit whatsoever came out of the surgeries. Herm described feeling shamed and humiliated for being a “freak show” for medical personnel. Herm was traumatized by the 14 surgeries on herms penis, and herm developed PTS. Val/Valerie reported feeling the need to fight surgeons for herms life. Val/Valerie remembered in vivid detail being 10 years old and fighting the medical personnel so hard that four people had to hold herms down in order to administer anesthesia.

Val’s/Valerie’s grades were average as herm found it hard to focus on schoolwork. Herm worried about peers during the day and parents at night. Gym was a significant concern since the curriculum varied between boys and girls, Val/Valerie was effeminate, and the dressing rooms were communal. The issues were sidestepped by not letting Val/Valerie participate in gym. Family life got better after herm moved out for as

some things could then be talked about. Intersex was never discussed as it was always a taboo subject.

Val/Valerie obviously knew herms penis was being operated on with the surgeries. Val/Valerie, however, did not know the name for herms rare condition until middle school. Val/Valerie read a note from home designed to excuse herms from gym. The note read “testicular feminization.” Val/Valerie observed that testicular feminization is an older term that has been replaced by partial androgen insensitivity, a biologically more accurate term. Val/Valerie’s body produced adequate testosterone, but herms receptors were not the right shape to receive all of the testosterone. The term “partial” means that some of the testosterone is able to be absorbed. If Val’s/Valerie’s testosterone insensitivity had been complete, as it is in individuals with CAIS, herms genitals would have been female typical.

Until adulthood, Val/Valerie had no summary awareness that herms surgical experiences were related to having an intersex variation. The closest description to intersex that herm knew about was hermaphrodite. Val/Valerie learned the hermaphrodite term around age 16 years. More recently as an adult, Val/Valerie researched and found more than 45 conditions related to atypical genitals. Herm reported now using the term intersex expansively to apply to them all. Herm stated that there is an ongoing controversy related to whether herms variation of hypospadias should be labeled an intersex variation.

In high school, Val/Valerie dated a few times. Herm would not let the relationships involve genital touching for fear of what would happen if the woman saw



herms “freak show.” Val/Valerie’s celibacy ended one relationship because herm would not take it further with the young lady.

At age 22 years, Val’s/Valerie’s friends decided that herm needed to lose herms virginity, and they paid for “a hooker.” The woman assumed that Val/Valerie’s severely scarred penis meant that herm engaged in self-mutilation kink. The hooker defensively said she did not do anything kinky. The comment was not intended as an insult but nevertheless shamed Val/Valerie about herms genitals.

Val/Valerie was married twice. On the second date with herms first future wife, herm said to the woman that she would notice that herms genitals were girl-like. Herms future wife was fine with that. Val/Valerie reported that the first marriage ended 15 years later as a consequence of herms coming out as an intersex person and beginning activism. Herms activism was highly public and influential. Herm was one of the leaders in the founding of Intersex Awareness Day in 2002. When Val/Valerie began giving lectures to help people understand intersex, the public responded positively but began to consider herms as only Valerie, a woman. Val’s/Valerie’s wife could not handle being perceived as a lesbian because she was having sex with “someone born with a vagina.” The wife’s parents pushed her to abandon the relationship, and she divorced Val/Valerie.

Val’s/Valerie’s second marriage, to a male-to-female bisexual transwoman, was very happy. The marriage remained solid after herms penis amputation. The marriage ended after 7 years when Val’s/Valerie’s wife died of brain cancer in 2012.

Regarding Val’s/Valerie’s sex life in marriage, herm reported that herms first wife’s only complaint was wanting more. Herms bisexual second wife liked all of herms body parts, male and female. Val/Valerie reported that they “did it every which way you

can think of' and had a "lot of good sex" up until the time of herms castration. Herm now believes that herms orgasm was destroyed from the amputation, though herm continues experimenting.

Val/Valerie reported that most intersex people remain in gender alignment with their birth assignment. In contrast, herm described two gender transitions. The first was at was at 8 months of age. The transition was from girl to boy. At that time, herm was named Val. The second transition occurred at age 47 after herms castration. At that time, Val/Valerie changed herms legal documents from Val back to Valerie.

Val/Valerie described having grown up in an internal battle, being told by friends and other intersex people to pick man or woman gender and stay with it. Despite enormous efforts, picking one did not work. Herm reported living day to day now with a fluid gender identity and not trying to control it. In Val's/Valerie's mind, as opposed to on legal documents, herm is not exclusively a woman but rather both a man and woman. Which one surfaces depends on the day.

Val/Valerie reported that "trans" as a self-descriptor makes sense but herms "trans" experience was not like endosex trans people who are born with a typical male or female body. Herm stated that herms "trans" experience pertained to having had many sex operations. First, herm had 14 hypospadias surgeries to align herms as a male, and then herm had penis amputation surgery to align herms as female. Now, Val/Valerie's passport's female designation does not agree with herms birth certificate X designation but does agree with herms designation F on herms driver's license. Herm reported currently working with state and federal legislation to allow X on state driver licenses and federal passports.

Val/Valerie stated herm was traumatized by the outcome of herms penis surgeries. Prior to castration, herm used to be able to achieve orgasm, though achieving it had been tricky given the negative impact to sensation from all of the surgeries. Val/Valerie stated without reservation that surgeons are the ones who destroyed herms orgasm.

Val/Valerie reported that the surgeons created a monstrosity surgically. Herm named herms penis Frank, after *Frankenstein*. Herm thought that the name was apt as herms penis looked “chopped up” with “scars all over his head.” Herms penis had “bits and pieces from different people put together to make a whole body.”

Val/Valerie reported developing PTS as a result of herms childhood medical treatment. Though Val/Valerie can go into hospitals to support others, herm reported that the situation has to be life and death to seek personal medical treatment. When Val/Valerie does have to be treated, herm experiences flashbacks of yelling and screaming in a fight for herms life. Herm remains traumatized by the memory of herms parents dragging herms into the car for the surgeries. Even as a child, herm knew that medical care was happening backwards compared to what was supposed to be happening. Herm went into the hospital feeling fine but left in pain.

Val/Valerie reported several other aspects of medical harm in connection with herms PTS. Herm was humiliated by medical photography during puberty. Herm was also shamed by being paraded around naked for physicians even though herms genitals had no bearing on the issue of hospitalization for pneumonia or a broken bone. Herm stated that patient abandonment has not been an issue; rather, the problem is that physicians do what they want to do and do not listen. Herm described being harmed by not being told the truth about herms body or what surgeons were going to do to it.

Surgeons lied by saying herm was deformed and needed to be fixed. Herm stated that peeing from a hole in an atypical place without surgery would have worked out fine.

Val/Valerie reported total obstruction from hospital administration designed to prevent herms from gaining access to herms medical records. Herm has no records from the first 20 years of herms life even though herm had been treated at a major medical hospital. Several attempts at obtaining the records were unsuccessful. The hospital's final explanation was that the records had been destroyed. Val/Valerie reported that hospitals destroy intersex records to keep themselves from being sued.

Val/Valerie attempted suicide two times. The first time was after herms parents discovered that herm, at age 15 years, had cross dressed in a bikini borrowed from a friend. When herms father and mother learned of it, the beating was one of the worst. The yellow bikini was cut up. Val/Valerie later climbed a 25-ft tree and purposely dropped. Herm reported being so relaxed at the idea of dying that when herm regained consciousness, there was no injury or pain. Val's/Valerie's parents thought herm fell accidentally, and herm did not tell the truth in order to avoid "the psych ward." The second suicide attempt at age 40 years was a passive response to appendicitis. Val/Valerie tried to delay treatment so as to die, but a coworker insisted on herms getting treatment. Val/Valerie reported no addictions but had used drinking in herms youth to drown out the ongoing internal gender war when forced to be only a man.

Val/Valerie did not have a psychiatric hospital experience. Herm described having two childhood experiences with counselors. Childhood counselors tried to "brainwash" herms into being a boy. From the questions, Val/Valerie knew that the counselor assumed that herms girl behaviors were optional; in other words, chosen ones.

Counselors had queried why herms liked being a girl. Herm replied that it was not about “liking” being a girl, it was something that “just comes with the territory.”

In recent history, Val/Valerie employed a counselor to help with anxiety and depression. Anxiety and depression arose in response to the increase in trans hate and trans murders under the Trump political administration. The harsh political climate triggered herms memories of childhood bullying and physical abuse.

Val/Valerie reported working at a hospital and sometimes being more effective there than the treating psychiatrists due to herms skill at gender switching. Herm described being particularly effective with people with gender dysphoria. Herm is able to provide specific resources such as a support group, where to go for hormones, and how to work with clothes and makeup. Herm is also able to cut through the “bullshit” of some of the people in treatment.

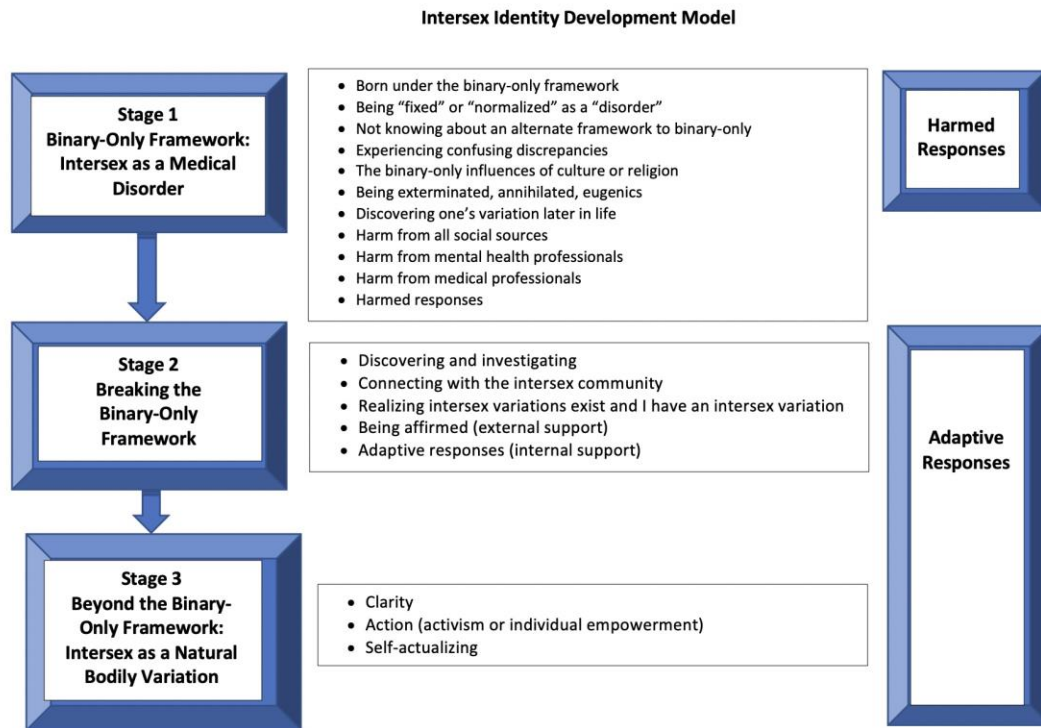
Val/Valerie reported that good things go along with having an intersex variation. Benefits include being able to pass as woman or a man, skill in acting, and a greater effectiveness at with people. A few years ago, Val/Valerie performed the same way that Julie Andrews performed in *Victor/Victoria*.

### **Introduction to the Intersex Identity Development Model**

The intersex identity development model (Figure 1) organizes the activists’ biographical material into themes and then the themes into the model’s highest level of three social contexts: Stage 1. Beyond the binary-only framework: intersex as a medical disorder, Stage 2. Breaking the binary-only framework, and Stage 3. Beyond the binary-only framework: intersex as a natural bodily variation. Following the graphic, Table 4 shows the themes organized under the three stages or contexts. The stages and themes are subsequently discussed in detail with representative quotes from the participants.

**Figure 1**

*Intersex Identity Development Model*



**Table 4**

*Intersex Identity Development Model Stages and Themes*

---

**Stage 1. Binary-only framework: Intersex as a medical disorder**

---

- Born under the binary-only framework
- Being “fixed” or “normalized” as a “disorder”
- Not knowing about an alternate framework to binary-only
- Experiencing confusing discrepancies
- The binary-only influences of culture or religion
- Not allowed to exist: exterminated, annihilated, eugenics
- Discovering one’s variation later in life
- Harm from all social sources
  - Abuse: physical, verbal, and sexual
  - Force-fitting: body and behavior
  - Toxic labeling
  - Family rejection and scapegoating
  - Isolated, secrecy, lies, and stigma
  - Pity
- Harm from mental health professionals
  - Psychiatric false diagnoses and drugs
  - Gender brainwashing
  - Erasure through invisibility
  - World Professional Association for Transgender Health (WPATH) standards misapplied
- Harm from medical professionals
  - Medically induced “trans”
  - Surgically erasing intersex
  - Hormonally erasing intersex
  - Loss of their natural intersex body
  - Robbed of normal quality of life
  - Lies and/or secrecy
  - Objectified as a medical “thing”
  - Neglected or unaddressed medical needs
  - Iatrogenic harm
- Harmed responses
  - Shame internalized: Sex related phobias
  - Emotional castration, psychic mutilation
  - Freak, monster, alien
  - Genital exposure trauma
  - Fear of doctors
  - Survivor guilt
  - Other emotional disturbances

---

## Stage 2. Breaking the binary-only framework

---

- Discovering and investigating
- Connecting with the intersex community
- Realizing intersex exists and I have an intersex variation
- Being affirmed (external support)
  - Support from intersex people
  - Support from close family and friends
  - Positive counseling
- Adaptive responses (internal support)
  - Self as superhero or powerful alien
  - Defensive faking or lying
  - Ending secrecy, accessing medical records
  - Self-soothing: Self-protection, self-care, humor, spirituality

---

## Stage 3. Beyond the binary-only framework: Intersex as a natural bodily variation

---

- Clarity
  - Sex and gender are on continuums
  - Money's model was a devastating error
  - Gender, chromosomes and genitals do not always align
  - Self-determination of gender and body is the goal
  - Terminology matters: "disorder" harms
  - Core LGBTQ+ variance: intersex medical harm
  - Intersex unique medical needs are not binary
  - Intersex people are not all infertile
  - Some intersex men give birth
  - Many intersex people are heterosexually oriented
  - 2006 Chicago Consensus did not stop infant sex surgeries
  - No happy silent majority with infant surgeries
  - Surgical results are dissatisfactory
  - Informed consent process is dissatisfactory
  - Infant surgeries create, not prevent stigma
  - Intersex people have great sex without surgeries
  - Automatic gonad removal harms
  - Infant anesthesia harms
  - Controversy: biology only and/or identity?
  - Controversy: "Delay is okay" versus "No body is shameful"
  - Controversy: Medical treatment: misguided or diabolical?
  - Controversy: Are intersex birth certificates important?



---

### **Stage 3. Beyond the binary-only framework: Intersex as a natural bodily variation**

---

- Action: activism or individual empowerment
    - Motivations and need
    - Prior conditions
    - Activities
    - Vision
    - Activist infighting
    - Intersex community subgroups
      - Variation groups
        - Variation group Mayer–Rokitansky–Küster–Hauser (MRKH) syndrome
        - Variation group congenital adrenal hyperplasia (CAH)
        - Variation group hypospadias/epispadias
      - Intersex heterosexual and LGBTQ+ groups
      - Intersex and race, religion, and/or other intersectionalities
      - Intersex police
      - Other intersex subgroups
    - Activist hardships
    - Activism changes over time
    - Activism responses
    - Activism successes
    - Future in activism
  - Self-actualizing
- 

#### **Intersex Identity Development Model Stage 1. The Binary-Only Framework: Intersex as a Medical Disorder**

All of the study participants reported growing up under an overarching false framework of reality, the BOF, in which all that exists is male/man/heterosexual and female/woman/heterosexual. Anything outside the framework is a “disorder” that requires medicalized intervention. Intersex people are disorders to be “fixed” or “normalized.”

All of the participants agreed that heteronormative binary is a myth and/or a lie. Sex is much more complex than what the tidy heteronormative binary represents as truth. Mitt stated, “We are not complicated, but we are complex. This isn’t nature or nurture,

that was a fallacy, it's another [false] binary. It's another either/or, it's another black or white when the whole universe is AND."

Many of the activists used the term "lie" to describe their original reality of the BOF. Each grew up in a particularized manifestation of the false framework given their particular intersex variations. Angelo's lie was that there was no such thing as a gestational father (i.e., father who gave birth). Mitt's lie was that if he disclosed to others that he was intersex, he would be killed because intersex equals "monster." Marsha's lies were explicit and implicit. The explicit lie was that she needed a hysterectomy (rather than have her testes removed) for a supposedly high cancer risk. The implicit lie was that real woman only have body parts that align as female. Val/Valerie's lie was that "real men" cannot sit to urinate so herm needed to have surgeries to "fix" herms penis so herms urine would exit at the tip like a proper man.

### **Born Under the Binary-Only Framework**

Three participants referenced John Money by name for his role in the BOF-based medical protocol that he promoted through his optimum gender of rearing model. Psychologist Money is viewed by the activists as a primary source of intersex medicalized harm. They referenced Money's protocol as the dark historical time that initiated the surgical and hormonal enforcement of the BOF on intersex people. Marsha referenced the model prior to 2006 as "a very medicalized model that assumes that a lot of intervention is necessary." As previously noted, the model is sometimes referred to as the concealment model. Another slang term for Money's model is the genitals make gender model. The activists all reported that Money's gender theory remained influential even though it was discredited. Money's theory led to surgically removing small penises and assigning the children as girls. His famous alleged success, the John/Joan twin case,

involving amputating a penis following a botched circumcision and assigning the infant a girl. Joan (David) in the Joan/John twin case, turned out to be maladjusted, and both David and his twin committed suicide.

Regarding Money's theory that genitals and gonads should surgically align with assigned gender for psychosocial adjustment of the child's assigned gender, Mitt said, That assumption is . . . not based on science, it wasn't based on evidence. It wasn't based on observation, he just pulled that out of his ass and called it a law like gravity. As a result, he has been proven wrong . . . People had faith in his assessment, and they acted as if it was real. They destroyed two generations of intersex people.

Angelo recalled the impact of the Money protocol that began in the late 1950s and early 1960s:

The surgeries didn't really happen until the late 50s . . . you are now a mental disorder, a circus sideshow freak, institutionalized, put in psychiatric hospitals, institutions, insane asylums, lobotomies, electric shock. Then they started messing with hormones . . . sometimes coercively, sometimes as a treatment. It mattered where you were [as surgeons and hospitals varied]. It became a nightmare.

Money's discredited theory was that gender could be trained provided that the child was not confused by having genitals that looked out of alignment with the assigned gender. As Angelo recalled,

John Money was it. He was the one that was the expert on gender identity, and he treated it as if everybody's born with a blank slate. If you happen to have a kid like me [intersex], you [supposedly] could literally teach the gender. And as we

know with the Reimer twins, that plan blew up in its face. It blew up in their face with me and thousands of others. You obviously can't teach that [gender]. You are it and it's a matter of being given the voice to be able to share who you truly are with acceptance, otherwise you're going to be shamed.

Money's theory involved lies and secrecy. As Mitt said,

[Money's model was to] lie to them and tell them that they were female and that we're all a blank slate. And so, if the parents lied well enough or if you [the doctor] lied to the parents well enough, everybody'd believe it and it would become reality. That's where they were, it's wrong, we now know that this is dead wrong, it doesn't work, it never works.

Money was a psychologist. As a result, the intersex community has associated the community of mental health professionals with harm. As Mitt said,

John Money was the biggest con man of human sexuality who ever lived. He wasn't, he wasn't a medical doctor, he was only a psychologist . . . [he] lied about everything. They [Money and his associates] had no business making any of the claims that they made.

### **Being “Fixed” or “Normalized” as a “Disorder”**

Under Money (the BOF), whatever did not fit male/man/heterosexual and female/woman/heterosexual was labeled in a way that assumed pathology. Pathology, in turn, conferred on medical and mental health professionals the presumed right to intervene to “fix” the pathology. As previously discussed, the official medical term for intersex as pathology is sex development disorder. Angelo described the medical hegemony over intersex bodies:

They're trying to normalize the bad that they're doing to you without realizing they're doing harm. So, if you're being treated like a pathology or a disorder or a diagnosis, they're there to "fix it," be it your parents, doctors, psychologists, counselors, teachers. Anybody that's brought in your path is there to make it so that we're not going to discuss this or talk about this. We're going to try to normalize the situation . . . anything that makes you stand apart is a part of this disorder.

### **Not Knowing About an Alternate Framework to Binary-Only**

Not knowing that there was anything other than the binary-only framework was a striking theme. The realization that they had not known was something that became apparent later in life. Participants talked about going from not knowing to a subsequent experience of realizing that they were not "disordered" after all. At its most fundamental level, the participants' "not knowing" pertained to being unaware of an alternative to the necessity of erasing their very existence. Angelo described battling counselors for his very existence as a gay boy who wanted to give birth:

I did not even know that I could exist [as a gestational father] so that makes it even worse. I didn't even realize I could exist until 2014. And when I started seeing [similar intersex] people exist, and like, wait a minute, what load of shit have I been fed?

Not having an alternate framework served to normalize the treatments being received. Therefore, activists did not realize that there was a less pathologizing way to think about all the things that were "wrong" about their individual bodies. As Angelo said, "Intersex really wasn't a word until the 1990s. It wasn't a word I used until 2014. I

was a ‘disorder of sex development’.” Angelo recalled what it was like living without having an alternate framework and being treated as a disorder:

If we don’t call it intersex, then we don’t have to look at reality that’s out there.

We can continue this myth of only typical people being allowed to exist . . . They didn’t call it an intersex variation, so you don’t even know you are intersex. I

guess in many ways, I would not even have known some of the reasons why I was being treated so differently.

Not knowing sometimes pertained to participants growing up without realizing that their physical differences from “normal” were related to having an intersex variation. Not knowing also arose in context of being confused about why they were getting so much attention on their genitals in medical contexts. Angelo said,

You become almost habituated in a medical situation to [your genitals] getting a lot of attention. And because it’s done in a socially acceptable manner, you’re not thinking: “Oh my god these people are crossing the line.” It wouldn’t be until I was 15 years old that I even knew what a typical woman looked like. So, I’m not even realizing why, really why, I am getting so much attention.

Not knowing also related to not even being aware of being physically different until discrepancies showed up at puberty. (See the theme of discovering one’s intersex variation later in life). Marsha recalled,

In my case I didn’t know I had an intersex variation until I was 41, so growing up I didn’t even realize my body was different until puberty. At that point my friends started getting their periods. My girlfriends started getting their periods and going through what you’d expect puberty to be.

## **Experiencing Confusing Discrepancies**

As the BOF failed to explain the factual reality of intersex bodies (and actually intentionally denied them), factual discrepancies began to pile up. The study participants all struggled to make sense of the confusing discrepancies. As Angelo described, one discrepancy related to how his body functioned as compared to those of typical males or females:

During adolescence . . . my body started to develop with higher testosterone, I mean I'm [supposedly a female and I'm] experiencing wet dreams, I'm experiencing ejaculation, I'm experiencing my first period, and I'm being told I'm a girl. And yet in sex education class I'm learning that boys do these things [ejaculate]. You want to talk about body shaming! Even a typical boy is afraid to tell their mom that they messed the sheets.

Another discrepancy related to how the body is supposed to experience sexual satisfaction. Angelo said, "It's very confusing because it's not like you have a typical penis . . . but you know you [erroneously assigned as girl] have given blow jobs and you know you would like one too." Confusing discrepancy may also be related to unexplained social rules. Angelo recalled,

It was around that time when my own curiosity of human bodies became very real. It's like: What's going on here? Why am I being excluded from gym with the other girls? Why are they protecting me without defining why?"

Intersex people, in other words, people different from typical males and female, are in fact real. Their experiences can be very different from typical males and females, physically and psychologically. When intersex people are forced into male/man and female/girl boxes, confusing discrepancies pile up.

### **The Binary-Only Influences of Culture or Religion**

The influences of culture and religion played a role in all of the participants as they lived with their intersex variation and processed the meaning of having been born with an intersex variation. Angelo cited the ethnic influence of *machismo* in his harsh personal treatments. He believes that his father was bound to very strong expectations for male and female roles that traced to the family's Spanish heritage. Furthermore, Angelo feels that his father's military background played a role in strict enforcement of gender lines and extreme measures of suppression of any rebellion. Angelo sees a positive influence of Catholicism in that surgeries were not conducted in infancy. He reported that not performing infant surgeries is in keeping with the church's teachings.

Val/Valerie sees the influence of Catholicism in her family in her harsh treatment for gender role transgression. In her case, however, Catholicism did not prevent genital surgeries in infancy and beyond. Marsha sees the influence in her life of Anglo-Saxon Protestant culture in which feelings were not discussed. Mitt sees his Jewish heritage as fostering the belief that he had to hide the fact of his intersex variation or he would be persecuted by the townspeople.

### **Not Allowed to Exist: Exterminated, Annihilated, Eugenics**

The most striking finding in this study was the quantity of terminology and conceptualization that referenced annihilation of intersex people as a result of the BOF. In first instance, the annihilation was definitional as the BOF framework does not recognize unique intersex bodies, only pathological exceptions to male and female bodies. The enforcement of the BOF's exceptions as disorders to be "fixed," however, was very real, very physical, and not just definitional. Erasure, annihilation, and eugenics



were experienced physically through surgeries, hormone treatments, and behavioral training. Mitt summarized the annihilation:

According to cisgender, heterosexual society, I should not exist. It's more than social rejection, it's complete annihilation . . . The medical paradigm cuts up, amputates, and disappears the queer body so they can ignore the rest of our queer selves and pretend that we're actually no different than anyone else when we are totally different from anyone else. They have just completely annihilated us, we actually get annihilated in one way, shape, or form.

Money's theory that caused the erasure/annihilation/extermination was distributed to hospitals throughout the United States. Mitt was treated by Ehrhardt, one of Money's main associates. He recalled an encounter with her:

[Ehrhardt, the psychologist] said [in front of Mitt and Mitt's mother and father], "In this society we have room for males and females . . . We do not have room for anything else, we have room for nothing else. And in your physical state you are nothing." I was 14 years old and [Ehrhardt, a psychologist literally] told me I "was nothing." I'm quoting. I'll never forget it. "You are nothing."

Even though Money was discredited for both his theory and not his retracting his theory when he learned it was causing harm, his practices took root in medical practice. Marsha said,

The surgeries, the interventions, the lack of real informed consent, the pressure to do medically unnecessary interventions, to do cosmetic surgeries, to impose these binary notions of body or to erase the intersex traits: It's still happening regularly.

Two of the four activists, one “trans” intersex and one unaltered intersex, stated that the annihilation amounted to eugenics. Angelo said, “This has been eugenics and genocide, and complete and total utter erasure.” Mitt said,

We . . . have a medical paradigm that is financially and professionally developed, and dependent upon what is essentially a eugenic operation of perfecting human beings through better living through chemistry, better living through surgery . . . but they don’t deliver that. They deliver agony, physical disability, and mental illness.

Angelo noted that intersex eugenics is insidious because it is not as explicit as holocaust eugenics. He explained,

It’s not explicit . . . It’s not like these people are just outright going, oh my god jeez, we need to just line them up like they did in Hitler’s days and just outright kill them, but you [as an intersex person] know you’re not allowed to exist outside of that [BOF] box. This is what’s proper, this is what’s accepted, this is how the world should be, and this is your treatment . . . and we’re going to convince your parents that you’re in the wrong body until they do it [consent to intersex surgeries].

### **Discovering One’s Variation Later in Life**

Some but not all intersex individuals are unaware of their variation until sometime later in life. The phase in life in which these individuals think they are typical male or female can be called preawareness. When they learn of their variation, they compare their prior self-concept with their new self-concept having an intersex variation. Preves (2003) cited feelings of deep shame and a sense of monstrosity at a realization later in life that

that when the intersex person was an infant, adults had to surgically alter them in order to behold them because they (the infants) were thought to be so awful.

How does this happen? There are several reasons. Some traits are not evidenced until puberty. Marsha was an example of this experience. Marsha did not know there was anything about her that was atypical from “normal” female until puberty. Another situation may occur when the person pursues a completely different medical issue and finds out through a blood test that their chromosomes are other than 46,XX or 46,XY.

Another situation has occurred when the individuals are lied to, told they are “normal,” and then discover later that they have an intersex variation. Marsha was told she needed a hysterectomy because of a cancer risk. She was not aware until her 40s that she had an intersex variation. In the later instance of being deceived, the individual will process not only having an intersex variation but also what it meant to be lied to by one or more authority figures (e.g., parents and/or medical professionals). When she discovered that she had been lied to, Marsha felt anger, betrayal, and robbed of self-determination. Hopefully, medical lying about the fact of an intersex variation was eliminated under the 2006 Chicago consensus protocol.

Intersex preawareness experiences stand in contrast with other intersex experiences in which genitalia differences are apparent early. Generally speaking, intersex people with visible genitalia differences are aware that something is different near or at earliest memories. Angelo and Mitt were immediately confronted as very young children with confusing discrepancies between their bodies and the norms.

### **Harm From All Social Sources**

As each of the intersex activists did not fit the BOF, they were subjected to efforts to enforce it. I categorized the sources of the harm into three major groups: general,

mental health professionals, and medical professionals. General harm broadly includes the harm that came from all sources, including family, school, romantic or sexual relationships, as well as professional mental health and medical providers.

The harm is unprecedented. Mitt stated, “You don’t do this to anyone else on earth. How dare you [society] suggest that this [medical and psychological treatments to reinforce the BOF] could work on us! You have no evidence!”

All parts of the intersex person are scrutinized for faults according to the BOF. Proper body part alignment must be maintained with only the “right” parts for male or female. Secondary characteristics are targeted through hormone treatment. Gender identity, behavior, and sexual orientation are targeted through therapy and social restrictions.

The different sectors used their specific professional tools to force fit discrepancies back into the female/girl/heterosexual or male/boy/heterosexual boxes (e.g., surgeons used surgeries, psychiatrists used drugs, and so on). Angelo described the stressful force fitting:

All my life it’s been stress on me and my parents and doctors, even a stress on them, to shove me into that female box in every way, the girl box, the woman box . . . We do it this way with the hormones, we do it this way with the therapy at 3 and 4 to teach [me that I’m] a girl. We do it this way with the psychiatrists, or even my parents, it’s just this constant stress on me and on them to make sure that I abide to these rules that go with this [girl] box. In my case, it’s not just the way [I] dress and gender identity type issues. It’s all the way to [my] hormones, the way [I] look, with [my] bloodwork, the all of it.

And it's all about heteronormativity too, so anything outside of being a heterosexual is also frowned on. The psychiatric community, [I'm] going to be diagnosed with a mental illness and they're going to pull anything out of their hat to justify what [they] need to do to fix [me]. And it sometimes can even be medications that were prescribed to fix me, so it's not always just talk therapy.

In summary, the general harm that comes from all sectors involving "fixing" or "normalizing" is not only surgery. Talk therapy, psychiatric medications, hormone levels, dress, clothes and makeup are also involved. The harm is masqueraded as something beneficial.

***Abuse: Physical, Emotional, and Sexual***

Two participants reported physical abuse by parents and peers, three reported verbal abuse, and one reported sexual abuse. Angelo described an experience of homophobic "corrective rape" from a boyfriend who attacked following Angela's/Angelo's request for sexual acts that would be pleasing to a man. For effeminate behavior and atypical appearance, Val/Valerie described family and peer beatings so severe that bones were broken. The effects of verbal abuse were not less harmful than for physical or sexual abuse. Mitt was suicidal following parental verbal abuse. Mitt described extreme verbal abuse:

I turned on the television. There's Billy Graham saying, "God loves you just as you are." I turned off the television, marched into my mother's bedroom, and I said, "God loves me just as I am." She said, "Good, go to God. There's no place for you here on earth." I was in counseling for 12 years for that.

### ***Force Fitting: Body and Behavior***

The two activists who were misassigned gender at birth described being forced to fit into the BOF. Angelo said, “My dad was constantly policing that [gender] wall that I can’t cross. No, you’re a woman, you’re a girl.” All parts of society worked to reinforce birth assignment. Angelo continued,

Jabs, jabs, jabs, this reminder that you can’t cross that [birth assignment] wall to become a man . . . we are going to jab you every chance we can. And it comes from the psychiatric community, the counselors, your sisters, your mother-in-law, your parents, society.

Behavior, physical development and appearance had to conform to male/boy or female/girl. Two participants were sent to behavioral therapy to “force fit” their gender assignment. Medical doctors force fit through surgeries, hormonal treatments, and psychiatric treatments. Angelo said, “[Doctors] just kept on enforcing us [intersex people misassigned at birth] with hormones and testosterone blockers and psychotropic drugs.” Angelo emphasized that appearance had to conform even in the family:

[My sister] was always very anxious around my appearance and would in a very shaming older sister way teach me how to feminize myself better to comply to being a typical girl and not cross that line, again you’re not allowed to cross that line [and appear too mannish]. [I needed] to make myself a more passable, acceptable woman. And because of her I know how to do amazing makeup.

### ***Toxic Labeling***

The activists reported a negative impact of labels. Labels included, for example, labels of mental illness, the medical label of patient noncompliant, and misgendering.

Angelo referenced the mental illness labeling, “I was assigned [label] girl at birth and yet I was coming out their gay teenage son. They had no choice but to lock me up. It was society’s expectation that that’s what you do. This [was labeled] a mental illness.” He added,

Labels just suck, and we need them in order to get our human rights, we need them to find each other, we need them to get help, and to understand each other, but it also causes divide. It also causes holocausts and genocides.

### ***Family Rejection and Scapegoating***

Family rejection appeared to strongly impact emotional adjustment. The participants discussed family rejection more than peer rejection. Three participants reported harsh family treatment that strongly influenced emotional adjustment. Angelo said,

My parents were constantly needing me to be the disabled scapegoat so that they didn’t have to acknowledge their own problems with my existence. They could constantly just blame it on me. They didn’t have to face their own homophobia, their own intersex phobia, their own dysfunction. And obviously my dad had a lot of problems that had nothing to do with me. He didn’t ever have to face his addiction or his alcoholism because they could constantly put me in the light and point fingers at me.

Parents were not always unified in their scapegoating. One parent might be the only one rejecting the intersex child. Mitt recalled,

She [Mitt's mother] did not want me. I was allowed in on the other things that she was doing with the other two . . . And that's how she referred to them, as "the other two" . . . No, there was never nurturing, there was always rejection.

***Isolated, Secrecy, Lies, and Stigma***

All of the participants reported secrecy, isolation, lies and stigma related to being intersex. Angelo said,

The shame and secrecy that I learned to live with was profound, and like how can my body be deceiving me like this if I'm supposed to be a girl. So, you know you have no one. You're utterly alone and you don't even know that others exist like you because nobody's told you others exist like you.

The two participants who appeared or behaved differently from typical boy or girls reported profound isolation. Angelo said,

I could never make a friend. Girls didn't want to play with me, boys didn't want to play with me. So, my mother rescued me by having me come home for lunch. We literally moved to a house where I could walk home for lunch.

Medical professionals fostered the isolation, secrecy, lies, and stigma. Surgeons lied to keep patients in the dark and isolated. Marsha was lied to by a surgeon who said the only person like her was a person in another country when the reality of others having the same variation was actually much more common. Through gender conversion therapy, therapists tried to hide, isolate, and keep secret any evidence of genital difference in order to convince Angela/Angelo that she/he was really a girl instead of the boy he knew he was. Angelo recalled,



It was kept from me. Remember all the Barbie dolls, all the baby dolls, sex ed, every one of those things are erasing the clitoris. Shh, you don't talk about it . . . We're not going to talk about that we're not even going to show it, we're not going to even acknowledge its existence.

### ***Pity***

Pity is a harm intersex people feel from a variety of sources. The following is a critical point. The activists see themselves and other intersex people as different but not inferior, therefore, pity is not compassion. Pity is harming. Pity reflects a fundamentally insulting and annihilating implicit viewpoint. Angelo revealed how the damage from pity happens when intersex natural bodily variation is judged as inferior. He said,

Often times when I see a doctor or counselor—not just counselors, even people who I have educated, like a gay man for instance—they are really sad to find out I don't have a typical penis. They almost have this grief for me that's really uncalled for. I get the same sympathy and empathy from some counselors and doctors. You all do not understand.

### **Harm From Mental Health Professionals**

Mental health professionals are not the “good guys” in the history of intersex medicalized harm. Mental health professionals have provided false diagnoses, over prescribed addictive drugs, participated in gender conversion therapy, invalidated through ignorance, and provided a theory that justified surgeries. Standards for endosex transition have been misapplied to intersex “trans” persons who might want to keep both their male and female parts.

### ***Psychiatric False Diagnoses and Drugs***

Angela/Angelo was sent to psychiatric hospitals three times for claiming he was a boy. She/he was medicated with psychiatric drugs for years for her/his alleged mental illnesses. Angelo stated that the psychiatric labels and years of psychiatric drugs damaged his brain and robbed him of formidable creative talents in art and music. Angelo recalled the horror of that time:

He [the psychiatrist] was a drug dealer. I was on 14 pills a day. Lithium, antidepressants, sleeping pills, benzodiazepines, we're talking drug dealer. That was not a psychiatrist. That was somebody shutting me up. That was somebody silencing me . . . I became the "living dead." I became disabled and I was receiving disability at that time.

### ***Gender Brainwashing***

Two of the activists (who later transitioned) demonstrated atypical gender expression in their youth. They experienced "brainwashing" mental health treatments under the assumption that their nonbinary gender expressions were mental disturbance. The experience of not being honored for their real gender left the individuals feeling that they were not allowed to exist. Val/Valerie said, "[Counseling was] just trying to brainwash me into trying to be a boy kind of thing." Angelo described being forced to be a girl, "There was no other word than conversion therapy to describe it. You are taking a child who knows they are a boy and convincing them [for a time] with a year of therapy that they are a girl." Angelo described Angela's/Angelo's conversion therapy in more detail:

So, you're working with a counselor who is trying to reinforce what they feel it's in your best interest. You've been assigned a woman. [The counselors in effect say] this is how we counsel women; this is how we've been trained. And [the counseling is] not working very well because obviously I'm not a woman. I'm not a typical man, but I'm not a woman.

Gender brainwashing was not only in gender conversion clinics. BOF gender brainwashing occurred through counselors, psychologists, psychiatrists, and other medical professionals. Angelo recalled,

You're given a very clear message that if you do cross that line [birth assignment] you are mentally disturbed and you're as good as dead. So, you might as well just die. And this is coming from the medical complex, the psychiatric community, and the psychological community.

Angelo experienced Angela's/Angelo's gender brainwashing as not being allowed to exist.

You quickly find yourself in a psychiatric hospital as a person assigned female saying that they're a boy attracted to boys. You want to wear pretty things, you like lace, you like flamboyant pretty things. You're not supposed to exist.

The therapists failed to realize that atypical gender identity or atypical gender expression was not illness. It was possible evidence that the person may need to transition, as in the case of Angelo. It was also possible evidence that the person may benefit from support for their complex ability to gender switch fluidly as man or a woman, as in the case of Val/Valerie.

### *Erasure Through Invisibility*

All of the activists stated that counselors are uninformed about intersex issues. All fields related to mental health demonstrated the same deficiencies. Two participants laughed when they saw the hotline phone numbers on the consent form for this study. They commented that cold calling counselors is a waste as counselors do not understand the needs of intersex people. Marsha described the low availability of intersex trained counselors:

We are starting at such a baseline. There aren't enough counselors with knowledge or experience. I mean even the same thing with doctors, because they're not getting education, medical education around these issues from the physical standpoint. Mental health is similar.

The very few professional mental health professionals who were helpful were so because they were willing to be open and learn from their clients. Angelo stated,

I've had every experience that I can imagine . . . psychologists, counselors, psychiatrists, social workers, hospital settings . . . I would imagine over 20 . . . they had it all figured out they were going to fix me. So, between social workers, counselors, psychologists, psychiatrists, I have only known two that even came close to being helpful and that has been in the last 4 years. It's because they took the time to allow me to educate them so that they could be helpful.

### *WPATH Standards Misapplied*

Two participants discussed differences between intersex “trans” people and endosex trans people. A key difference is that, although both intersex “trans” people and trans people struggle with their medical support, intersex “trans” people often seek to

prevent unwanted sex surgeries and endosex trans often struggle to get access to sex surgeries. Endosex trans people either have the typical male or the typical female body. Intersex “trans” people have an intersex body.

Angelo, who is intersex “trans,” was negative about WPATH standards as applied to intersex people who might want to keep both “female” and “male” body parts:

I was given the same to-do list as a trans man. I was told that I needed top surgery, bottom surgery, I needed this hormone level, I needed to dress this way, act like this, I might need speech therapy to change my tone of my voice, I might need this, this, this. You’re literally given this to do list that is outlined by WPATH for your better good. This is the treatment for your “gender dysphoria.” So I was mortified, I’m being taught [differently] at that same time by [an intersex activist] that no physical body is shameful. I’m also [similarly] being taught by (name deleted), who is a trans man, that WPATH is not correct. I realized I want my vagina, I do not need a phalloplasty, I do not need my vagina removed, I like my vagina, I’m actually going to do some estrogen for my vagina. I uncovered a mess. I uncovered that the standards for care for transgender people were coercing them no differently than the [intersex] parents were being coerced with their kids.

Angelo expressed his dislike of the term gender dysphoria, used by WPATH, when applied to intersex people as it implies an internal issue instead of the real cause, namely physician error:

They are wanting to diagnose me with gender dysphoria. I’m like this is *your* problem. This has nothing to do with me [as you assigned me incorrectly]. This is society. This is an “invention of sex” that’s created this. This has nothing to do

with me; and how dare you try to diagnose this. How dare you try to even medicate it.

Angelo discussed how the language intersex “trans” people want to use may vary from endosex trans terms:

The language [of trans compared with intersex “trans”] is so different. When you talk about transgender people, you’re [they are] not saying “No Body is Shameful,” you’re [they are] saying you’re born in the wrong body. The transgender folks are saying, “I’m born in the wrong body.” The way I say it as an intersex advocate, I’m waving the flag “No Body is Shameful” . . . So, the language is very different. They’re saying boy parts, girl parts, and if you are wanting to be a girl, you need those parts and we’re going to surgically give you these fabricated parts. And here I am saying, “Wait a minute, I can exist without all that [alignment of parts by male or female] and I can still be a man . . . Every time they get the language wrong and it’s wrong about an intersex child, I truly believe that they are driving genital mutilation.

Angelo added that some intersex “trans” people may be adamant about not having surgeries that alter intersex bodies:

You don’t have to get on a surgery table. They’re [WPATH] are not talking about that. With the nonbinary movement, the WPATH is starting to dabble more with that (less emphasis on surgeries), thank goodness, but they still want to call intersex a disorder of sex development. They still want to stress needing to be fixed if you’re transgender or intersex. It’s just huge with WPATH and its greatly problematic. Because it drives that medical complex . . . even though they’re

doing harm, that's just the life of the surgeon, the transgender surgeon [to promote surgeries].

Insurance coverage is a backdrop to discussions about intersex medical treatments. Unwanted surgeries may be performed because there is insurance coverage. Insurance payment creates an incentive for the medical profession to conduct intersex treatments. Conversely, desired surgeries and other treatments may not be provided if insurance coverage is difficult to obtain. In other words, class privilege is a backdrop to discussions of insurance. Surgeries and other treatments are likely accessible only for those with the funds to pay privately or pay for the insurance to access them.

### **Harm From Medical Professionals**

The activists reported harm from medical professionals including medically induced “trans” (through wrong birth assignment), surgical harm, hormonal erasure, loss of their natural intersex body, being robbed of normal quality of life, lies and secrecy about variations and treatments, being objectified as a medical “thing,” neglected or unaddressed medical needs, and iatrogenic harm.

### ***Medically Induced “Trans”***

When physicians misassign the gender of an intersex person, it sets up the possible need for something akin to a trans experience. At some point the person may want to change gender in order to be who they really are. For example, Angela/Angelo was misassigned as a girl and later “transitioned” to man. Angelo liked to describe his transition experience as “emancipation” because of earlier misassignment.

Angelo was very careful not to call himself a trans person because his experience was not like that of an endosex trans person. Angelo is not binary (male or female

typical) like a typical trans person. Angelo does not believe he had gender dysphoria like an endosex trans person prior to transition.

The need to transition from one gender to another for an intersex person may happen for reason of physical health or social safety, not only for gender misassignment. Though Angelo was misassigned, the actual reason his “transition”/emancipation took place in his 40s was for his health. He could no longer physically tolerate feminizing treatments that kept him looking like a woman. He emancipated back to man due to needing to return to high levels of testosterone for his health. The visible masculinization that occurred with high levels of testosterone made living as a woman no longer viable (and likely even dangerous given transphobia). To allow for proper urinary drainage, Val/Valerie had his penis amputated. Herm transitioned to girl on legal documents after herms amputation of herms penis for having a girl document with no penis was considered unsafe.

### ***Surgically Erasing Intersex***

As described in Chapter 1, intersex people are subject to surgical efforts to reinforce the BOF. The activists reported genital mutilation and scarring, having to self-catheterize when the penis surgeries failed, loss of orgasm, and loss of natural hormone production capacity. Marsha, who had her gonads removed without her consent, reported that she is forced to take HRT for the rest of her life. Val/Valerie had surgery after surgery on herms penis until the pain and scarring were too much to bear and had herms penis amputated. (Not all intersex infant surgeries are harmful; in a few instances, intersex infants require life-saving surgical intervention.)



### ***Hormonally Erasing Intersex***

In addition to surgeries, the BOF is reinforced by hormones and hormone blockers. For example, Angelo/Angela was treated with estrogen and testosterone blockers to reinforce Angela/Angelo's body according to her/his (misassigned) gender as girl. Val/Valerie received testosterone for a time to counteract the feminizing (breast development) that was happening to herms when herms was assigned boy. Angelo described negative effects of the hormonal treatments:

You have to remember that hormonally they did that to me. And here I am . . . not even knowing if I'm ever going to be able to achieve an orgasm again, am I ever going to be able to trigger an orgasm again?

Not all hormonal treatments are harmful. Mitt needed hormone supplements for growth and bodily development at puberty. Angelo reported needing extra testosterone for adult health.

### ***Loss of Their Natural Intersex Body***

One activist expressed grief that years of hormonal treatments designed to reinforce her as girl erased the more masculine body he could have had. Another described grief that the failed surgeries on his/her penis resulted in need for amputation and loss of his/her natural orgasm capability. Yet another regretted the unnecessary removal of gonads that required ongoing HRT and its negative side effects of loss of libido, mood, and weight issues.

### ***Robbed of Normal Quality of Life***

All of the study participants expressed grief about how living under the BOF impacted their quality of life. Mitt developed a fearful preoccupation that he would be

killed if others knew he was intersex. Angelo lost artistic gifts due to brain damage from years on high levels of psychiatric medications. Marsha developed PTS about cancer due to the lie that her surgeon told her to shield her from knowledge of her intersex variation and internal testes. In other words, the lie surgeons told Marsha to protect her from distress due to having male chromosomes and testes backfired by creating a different kind of severe long-term distress that impacted her quality of life. Val/Valerie had to go to unusual and painful efforts to urinate.

### *Lies and/or Secrecy*

Two activists experienced hidden medical records. Val/Valerie never received access to medical records despite having had treatments at major medical institutions. Marsha received access to her medical records only in her 40s. Her records contained the lie that she “consented” though neither she nor her parents were told that the so called “necessary hysterectomy needed for cancer prevention” was actually removal of healthy testes.

### *Objectified As a Medical “Thing”*

Three participants described the shame and humiliation of being treated as an object of study. Angelo described inappropriate examinations:

When you are going in for irritable bowel and you’re going in for gas or cramping and diarrhea, there is no reason to be touching somebody’s phallosclitoris. There’s no reason to be doing certain things, and he was . . . One of his physician assistants examined my genitals and was so inappropriate. She said she wished she had one. I kid you not. Just like the GI doctor would not stop fondling [my

penis]. But by then as an adult, I'm 47 years old. I had learned to be flippant.

She's saying, "I wish I had one," and I said, "I bet you do."

Marsha described going into a dissociative state while teams of physicians in a teaching hospital examined her genitals. Val/Valerie described being a "freak show" for doctors and being made to stand naked against the wall for medical photography.

### *Neglected or Unaddressed Medical Needs*

The data in this study showed that the focus of BOF effort, namely to force fit intersex people into binary-only boxes, or alternatively force fit them into known intersex variation boxes, resulted in the real and complex needs of highly variable intersex people not receiving proper research and medical attention. Hospital care may be inadequate if staff distances from atypical genitalia. Even trans friendly physicians and surgeons may turn away from intersex people for being too complex. Three participants described having complex intersex medical needs that were not well addressed.

Hormone management is not well understood for any of the variations. With disastrous effect, "trans" intersex people may be treated formulaically according to trans hormone protocol for typical male and female bodies. Angelo summarized, "There's no one to refer you to so you end up just being thrown around like a piece of garbage."

Marsha said,

I never had a doctor that really knew. There really aren't many doctors that know anything about this . . . There are no best practice standards. They don't have a lot of expertise based on experience or research. I mean it just doesn't exist.

Mitt stated that intersex people are often put in the position of having to educate their medical professionals:

Intersex people have to educate our physicians . . . most endocrinologists do diabetes and nothing else . . . If you come in with complex hormonal problems, they can't take you on, and they don't know anything about balancing sex hormones.

Physicians turn away intersex persons because they are too complicated, which can lead to despair and suicidal ideation. Angelo said,

One transgender doctor after another is saying you're too complicated . . . If I can't even find a transgender person doctor to take me, what am I going to do? . . . If you can't get help and you're that sick and you're that mentally fragile and you're that physically fragile, your only option is euthanasia. And we would call it suicide, but I'm calling it euthanasia.

A tendency is to think that intersex variations can be labeled into a finite group of 15 or more variations. In fact, since sex is along a spectrum, there are many unspecified intersex variations. The different types of intersex "trans" bodies are in this grey area of intersex variations. Angelo noted that assuming all intersex variations are known can lead to dangerous treatments:

There's this grey bunch [of intersex variations] that are . . . unspecified . . . we're in the limbo. It's horrible. It's a really bad place to be because the medical community wants its little boxes to put things in. And when you have a variation that includes polycystic ovaries, that includes hormonal intersex, that includes these things that don't fit into these nice little categories it becomes very, very dangerous, very fast because then you don't get the medical care you need . . . they think they've categorized it all, but they haven't even come close.

### ***Iatrogenic Harm***

As hormone levels are not well understood, treatments can lead to medically created harm. Angelo reported that his iatrogenic feminizing treatments, in combination with undiagnosed mitochondrial needs, resulted for a time in life in a wheelchair. Angelo described the experience of hormonal mismanagement:

What happens to a lot of transgender women, they're dropping the testosterone to zero instead of regulating it at a level that would be more desirable for bone health, mental health, sex health, autonomic nervous system health. Now you mess up your autonomic nervous system and now you even have gastro immobility. Your GI system no longer even moves right. So, you're going end up with the irritable bowel, diarrhea, constipation, sometimes outright blockage, gastroparesis where your stomach doesn't even move anymore. I mean these are not just sex hormones.

### **Harmed Responses**

Under the BOF, exceptions to male or female are treated as disorders. The harms produced by the BOF were described previously. The harms, in turn, created harmed responses in intersex people as detailed next.

### ***Shame Internalized: Sex-Related Phobias***

Three participants talked of the shame they internalized for being intersex, having atypical genitalia, or for the unique way their body functioned. Angelo, who has both a vagina and a penis, stated:

You're not supposed to be a girl penetrating a guy, even though that's what I wanted to do and that's what he wanted. You know that that just doesn't make

sense, you're not taught that that's okay. That just crossed lines that even gay guys don't cross . . . it's the shame, you're so ashamed of yourself.

The shame of being intersex can lead to profound self-esteem issues. Mitt said,

My counselor said, "I have never met anyone like you before. You don't have low self-esteem. You have no self-esteem. You should listen to the way you talk. You don't think you're entitled. You don't think you're entitled to your own life.

Without trained counselors, intersex persons must deal with their own mental health needs at the same time as dealing with unaddressed medical needs. Angelo spoke of needing to change his own internalized transphobia before giving himself permission to transition for life-or-death health reasons: "I was literally having to work through my own transphobia. And I'm going to tell you, without a counselor that's trained to do that, I am a fucking miracle! Can I raise my hand!"

### ***Emotional Castration, Psychic Mutilation***

Angelo endeavored to find words to describe the annihilation one feels emotionally when one's existence is not recognized. He said he sometimes used a term he created—emotional castration. Emotional castration was a central feeling in his life as he was not allowed to be a gay man with a vagina who wanted to grow up to be a father who gave birth.

My family treated me with complete utter erasure and denial that I could possibly be any different than my [curvaceous] two older sisters. And even though I was visibly different [straight and narrow] . . . They coped with it with denial. They didn't want to acknowledge that my existence could even exist . . . Every time I tried to be in their face with the way I dressed, the way I acted, it was always what

I call emotionally castrated. “Well you’re, you’re just a tomboy.” . . . and then the conflation of sexual orientation with my gender. [Others said] “You’re obviously going to be a lesbian.” . . . the automatic assumption was that I had to be a butch lesbian. Even though what they were truly seeing was an androgynous gay man.

In addition to the term emotional castration, Angelo liked Preves’s term—psychic mutilation—to describe his annihilated mental and emotional experience.

### ***Freak, Monster, Alien***

Freak, monster and alien are in vivo codes. The concepts reflect the participants’ terms to describe their internal reality of knowing that they existed outside of the BOF world that others successfully lived in. They were stigmatized as being outside of all that is supposed to exist. Mitt, who was not surgically altered, stated to his therapist, “I’m a freak. People can’t stand the fact that I exist. If I don’t give them a reason to keep me around, they will kill me.” Mitt’s mother used freakish terms to refer to him:

[My mother] called the parents of all my friends and told them to call the parents of all their friends and tell them that I was a sexual freak of nature and that they should not allow their kids anywhere near me. I was 15 years old at this time. My mother was my bully.

Two activists expressed the sense of being from another planet. Angelo said,

That feeling of truly being an alien visitor really started when I was very young. And how else can you interpret it? Be it imagination or whatever. You have to somehow justify it in your mind why you are standing out so much. So that was just almost the “go to,” I must not be from this world.

Val/Valerie used a monstrosity image:

[My] penis [was] kind of chopped up. In fact, I called him Frank, pun intended, after Frankenstein . . . He's [Frankenstein's] got the scars all over his head, and bits and pieces from different people put together to make a whole body. My penis looked like that [before amputation], all the scars and bits and pieces put together to make a penis.

Marsha described her reaction at 15 years of age to a surgeon's instruction to use a makeshift dildo to stretch her vagina for a future husband as dirty, wrong, bad and weird.

I was sent home and told to dilate, to stretch as much as I could . . . to avoid [vaginoplasty] surgery. So, I tried that a little bit, hated it obviously . . . I felt like that was dirty and wrong and bad and weird. So, I didn't really follow through with it.

In summary, being outside of "normality" was sometimes described in extreme terms as monster, freak, or alien, and sometimes in less extreme terms such as dirty or weird.

### ***Genital Exposure Trauma***

Two activists described extreme fear related to exposing their genitals in intimate situations. Val/Valerie recalled not letting teen relationships get intimate for fear of what would happen if a potential partner saw herms "freak show." Angelo referenced another activist who helped him understand his own genital exposure trauma:

My friend [another activist] describes it perfect. He calls it genital exposure trauma. You know, that shame that you're different, and the way people, you know, every time that that first boyfriend turned me around [to not look], that's genital exposure trauma. You're not allowed to exist, we're not going to even look at it, we're going to pretend [atypical genitals] are not even there.



As seen in Angelo's comments, genital exposure trauma is an in vivo code.

### *Fear of Doctors*

PTS due to physical and emotional harming by physicians was a common theme among the activists. Two reported being so fearful that they now always have a bodyguard (relative) accompany them on physician visits.

There were other fears about doctors. One fear, as identified by Angelo, related to not being able to find a physician willing to work with intersex medical complexity.

Angelo explained the fear:

One by one, people start coming in [saying], "You're the first [intersex person] that we've ever met. Could I please sit through your consultation?" . . . To make sense of how horrible this was, I couldn't say no to any of those people because I had already been [a] patient abandoned by doctors prior. I didn't know if he was going to take me on as a patient. I would have said no to each and every one of them. But because I was vulnerable and desperate for help, I had no choice but to say yes.

The fear of not gaining support from doctors can extend to an entire network. Angelo described being blackballed by an entire network of physicians because he refused to continue treatments that were creating iatrogenic harm, yet he still needed medical care:

It is terrifying when you have been blackballed and you've been branded, so it's not just patient abandonment. They outright will break HIPAA and somehow get away with it. And before you know it, the entire state has shared this because of the electronic medical record being able to be shared everywhere now. And you

can't find the doctor because of your reputation of being too complex, too taboo, and patient noncompliant. It's terrible, you think you can run to another country to save yourself and then you find out that even those countries are doing this. You start to feel the argument of eugenics and genocide. They are trying to kill you.

Out of his fear, Mitt developed an elaborate strategy to test whether a physician was intersex safe:

I started with a physician at the beginning of my career in 1981. He saw me for 5 years before I told him [I was intersex] . . . I found my physicians according to whether or not they were gay friendly. Then I would interrogate them about their feelings about trans people. And then I would hope that that meant that they might not think I was a monster if I told them that my anatomy wasn't standard.

### ***Survivor Guilt***

The fact that genital surgeries annihilate or impair orgasm in intersex people deeply distressed all four activists. Two activists who had not been surgically altered reported having survivor guilt from learning that other intersex people had been surgically mutilated and/or deprived of their orgasm through surgery. Mitt said, "All I did was cry, but I had nothing to say . . . I'm whole, I'm normal, I still have all my stuff and it works really well. I have sex as much as I want, I have love, I have a family." As shown in Angelo's comments, survivor guilt can be overwhelming:

Hearing the story [of a surgically harmed activist whose orgasm was destroyed] ripped a hole in my heart. I had no idea [crying] . . . I have survivor guilt because

. . . now [my endocrinologist] brought back my ability to orgasm, and that person will never even have a clue the joy that was taken.

### *Other Emotional Disturbances*

The activists described a variety of emotional disturbances in their reactions to BOF. Three participants reported PTS related to medical personnel and medical care. Marsha said,

I literally can't control as much as I try . . . the fact that I might get triggered and start crying when you're trying to be really strong and put on a tough face. That personal emotional triggering piece makes [activism] hard.

Val/Valerie reported depression following surgery to amputate herms penis due to unnecessary surgeries. Mitt described suicidality following his experience in the Money-style intersex clinic run by Money's associate, Anke Ehrhardt:

What if the whole world was going to see me as nothing but a freak, a worthless freak and want to kill me? What if nobody would love me? What was the point in going on any further? I was tired, and I wasn't even done with high school and I was exhausted. And what the hell kind of future could I look forward to. I wasn't sure, I wasn't sure it was worth it and I looked at every day, is this the day I should leave? I intended to go for a train ride the hard way.

Anger was described by all the participants. One participant spent time searching for his medical records because he was angry and wanted to sue his surgeon for assault and battery. Another was angry about her loss through nonconsensual surgeries of hormone producing gonads. Angelo reported a rage level of anger: "You could become that angry when you find out what happened to you and you find out what happened to [a

surgically harmed activist deprived of orgasm]. It could bring on a rage that's homicidal without a shadow of a doubt."

Two participants (one who was a man his whole life and the other who is "trans" intersex) reported fear for their lives for being intersex. Mitt said,

It's more fear than shame. I didn't think there was anything wrong with me. I was afraid that everybody else was going to go, "Eewww, a bug [smacks hands] . . .

I've been told and told and told and told, "They'll want you dead."

Fear of being murdered may be especially high for intersex "trans" persons, as reflected in Angelo's comment:

[My father] outright said, "If you tell the world, they'll want you dead." He put the fear of my life in me to keep me in line, and he was right, he was right. When you cross that line against your birth assignment, being intersex ["trans"] or transgender, you've become the most feared and the most hated person.

Angelo also described fear over an inability to sexually release in the presence of a lover. "It was a complete form of emotional type of impotence where I could not release because of fear of 'Oh my god what are they going to think when they now have a mess just like they make'."

Difficulty accepting the uniqueness of one's intersex body may lead to jealousy of "typical" women. Angelo said, "That [shame over ejaculation] literally drove my hatred towards typical women, a jealousy that their bodies did not deceive them." In summary, the activists described a variety of emotional disturbances from being annihilated under the BOF, including anxiety, depression, disassociation, PTS, suicidality, fear of or anger

at physicians and surgeons, fear of sexual release, body rejection, grief and jealousy due to medical harm and lost quality of life.

### **Intersex Identity Development Model Stage 2. Breaking the Binary-Only Framework**

The activists all described growth processes that led them to investigate and discover alternative information. The discoveries helped lead them out of the BOF. In other words, growth processes led to breaking the BOF. The themes of Stage 2, namely (a) discovering and investigating, (b) connecting, and (c) realizing, were not linear. For example, realizing led to discovering, which led to connecting, which impacted realizing, which produced more investigating, more connecting, and more realizing.

#### **Discovering and Investigating**

All of the activists described taking some form of action that opened up their knowledge. Angela/Angelo was driven to new discovering and connecting in order to get healthy. She/he grew through an iterative process of discovering some things, investigating them deeper, and connecting with others. Angela/Angelo discovered that there was a medical need for intersex bodies to be treated differently from typical male and female bodies. “And that’s when I started to get really, really smart. I started looking into the different ways people were medically being treated to get out of wheelchairs. How were these people achieving this?”

Marsha’s PTS symptoms, an unintended consequence due to being lied to about having cancer, caused her physician to release hidden medical records to diffuse her anxiety. Marsha’s medical records revealed the cancer lie. Realizing the truth about her body, namely testes removal instead of cancer, led Marsha to the Internet to investigate

the meaning of the terms in her medical records. Internet investigations led to even more realizing through connecting with other intersex people.

Mitt was driven to go public with his body at a nudist camp to face his fears of coming out as visibly intersex. His partner was seeking outside relationships and wanted the “cute” participant to help make that happen. Mitt discovered that the gay community would not chase him with pitchforks, a lie he had been told, for showing his atypical genitals. He also realized through connecting that his intersex body was desirable as exotic.

### **Connecting With the Intersex Community**

All of the activists emphasized the life-changing experience of realizing via the Internet that there was an intersex community to provide knowledge and support. Angelo identified Angela’s/Angelo’s connecting with the Interface Project as particularly powerful. “That project helped me more than you could ever imagine because they had people literally sharing their story about how they’ve been mutilated and how their lives have been destroyed.” For Marsha, connecting led to knowledge about having an intersex variation: “After I had found out the truth [her intersex trait], and I got to the support group, I learned that there was such a thing [as intersex], then there were options.”

For early activists like Mitt, the now defunct ISNA was particularly influential in connecting. “And we finally had the Internet and the first thing I started looking for on the Internet was the word intersex. And I found other people . . . the year ISNA started, and that pushed me into activism.”

Connecting was not always joyful. Connecting, though life-changing, could be very painful because some participants discovered even greater horrors beyond what they had personally experienced. Mitt recalled,

When I came out of the closet as a gay man, it [was] like Oz . . . I expected I was going to find that [a similar yellow brick road of happy friends] when I threw open the intersex closet door. You know what I had? A brick wall right here. . . All of those early members of ISNA were mutilated beyond repair. They weren't just mutilated physically. They screamed, "I wish I could get my hands on that surgeon; I'd start cutting things off of him with a razor blade one by one, inch by inch." That's all there was to them.

### **Realizing Intersex Exists and I Have an Intersex Variation**

Three activists described dramatic and memorable realizing experiences that made them aware there was such a thing as intersex, and they had an intersex variation. As distinct from their early and vague awareness that something was different about themselves from typical endosex children, fully realizing the phenomenon or meaning of having an intersex variation occurred only in middle age for all of the activists. These adult realizations evolved in time to full understanding that intersex was different from being a disorder of male and female only. Angelo recalled the relative suddenness of his realizing:

Every one of them [online] without even talking to each other were replying [to my questions] the same way, "If this [the person's physical features] isn't intersex, I don't know how to describe it." I'm being told at the age of 46 the truth by complete strangers.

Angelo continued,

Not even knowing that I could exist, so that makes it even worse. I didn't even realize I could exist until 2014. When I started seeing [intersex] people exist, it was like, wait a minute, what load of shit have I been fed?

Marsha had a long-term pattern of dissociative blackouts. The impact of her realizing was so strong that her blackouts ended with her understanding that she had an intersex variation. “In my 20s . . . whenever anything was highly emotional . . . or negative . . . I would black out . . . Interestingly, that stopped when I found out I was intersex, and I found out the truth . . . meeting other people, and I realized I’m not alone and not a freak.”

Realizing may involve learning how one’s intersex body functions differently than typical males or females, or, that one’s gender does not have to align with one’s genitals. Angelo said, “I realized really fast that all my experiences with ejaculation, all my experiences that were not typical girl were guiding me down this road I was told I couldn’t go down.”

Angelo described a life-changing experience of realizing when, as Angela/Angelo, her/his unique intersex body was accepted by her/his lover, she/he could have sex like a gay man and be accepted for a volume of ejaculation atypical for a female. “It’s just like in the movies, it’s just like fireworks. Oh my god, I can actually exist and not scare the hell out of somebody.”

Realizing resulted in a negative viewpoint regarding medical or mental health professionals who engaged in “fixing” or “normalizing treatments. Angelo stated, [Doctors] always did it in the disguise that they were doing you favor but then you learn that this is punishment [similar to what happened to gay people who were court ordered to take testosterone blockers to lower gay libido]. And then the light bulb turns on: What the fuck just happened to me?



Realizing may involve discovering differences that are atypical even in the intersex community, for example, intersex “trans” differences, as in Angelo’s case.

And you’re just like “Why, why haven’t I been told this? Why has this been kept from me?” And then I’m learning about the transgender men. And I’m finding out something amazing that even though the vast majority of transgender men want to be with women, that there’s this small little subgroup who want to be with men. I realize I could fucking exist. And you’re learning that at 46 years old, after all your life has gone by, that you can finally exist.

An important component of deeper and deeper realizing pertained to reading scholars who helped to explain the heteronormative assumptions behind the BOF. Mitt said, “I started reading sociologists, I started reading psychologists, I started exploring what had been done with intersex children, with gay children, and lesbians, and transgender people, and I just kept [going]. I’ve not stopped reading yet.” For Mitt, realizing, as fostered by scholarly work, opened up a new framework other than the BOF: “I am intersex. As a community, intersex people grabbed, embraced, and started to run with the word intersex because now we had an umbrella term broad enough to encompass all of us and descriptive enough that it was intuitive.”

Mitt observed that many people who are intersex have not gone through realizing. They do not know that they have an intersex variation and they have not learned the history of their (unknown) community. The unawareness could be for a number of reasons. It could be because there are no visible traits, so the person has never had any indication of difference. The individual could believe the BOF and therefore not pay

attention to intersex history. Furthermore, even if the individual knows they have an intersex variation, they may not be interested in academic scholarship. Mitt said,

[Bioethicist] Karkazis is the first and probably greatest storyteller of what the hell happened, and most of us are not [aware]. We don't know what happened to us, very many of us to this day, don't know that anything happened to us.

### **Being Affirmed (External Support)**

The activists reported that being affirmed from others was instrumental in their developing a new positive framework in which they were not a pathology to be fixed or normalized. They mentioned several sources of support, other intersex people, close family and friends, and positive counseling.

#### ***Support From Intersex People***

Without exception, the activists pointed to connecting with other intersex people as the sine qua non for leaving the BOF and moving into a positive framework of nonpathology. The participants' first connections with intersex people were facilitated through the Internet. For three participants, contact with other intersex people dispelled the myth that there was no other person on the planet like them.

#### ***Support From Close Family and Friends***

Close emotional connections with family and friends were key in developing positive self-image. All participants had or were engaged in long-term relationships. Mitt described unconditional love from a parent:

My father completely affirmed me and said all he cared about was [that] I did not grow up to be alone. And that if I had to fight battles in order to survive in society as what I am [intersex], then he would pick up a sword and shield and fight along

beside me because I was his and he loved me unconditionally. I was unconditionally loved by my father.

### ***Positive Counseling***

One participant experienced 12 years of life-changing counseling. Two others discussed positive counseling experiences for anxiety and depression. More detail on these advantageous counseling experiences is in the section titled Activists' Perspectives on Positive Counseling Experiences.

### **Adapting (Internal Support)**

All of the activists described making personal efforts to feel positive in spite of their pathologized existence. Many self-soothing skills were described. Also noteworthy was a positive frame about being an exceptional being on planet Earth.

### ***Self as Superhero or Powerful Alien***

In contrast with the terms monstrosity, freak, and alien that the activists used to describe their negative experiences, the same three activists used metaphors of "other world" in a positive manner. One found a spiritual meaning in seeing self as an alien. Another thought that their ability to code switch as both man and woman provided superpowers in a binary-only world. Mitt found that self as Superman provided social currency among peers:

[I'm playing with the neighborhood kids and I tell them] "I'm Superman. But you can't tell any adults because you know what they would do, right?" And I'd drop my pants and they'd go "Wow!" I didn't have testicles; I had a very, very tiny penis. They didn't beat me up for that. It was probably the way I sold it! But I felt like that could very well be true [being an alien superhero], and wouldn't that be fucking cool!

### ***Defensive Faking or Lying***

Living under the BOF was a catalyst for learning when it was perilous to be oneself and developing a skill of presenting self in a safer manner. Three participants described a survival strategy of going underground with the truth when it was not safe to tell the truth. All three had some type of performing arts in their resumes. Angelo stated,

You are taking a child who knows they are a boy and convincing them with a year of therapy that they are a girl. It's no wonder why I'm such a good performer and I could become the master of ceremonies within just a few months. I was taught to perform at age 4.

### ***Ending Secrecy, Accessing Medical Records***

All of the activists described finding agency in themselves to move from the BOF's environment of secrecy and lies to one in which seeking truth was the norm. They all reached out to other intersex people in the effort to determine more about intersex. Three participants tried to obtain their past medical records.

### ***Self-Soothing: Self-Protection, Self-Care, Humor, and Spirituality***

The activists reported many self-soothing activities as they evolved in understanding of themselves as intersex. Humor, being authentic, and spiritual practices were identified. Good books, massage, walking in the woods, and release crying were also named. They described several behavioral measures they took to feel safer such as selecting women's bathrooms or having a bodyguard (relative) with them at medical appointments. Mitt took action to feel better by disproving his mother's negative assessments of him as a stupid, unworthy "freak":

I proved to myself that my mother was wrong. I was not an idiot. I was not a waste. [Straight A's in college] gave me the realization I wasn't stupid. I wasn't absolutely guaranteed to be a failure and it was altogether possible that I could just, I could just work hard, and that would be enough for me to be able to survive and to get along in society.

### **Intersex Identity Development Model Stage 3. Beyond the Binary-Only Framework: Intersex as a Natural Bodily Variation**

Following the upheaval, growth, and reorganization of life perspectives in Stage 2's processes of discovery and investigating, realizing, and connecting, the activists achieved enlightened clarity in which they were confident of their status as people with an intersex variation and did not see themselves as a disorder of male or female. The minimum criterion for clarity involved moving beyond sense of self as a disorder into a nonpathologized self-view and clarity about the harms created by the BOF.

It is important to note that intersex people who arrive at the Stage 3 theme of clarity may have somewhat different opinions from each other about issues of importance in the intersex community. Furthermore, not all intersex people who achieve clarity about the BOF will necessarily share the depth or breadth of clarity that activists have. Activists may reach an especially broad and rich level of clarity by virtue of their immersion in the community. Clarity does not mean an absence of controversies in the activist or intersex community. The activists discussed several controversies, which are detailed in the following section. I did not consider unanimity regarding the content in the theme of clarity, nor the degree of activity in the theme of action (discussed next) to be salient in this study.

Action (enlightened by clarity) is another theme that marks this stage. The activists modeled a very high degree of action that flowed out of their clarity. The data, by virtue of coming from a sample of dedicated activists, demonstrated strategic action directed toward dismantling the BOF. Most likely, not all people who achieve nonpathologized clarity about having an intersex variation are as highly oriented to action as the activists in this study. The activists in this study were committed to dismantling the BOF for the rest of their lives. Action may rise and ebb over the lifespan. Furthermore, action may be important and small as when taken on the individual's level. For example, individual action is evidenced by refusing to go to a doctor's office without a bodyguard (relative). Collective action is evidenced by important and big actions such as fighting for legislation that bans infant optional sex-related surgeries.

A final theme of self-actualizing was witnessed in some degree. However, a unitary vision for self-actualizing was not in evidence. Self-actualizing was individualized.

### **Clarity**

The following section on clarity covers various understandings presented by the activists as they moved from clarity to their enlightened actions as activists.

### ***Sex and Gender Are on Continuums***

The Stage 3 theme of clarity conceptualizes an intersex birth as a natural bodily variation that occurs along a continuum of sex development. As Marsha said, "Sex is on a continuum and always has been. It's just we know more about it now . . . That understanding needs to become more common and then it becomes less of a big deal." The study participants all noted that science disproves the BOF.

### ***Money's Model Was a Devastating Error***

Optional sex-related intersex infant surgeries were happening before the 1950s without a standardized protocol, so surgeons followed only their own impulses. Money marked the time of the first standardized protocol regarding intersex infant sex-related optional surgeries. The activists in this study, however, understandably seemed to mark Money's standardized protocol to align body parts according to male and female as the focal point in intersex history that began the devastation on intersex bodies. Money was a psychologist, so the professional mental health community is associated with the genesis of intersex harm. Angelo described Money as the origin of intersex harm,

John Money was it. He was the one that was the expert on gender identity, and he treated as if everybody's born with a blank slate. If you happen to have a kid like me, [supposedly] you could literally teach the gender . . . that plan blew up in its face. It blew up in their face with me and thousands of others.

Angelo continued, "Genitals do not define what's in between our ears. So, no matter what an amazing surgeon does to this toddler or child, you cannot create what was there in the brain." All of the activists firmly held that surgeries do not work to create gender.

### ***Gender, Chromosomes, and Genitals Do Not Always Align***

Some people believe gender follows chromosomes and they will falsely and unscientifically assume that a 46,XX karyotype baby will always identify as gender female. This is known to be false. Angelo, who possesses CAH variation, is an example of a 46,XX karyotype person who identifies as a man. They will also falsely and unscientifically assume that a 46,XY karyotype person will always identify as gender

man. Marsha, who possesses variation CAIS, is an example of a person with 46,XY karyotype who identifies as a woman.

People who make genitals, not chromosomes, the prime factor in sex determination are prone to scientific error as well. Those using genitals as the key to defining gender will tend to assume that anyone having less than a full-size penis will identify as female. Mitt is a person with a small penis who identifies as male.

The most effective method for typing gender is the easiest. A person should state their own gender. For this reason, all of the activists held that the proper approach to gender assignment, as well as to irreversible medical treatments, is self-determination by the intersex person themselves when mature.

### ***Self-Determination of Gender and Body Is the Goal***

Self-determination, in other words, the right of the individual to freely choose gender and any irreversible surgeries, was held by all activists to be the proper stance regarding intersex bodies. Mitt said, “I know plenty of intersex people who were given self-determination. I was one of them. I’m fine. Those who had forced gender assignment are not.” Val/Valerie said, “There are a lot of stakeholders (e.g., doctors, psychiatrists, endocrinologists, pediatric gynecologists, and parents), but it should be the kid who is the decider.” However, the activists were not against all medical “fixing” treatments. Angelo said,

If they are an adult with informed consent, they know the consequences of surgery, they know the bonus of surgery. They say, “Okay, I am a man and I really want a phalloplasty, I really want testicle implants, I really need this, this, and that.” That’s informed. They sign on the line, they get on the surgery table,



they deal with whatever ends up happening to them, be it good or bad. [But] when you do that to a child, over 10 human rights organizations are saying, “That’s a human rights violation.”

In other words, for the activists, the core condition for self-determination is fully informed consent by a mature intersex adult, the one who will be affected by irreversible surgical decisions.

***Terminology Matters: “Disorder” Harms***

All of the activists were sensitive that words mattered. Marsha said, “I think it’s such an important issue [disorder versus intersex terminology]. Disorder language is the gateway to surgeries.”

Intersex biology can be made to disappear by calling it a disorder. Calling an intersex variation a disorder instead of a natural sex variation gives the medical and mental health professions domain. As Angelo put it, “If you’re being treated like a pathology or a disorder or a diagnosis, they’re there to fix it, be it your parents, doctors, psychologists, counselors, anybody.”

Angelo further noted that not associating a child with the label of intersex variation can unknowingly lead to abortion. “Parents don’t even know that they aborted an intersex fetus. They’re being told this is a disorder and syndrome . . . this child is just going to have so many problems and it’s going to cause you problems.”

The preferred term, intersex natural bodily variation (or intersex variation), encompassed a richer and healthier meaning for the activists than DSD. The United Nations, in concert with activists and advocates, developed the preferred term, intersex natural bodily variations, in lieu of DSD (United Nations Office of the High

Commissioner for Human Rights, 2015). Angelo said, “Intersex natural bodily variations is what it is, that’s reality. Calling it anything else is an invention that the medical complex and the government created.”

When intersex people are recognized as real and not just a disorder, they are in position to demand their equal rights—for example, of not being surgically altered without consent. Angelo noted that words reveal the human rights issue behind the terminology: “If we don’t call it intersex, then we don’t have to look at this reality that’s out there. We can continue this myth of only typical (male and female) people being allowed to exist.”

The terms intersex variation or intersex natural bodily variation imply that intersex people are a category of humans that indeed exist. People who are intersex exist just as people who are males exist and people who are females exist. People who are intersex have a history, a community, support groups, and members who can testify to happily lived lives without surgery.

### ***Core LGBTQ+ Variance: Intersex Medical Harm***

The core difference between other LGBTQ+ groups and intersex people is the human rights violation of irreversible medical efforts to alter intersex infant bodies. The harm that happens to intersex people because of bodily difference is why the intersex community must be distinguished from other LGBTQ+ communities. Marsha said,

Intersex is such a broad umbrella term. It encompasses all these different intersex traits and possible narratives, but the one thing we almost all have in common is the experience of being oppressed and discriminated against based on bodily difference, so that piece is what brings us together.

Furthermore, as Marsha noted, the unique bodily harm happening to intersex people as compared to other people in the LGBTQ+ communities is irreversible:

I think intersex is different from almost all of the other [LGBTQ+] groups by the harms and the discrimination that's done to us as babies and as children, often before we're even able to express a gender identity or a sexual orientation . . . it's trying to erase the intersex-ness out of us before we even have a voice. And these are very physical and emotional harms. They're irreversible.

### ***Intersex Medical Needs Are Not Binary***

The activists discussed the nuanced needs of intersex people regarding hormone management. Intersex people may be improperly treated by formulaic male or female hormone management. Under a formulaic binary approach, for example, if the intersex person is assigned as a woman, estrogen might be provided and/or testosterone blocked. If the person is assigned male, then estrogen might be blocked and/or testosterone provided. If, however, as in the case of Angelo, the intersex body was biologically designed for receiving high levels of testosterone, then a cascade of negative effects could transpire by total testosterone blocking. Angelo also shared that an intersex person might want estrogen for his vagina and testosterone for other health needs, which is a different complexity than for endosex trans people.

An important medical reason for not forcing intersex people into binary male and female boxes is that it can be life threatening to follow medical assumptions for male and female bodies. Angelo observed that medical mismanagement in the form of improper hormones or improper regulation of hormone levels creates drug induced harm.

Every single part of your body is affected by estrogen or testosterone. So if you are a person created in utero to have these receptors for testosterone and they take them away, you're going to have autonomic nervous system failure, you're going to have osteoporosis, you're going to have stress fractures, you're going to have problems with your mental health, your ability your intellect, your energy. . . . problems regulating your temperature, problems regulating your blood pressure, and then the obvious, you have sex dysfunction, no libido, your inability to orgasm.

Surgeries tend to be cited most often as the core source of medical harm, but, as Angelo noted, hormonal medical mismanagement affects all parts of the body:

It's what happens to a lot of transgender women [and intersex persons who identify as women], they're dropping the testosterone to zero instead of regulating it at a level that would be more desirable for bone health, mental health, sex health, autonomic nervous system health. Now you mess up your autonomic nervous system and now you even have gastro immobility. Your GI system no longer even moves right So you're going end up with the irritable bowel, diarrhea, constipation, sometimes outright pseudo blockage, gastroparesis where your stomach doesn't even move anymore. I mean these are not just sex hormones.

Hormonal mismanagement may impact different variations disproportionately.

CAH might be one variation prone to iatrogenic harm. Angelo described witnessing what he believes is CAH medical mismanagement:

The women in those congenital adrenal hyperplasia [online] groups are some of the sickest. What I saw happening in the congenital adrenal hyperplasia groups

was iatrogenic . . . the congenital adrenal hyperplasia women suffering, this is created by the [formulaic] treatment [i.e., only providing feminizing hormones].

Proper hormone management for intersex persons is layered with gender issues as well as medical complexity. Not all intersex women, for example, will be open to testosterone treatment to feel better. Some women with CAH may not be open to masculinizing testosterone treatment, even if their body needs it. Angelo said, “The vast majority of the ones [CAH] that were truly women in their brain said they would rather die than to live their life appearing as a man.” In other words, some intersex people have a strong drive to identify on one side of the binary regardless of the potential detriment to their health.

### ***Intersex People Are Not All Infertile***

All of the activists recognized that the notion that all intersex people are infertile is false. Intersex persons sterilized or born without gonads are indeed infertile, but intersex people born with gonads or partial gonads may have the ability to produce viable eggs or sperm. Angelo noted that fertility rates do vary by variation: “A vast majority of intersex people do have gonads that do not develop so they would be infertile . . . That’s just a reality. However, there are many of us that do have our fertility.”

The myth of infertility in all intersex people overlaps with two other myths, the myths that healthy gonads should be removed to prevent cancer and the myth that body parts should align to gender. Practices that surgeons perform according to those myths actually create intersex infertility through sterilization. First, taking out healthy gonads to prevent future possibility of cancer results in sterilization. Second, under the

heteronormative alignment myth, aligning body parts to assigned gender can result in sterilization.

Angelo described the unnecessary sterilization that is caused by surgical alignment of body parts to assigned gender. He reported that an intersex baby assigned male might have any so called “nonaligned” ovarian tissue taken out and an intersex baby assigned female might have so-called “nonaligned” testes tissue taken out:

After they do a “corrective” surgery, almost every single time they are removing gonads, ovaries, or testicles in order to affirm that assigned gender that they’ve placed on that baby. Like for example if they assign girl, well then, the testicles have to go because [supposedly] no girl could possibly have testicles in this binary world of ours, which is not true, but this is what the invention of sex has created.

The bottom line is that taking out healthy intersex gonads for whatever reason results in medically induced infertility (i.e., sterilization).

### ***Some Intersex Men Give Birth***

The activists recognized that in rare cases intersex fertility can crisscross gender (as it does with endosex male to female trans and endosex female to male trans). In other words, of the intersex people who are fertile, some intersex men can be fertilized and give birth, as Angelo explained:

In the real world, in reality . . . women can have sperm and guys can have eggs, and [even] the people that are undifferentiated, now with science, even their fertility is [possible], and [all those types of fertility are] being taken if they [surgeons] remove these [gonads].

The fact that some intersex men can give birth can confuse even those in the intersex community. Some persons in the intersex community have assumed that all intersex people are infertile. They then erroneously attack as frauds the intersex men who gave birth as supposedly being endosex trans people masquerading as intersex people. It can be very hard to be “a rare among the rare” intersex person who has the fertility of the “opposite” gender. It is painful to be erroneously deemed a fraud by members of one’s own intersex community. Angelo was attacked as a fraud intersex person by some in the intersex community for having given birth.

### ***Many Intersex People Are Heterosexually Oriented***

One of the participants is heterosexually oriented. This participant reported a pervasive myth that all intersex people are gay or queer. The truth is that some intersex people are gay or queer and some are not.

The issue of orientation gets complicated in the case of intersex “trans” people because their orientation will be reclassified in the transition. Since the person was misassigned, the new orientation was actually the original truth. For example, Angela/Angelo knew she/he was a gay boy but did not make Angelo’s “transition/emancipation” until in his 40s. Prior to the transition, Angela/Angelo was married to a man and was therefore perceived by others as heterosexual. After the “transition/emancipation,” Angelo was considered gay by being perceived as a man and remaining married to his husband.

### ***The 2006 Chicago Consensus Did Not Stop Infant Sex Surgeries***

None of the activists thought that replacing Money’s 1950s protocol with the 2006 Chicago Consensus model ended the surgeries. Angelo said, “It’s a total myth in my

opinion that since 2006 things are no longer a problem, what I see is an increase in diagnosis.” Marsha said, “Perhaps vaginoplasties are not performed as much on youths, but they are still done. The techniques for clitoral recessions or reduction have improved but the surgeries are still being performed.” Two activists described the rate of intersex infant surgeries in 2019 in the United States as often as five a day. Marsha said,

At [a] systemic level it’s still happening. We know it’s happening; we know from talking to parents and talking to young people . . . The surgeries, the interventions, the lack of real informed consent, the pressure to do medically unnecessary interventions, to do cosmetic surgeries, to impose these binary notions of body and to impose these notions or to erase the intersex traits. It’s still happening regularly.

Mitt described the rate of ongoing optional infant sex-related surgeries exactly the same as Marsha:

Leave it the fuck alone, damn it. Put the knife down, there’s no help in that. But you will be counseling people this has happened to, it’s still happening at the rate of five a day in this country. You’re going to run into them if you start counseling intersex people.

Intersex activists know the surgeries are continuing because they are exposed over and over to narratives of continuing harm to intersex people. Marsha said,

[My perspective comes from my personal experience and] the hundreds of narratives I’ve heard from other intersex people who have suffered. It’s just so outrageous, it’s such a human rights violation . . . it’s such a bad thing. . . I have a personal connection to it, obviously, that’s how I came to this, but I think what



keeps me going is . . . the bigger . . . picture, it's all the different types of interventions and harm that's happening to people and continuing to happen to young, young babies and children.

Angelo believes that the reason for surgery increase may be two-fold. First, the renaming of intersex to disorder in 2006 promoted insurance-reimbursed surgeries. Since that time, parents are hearing the term disorder and experiencing their child as having something that needs (reimbursable) medical fixing. In other words, parents are not understanding their child under a nonpathologized framework of intersex. Second, parents may have been stirred up by increased anti LGBTQI+ rhetoric and may be feeling pressure to surgically alter their child's genitalia to avoid LGBTQI+ status. Angelo described his perception of parent phobia about their child being a member of a sexual minority community:

[Parents want surgeons to] fix this kid so that they're not one of those LGBT people. And historically speaking doctors are not stupid, they know that we've appeared the queers, we appeared the lesbians, we appeared gay, we appeared the bearded women, we appeared the real feminine men with breasts or whatever. They know that we're the ones that stood out in history.

Marsha attributed the continuing surgeries to the power imbalance that exists in the medical context. There is something culturally decisive about medical authority in a medical environment stating that one's child is disordered.

I've had parents tell me, "You know I've got a masters and a Ph.D. and still, when it came right down to it and this doctor was telling me [to consent to infant surgeries], I felt so vulnerable." You know there's really, there's some[thing]

culturally, I think, something [in] our society that has an impact even before the words are spoken.

Mitt believes that the number of surgeries since 2006 is actually higher since more physicians are involved under the new DSD multidisciplinary team (DSD MT) clinic approach and they all have a financial motive. He explained,

Now you don't just have to deal with one doctor telling you your child is an abomination and a freak of nature, you've got a whole team of them . . . What makes you think these people are going to give up their money stream, their way to make a living, and their way to be professionally renown, because they're hurting their patients. What makes you think that!

Marsha reported that the DSD MT clinics have made some improvements. Money's concealment model has largely been replaced with disclosure of the variation to the family. It is also an improvement in care to have the content expertise of other specialties represented rather than just surgery.

Despite the improvements, Marsha observed that the 2006 Chicago Consensus model nevertheless remains a medical model that assumes medical intervention is necessary and thus the harming continues. Marsha observed that there are two ways to think about ongoing harm. Surgeries still being performed is one way and the second pertains to the ongoing harm in people who were harmed in the past. "Some were harmed in the past. That harm, the impact of that harm, continues. We know it's happening [in the present too]. We know from talking to parents and talking to young people."

### *No Happy Silent Majority With Infant Surgeries*

One of the medical arguments for continuing surgeries is that there is supposed to be a happy “silent majority” of intersex people who were had the “normalizing” treatments. Furthermore, surgeries improved from years ago, so that the “few” bad results of the past supposedly do not happen any longer. According to that medical argument, activists only represent the rare disgruntled patients whose results went awry.

All of the activists thought that bad surgical results are not a thing of the past. There is no silent majority happy with their surgical results. The surgeons are at best confounding proximate surgical results with long term quality of life results. The activists stated that surgeons have no business making claims of surgical success since they are not tracking long term quality of life. If they tracked long-term results, they would know that the results are not good. As Marsha stated,

Yeah, it’s definitely a myth. The myth of the silent happy majority was created by the medical institutions to just basically say, “Listen . . . we’re not hearing from patients coming back upset and angry. So, there’s only a few of you disgruntled.” In the best scenario, the doctors will say, “We’re sorry that that happened 25 years ago and our techniques are so much better now.” But there’s no medical follow up, there’s no research, there’s no qualitative data even . . . they’re not asking people, right? So as more and more of us are speaking up, there is more and more qualitative data, but it’s not [quantitative] so you know it can be dismissed so easily.

Mitt noted that even when studies report success, the findings are fraught with bias:

There are a lot of errors out there because there has not been sufficient demographics. There has not been sufficient follow through. There has actually been an attempt to cover up facts, demographics, to not even keep track of what happens to people . . . Any claim being made by the medical establishment is based on a sample size you couldn't write an undergraduate paper based on.

Three participants made even stronger claims. They had interacted with hundreds or thousands of people online, yet they had yet to meet a single person who had been operated on in infancy without their consent and who was happy in adulthood with their results. Angelo said, "I've never yet had somebody say I'm happy about my surgery as a child." Mitt said, "I have yet to encounter a person who says I have it all [the surgical and hormonal "fixing"] and I am wonderful, I couldn't be happier. Val/Valerie said, "I haven't met one, and I've met a bunch."

### ***Surgical Results Are Dissatisfactory***

The activists reported that normalizing surgeries do not produce satisfactory physical results. In fact, the surgeries produce disastrous results. Angelo said, "These fabricated genitals [on infants] are causing suffering and I'm getting to see it all. They're coming to me [now as adults] and I don't know what to do." Mitt said, "No one has ever made a normal, ordinary male or female out of an intersex person." Sutures designed for infants do not have the same effect in adulthood, which may lead to more surgeries and disfigurement.

The surgeries damage sexual organ function and sexual experience, if not in infancy, then by adulthood. As Angelo described the harmful effect:

You can never take what Mother Nature has created and fabricate it on a surgery table . . . no fabrication team can ever even come close . . . This at the very best is just C medicine [poor quality] . . . the majority of these surgeons aren't even close to being the best.

Surgery can greatly diminish the ability to orgasm, as Angelo noted.

If sex was just about dropping your pants and looking perfect and it wasn't about sexual function, it wasn't about orgasming, it wasn't about intimacy with your lover, yeah [making genitals look pretty] then [visual appearance would be] a pretty good way [to judge surgical results]. . . But the vast majority of these people that are having these surgeries, their ability to orgasm is gone. If they can still orgasm, it's definitely diminished.

Surgeries on genitals produce inevitable scarring and scarring impacts sexual sensation. Angelo noted that there is no sexual sensation in scarred tissue: "You can't take the glans of a clitoris or a penis and chop on it and expect that to have normal sensation. Doesn't work like that, nerves are being cut. Cutting tissue causes scarring, scarring has no sensation."

Surgeries performed on infants for visual purposes in youth are not adequate for the arousal needs of a future adult. Angelo stated that stitches in infancy do not accommodate aroused tissue well in adulthood. Clitoris recessions produce pain upon arousal.

One of the things that people do not realize is what is the development of a clitoris. I would also include phalloglitoris. The amount of that organ, that phallic organ, I'd have to show you a picture, but about two thirds of it is inside the body.

Even with a typical penis, a good amount is inside the body. So when they start doing all these surgeries, when you become aroused and they've buried [the clitoris] and you start to become aroused, you're in excruciating pain . . . and it leads to surgery after surgery after surgery until you no longer can even orgasm. Then it is a nightmare, a nightmare.

### ***Informed Consent Process Is Dissatisfactory***

Marsha stated that informed consent process remains inadequate following the change in protocol called for in the 2006 Chicago Consensus model. The informed consent documents in hospitals probably do not disclose that the United Nations has deemed infant nonconsensual surgeries as torture. Parents should be informed that there are other children with the variation. Parents should be supplied several lists, including adults with the variation, other parents, and support groups. Most importantly, parents should be told that delay is a viable option. Marsha stated that parents have even been pressured by physicians in the extreme:

Consent needs to include, for example, the option described to parents to delay intervention and do nothing. Tell them that's a reasonable option. I don't think they're ever really given that choice . . . They're not in most cases. They are still not told that that's a reasonable, respectable option. I mean we've even heard doctors saying if you don't this, I would consider this child abuse not to do this surgery. I also think fully informed consent would be letting parents know or [people] making this decision on behalf of their kid, that the United Nations has deemed this a form of torture . . . I am pretty sure they're not telling patients that.

Marsha also stated that the counseling supports are not in place at the level they should be. DSD counseling is not effective if it is social worker who talks to the families once or twice. Marsha believes that comprehensive DSD counseling is probably not happening as much as it should because it probably is not getting reimbursed well.

***Infant Surgeries Create, Not Prevent Stigma***

The rationale that these surgeries prevent stigma is totally false according to the study participants. Mitt said, “It [nonconsensual infant surgery] doesn’t just cut off your penis, it cuts out your soul.” In other words, the surgeries and attendant medical examinations actually create horrific stigma and PTS instead of preventing them. In Mitt’s words,

All they managed to do is cut it off, and shut us up, and shut us down. All they can do is instill terror and shame and a feeling that we are aliens from another planet who fell to earth. And that we are not members of the human race. And that they do very well.

Angelo’s perspective is that safe networks of friends and affirming services are protective against stigma for intersex people. The appropriate treatment for social stigma is not surgery but interaction with supportive people. Angelo described the importance of safe resources:

I am literally . . . helping people find those safe circles, those safe resources, those safe doctors, safe counselors, those safe friends, safe schools, safe states, the list goes on. And they are proof that yeah there is a frickin’ stigma out there but it’s not theirs, it’s society’s issue. And when you do find your safe circle, these kids and these families are thriving and they’re not chopping on their genitals. When

you find your safe circle and you find your people, you get adequate support, these parents [who did not opt for surgeries] that are raising these kids, that are whole with self-determination, are not suffering some horrible tragedy.

### ***Intersex People Have Great Sex Without Surgeries***

The activists dispelled the myth that unaltered intersex infants need surgical and hormonal treatments out of pity for their future sex lives. Val/Valerie said, “I had a lot of good sex. She [herms wife] was bisexual so she liked my guy parts and my girl parts. So, when we got married, we did it every which way you can think of.” Angelo stated that when unaltered intersex people have shared details of their sex lives, they are envied by heterosexual people. Three participants reported that unaltered intersex people are sexy, desirable, loveable, and wanted in long-term, loving relationships.

Angelo’s description of his sex life was illustrative. In his 40 years as Angela/Angelo, he enjoyed breast stimulation and vaginal penetration. She/he also enjoyed the joys of erection and ejaculation. As a man, Angelo continues to enjoy all the same pleasures. Angelo described the sex he enjoys as hermaphrodite sex. He and his husband take turns being top or bottom. Angelo reported that he can orgasm in three ways: gland stimulation at the same time as vaginal penetration, anal, and gland and anal at the same time.

Angelo did not want to alter his body through surgery according to the myth that his body parts have to be aligned with male gender by removing his female parts as it would diminish his multifaceted capacity for sexual pleasure. Furthermore, Angelo reported that all his parts were enjoyably integrated into his sex life with his long-term partner of over 30+ years. In summary, as a woman, Angela/Angelo enjoyed aspects of



sexuality traditionally thought of as belonging to man. As a man, Angelo enjoyed aspects of his sexuality traditionally thought of as belonging to a woman. According to two participants, the myth of unsatisfying intersex sex is not just false, it is dangerous to intersex bodies. Heteronormative bias leads to surgeries under the false assumption that intersex infants will all grow up to want bigger penises or vaginas sized for use by average penises.

### ***Automatic Gonad Removal Harms***

Healthy gonads in intersex people are commonly removed because of the possibility of developing cancer in the future. Two activists commented that the automatic need to do so is a myth. Angelo stated that the practice is akin to automatically removing the breasts of all women with a family history of breast cancer. The appropriate response to cancer risk is to closely monitor, not automatically operate, as a first course of action.

They [intersex activists aware of the issue] are starting to speak out and they're saying, wait a minute, you [surgeons are] lying to these parents about this being an urgent emergency to remove these streak gonads. Yes, there is a high risk, I'm not going sit here and lie about that. But it's like some families have a higher risk of breast cancer. Do we remove the breasts of all the teen girls in these families, of course not. We watch them and we get ready to jump on it if it happens.

One of the reasons removing healthy gonads is so controversial is because of the hormonal benefit that healthy gonads produce. Val/Valerie, who has PAIS and therefore a partial ability to absorb testosterone, stated:

My gonads made the right hormones for me . . . not for you, not for anybody else, but for me. . . The dihydrotestosterone I wasn't using [was not able to be absorbed] converted to estrogen, giving me tits. And it was fine for me. It's when that was removed or when they start changing it and started adding more testosterone . . . That's when it got all messed up.

Surgical removal of functioning gonads allegedly for cancer risk have been pursued because of heteronormative bias. In practical terms, an intersex child assigned female would have male parts removed; an intersex child assigned male would have female parts removed. Marsha, who had her healthy gonads removed, noticed the underlying heteronormative alignment motive hiding behind the lie about her having a high cancer risk and said, "I think it does relate to just the conception that testes shouldn't be in a female." Heteronormative bias falsely assumes all people want to be heterosexual in orientation and to have heteronormative body part alignment, either all male parts or all female parts.

Marsha, who had her healthy testes removed without her consent, expressed anger that a life requiring HRT ensued. HRT is not without its own difficulties related to the difficulty of regulating levels, with impact on moods, libido, and weight.

I do feel a little robbed of not, very possibly not, feeling as good as I could have all these years, or had maybe the sex drive I could have had, or not struggled with my weight as much had I not had to deal with hormone replacement, or, had I not had some healthy . . . hormone producing gonads removed from me . . . so yeah, I can be angry about that.

Marsha noted intersex variation differences in terms of the degree of cancer risk. A single approach for all variations who have the issue of gonad removal for cancer risk is not viable. Marsha was optimistic that the goal of not performing automatic removal of healthy gonads might be an area ripe for making progress in lessening medical intervention.

[Cancer risk] is something to monitor in CAIS. I mean its [risk] differs from PAIS. There's a little bit of an increased risk. So, I mean there are differences. You can't have a blanket standard of care, but certainly for people like myself, which is one of the more common intersex traits, CAIS, they [gonads] should be monitored [rather than automatically removed]. I think that's an area that we're starting to see a shift. It might be, if you dare even call it this, "the low-hanging fruit." Maybe we can start to get hospitals and practitioners to agree on [monitoring rather than automatic removal]. I think that might be one of the places where we could start.

### ***Infant Anesthesia Harms***

Research has indicated that anesthesia can damage an infant's brain. Possible brain damage is cited by some of the study participants as justification for stopping optional intersex infant surgeries. Brain damage due to anesthesia may become an increasingly important argument against unnecessary sex-related surgeries on intersex infants. Angelo said,

So, here's the controversy with anesthesia, they now have outright proof that when you give anesthesia to a baby or toddler or young child, it is permanently damaging their brain. Man, is that a wake-up call. That right there is an argument

to wait until the child could decide on their own if they need surgery or not. I mean this is significant.

Anesthesia used on intersex infants might create learning disabilities, as Marsha noted.

The FDA came out with that advisory a couple of years ago based on a study, I think in Australia, showing . . . learning disabilities or problems particularly with reading, I think it was, in children that had been exposed to anesthesia, I think it was under the age of 3. I think that's noteworthy.

***Controversy: Biology Only and/or Identity?***

The activists observed that language tends to conflate biological sex with gender, so discussions about what intersex is or is not can be confusing. Activists often witnessed a confusion of intersex (congenital biology) with nonbinary gender identity. Angelo stated that some endosex people want to say they have an intersex gender identity, which he considered distasteful:

Do we call intersex an identity? I personally don't want to because I want it to remain about genitals, hormones, and chromosomes. I don't want it to mix up with the brain [gender] because . . . then you start getting things really muddy really fast.

Marsha wants to be supportive by valuing every person's right of gender choice. Ideally (in a perfect world) people should be able to claim any gender identity. She believes, however, that there are limits given a real possibility of hurting the intersex community and their advocacy efforts. A baseline criterion should be present before anyone makes a claim of intersex gender identity. In her view, the person should actually

possess a congenital intersex biological variation before claiming an intersex gender identity:

A part of me is like . . . why should I care [if someone without the biological trait claims to be intersex] . . . I care because I think it diminishes the issue a little bit. It diminishes the human rights violations . . . the most serious issue in our movement, in our community, is about the harms that are happening to children . . . [Claiming to be intersex just as a gender identity makes intersex seem like] just an identity issue. It makes it seem like [intersex is] something that people can choose. You can't choose to be intersex.

In summary, the human rights issue affecting intersex infant bodies should take precedence over gender identity free will. Harm that is being done to children on the basis of their biological variation is the core issue that the activists want to keep front and center.

***Controversy: “Delay is Okay” Versus “No Body is Shameful”***

There are two mottos activists use to orient parents and youth toward not opting for any optional surgeries during infancy—“Delay is Okay” and “No Body is Shameful.” Both mottos are similar in that they encourage parents and youth to avoid succumbing to pressures for surgeries in infancy and childhood. Among activists, however, there can be sensitivity over the possible conflicting meanings of the two mottos in regard to what happens as the child approaches puberty.

On one hand, “Delay is Okay” may be viewed negatively because it supposedly emphasizes slowing down the timing of surgeries but not avoiding surgeries all together. In this view, “Delay is Okay” supposedly perpetuates the business of infant surgeries

since it embeds by the word delay the notion that one day the surgeries will be wanted. In other words, in this view, “Delay is Okay” actually feeds into the binary-only model. Under this view, the other motto, “No Body is Shameful,” is thus more to the point, namely that optional genital surgeries are not necessary for fulfilling lives. As Angelo elaborated,

“Delay is Okay” seems to mean we’re going to wait until the age of consent and you’re still going to have to decide M or F. You’re not going to be able to make this amazing choice like [I] made or many others have made that you don’t need surgery . . . It kind of rubs me a little wrong, you know. If “Delay is Okay” with informed consent [is] about not having to have surgery, awesome, but that’s not what I see happening. What I see happening is “Delay is Okay” until we can finally give you consent to make the choice M or F, but we’re not going to let you know this [not having surgery] is an option.

On the other hand, the two mottos, “Delay is Okay” and “No Body is Shameful,” can both be interpreted as roughly synonymous and desirable. Martha explained,

I can see how . . . people could say well if you’re saying “Delay is Okay” then you’re implying that it will be done at some point. That’s obviously not what we mean. Let the child decide basically, let the person decide, delay the decision you know? And the decision can still be no. It probably should be, but that’s not my decision, it’s your body. But the alternative motto has merits. “No Body is Shameful” is great, I like that one a lot.

***Controversy: Medical Treatment: Misguided or Diabolical?***

Two activists saw a benevolent, albeit misguided intent behind the medical “fixing” treatments. Angelo said,

All these people in the gray, be it intersex, transgender, transsexual, transvestite, all the words that we’ve been called, I do believe because of good intent they wanted to do these surgeries. These treatments, be it lobotomies, hormones, corrective genital surgeries, were to get us out of those institutions to give us a life where we could be typical men or women.

In this “good intent” view, the harmful treatments were well meaning for the purpose of giving people born outside the BOF a “normal life.” Marsha said,

I don’t think it’s diabolical . . . people don’t go to medical school, go through all that training . . . to have some pathological need to cut clitorises, I don’t think . . . maybe there’s one or two, I don’t know . . . I think it’s good intentions gone wrong.

Val/Valerie tied the original good intent to a specific variation, CAIS. Physicians were apparently well meaning by trying to shield CAIS women from the knowledge that they actually had XY chromosomes and testes. Herm also sensed the surgeries were an effect of a system doing what the system was designed to do. In the medical system, surgeons operate, their system is designed to fix by surgeries. By virtue of intersex being classified as a disorder, the surgical system, unless stopped, is going to do what it does and thus operate on intersex people.

The activists distinguished the original intent of the medical and mental health professions from the effect of their surgical, hormonal, and behavioral treatments. The

effect was so devastating that two activists defined the treatments as diabolical. In other words, the damaging effect was so great that good intent was not excusatory, and the term diabolical applied. Angelo said,

The intent was good, however, it ended up being diabolical because they were taking away our fertility, they were taking away our ability to orgasm, they're taking away a lot of stuff that is our human right.

Mitt did not see good intentions. He only saw diabolical ones. Surgeons lied and lying is coercion. Coercion is inconsistent with good intent.

This [intersex infant surgeries] is not an emergency [as some surgeons claim]. It's not. That was an out-and-out lie, and they knew it was a lie, and that's diabolical.

They know it's a lie right now and that's a diabolical act. That's coercion.

Mitt stated that surgeons are diabolical also because they know they are performing medical treatments on healthy people they are claiming to be disordered.

Were these people crazy? Well, yeah, they were! They were also diabolical as hell! My parents picked up on the diabolical, they picked up on the fact that they [the children's hospital clinic run by Dr. Ehrhardt, psychologist associate of Dr. Money] wanted to slice and dice me in order to make my body conform to whatever thing they thought everybody has to be. And they knew there was nothing wrong with me.

Angelo assessed the origin of diabolical treatments on intersex people as implicit homophobia and transphobia.

These people [who foster surgeries to align intersex babies to male or female] are so upset about gays and lesbians and transgender people, [they are] just going to



cut the gay out [of intersex people] . . . it's not explicit. The implicit bias and prejudice against gays, and lesbians, and transgender people are a very unconscious thing.

The actions taken on intersex people are indeed so devastating that linkages were made to Nazi Germany's program of eugenics. Angelo said, "You cannot help but see the parallel between eugenics and genocide and their taking away your fertility." Mitt's father drew an explicit link between Mengele's eugenic operations in Nazi Germany and Anke Ehrhardt's intersex medicalized treatments. Mitt's father came to his conclusion about the Nazi parallel after experiencing Anke Ehrhardt's clinic for 6 months: "[My German father] had a view of Anke Ehrhardt that what he was hearing was pure eugenics . . . . What he said to me was, we might as well be listening to Mengele himself. He'd read Mengele. He knew what he was talking about."

Sentiment about the diabolic nature of the surgeries may be felt so very strongly that actual Nazi physicians or Nazi sympathizers are sometimes speculated to have found their way to Money's Johns Hopkins's clinic. Angelo said,

There is speculation, that is completely improvable, that Dr. Mengele possibly escaped into America and had influenced or outright changed his name to being some of the surgeons that did stuff with Dr. Money. There's no proof, but there's speculation.

In summary, whether from good or diabolical intent, all of the activists viewed the surgeries as unethical, with horrific and diabolical effect. Mitt interviewed surgeons outside the field of pediatric surgery and learned that even other types of surgeons frown on optional sex-related surgical treatment on intersex infants as unethical. "I'd ask them

about sex reassignment surgery on [intersex] children in order to erase pseudohermaphroditism. That's the word they understood. I invariably got 'That's horrible, that's despicable, that's unethical, I would never even consider such a thing'."

***Controversy: Are Intersex Birth Certificates Important?***

There are unsettled issues surrounding legal document sex notations. Angelo held that an intersex birth certificate is a valuable means for protecting intersex children from unnecessary surgeries. Angelo believes that if intersex is one of three recognized sex designations (i.e., male, female, and intersex), then intersex could not be considered disordered any more than male or female. As Angelo described, "I am a category, a human, and because in my own right, I exist, you don't get to touch me." Angelo added that achieving a birth certificate with a third sex designation can feel like restitution for all the harm done from trying to force the person into male or female.

Val/Valerie believes that a third sex option is needed because it is a lie on legal documents when an intersex person is forced to select male or female. Herm observed that a third option would help the problem that an intersex person can end up with contradictory notations of sex on legal documents of birth certificate, passport, and driver's license because they are issued by different government jurisdictions.

On the other hand, a danger might occur by making intersex biology clear on a birth certificate. Marsha observed that if parents hold the bias that their intersex child is disordered, then the parents might feel pushed to surgically "fix" the alleged disorder immediately through unnecessary surgeries to avoid having an intersex designation on their child's birth certificate.

### **Action: Activism or Individual Empowerment**

The second theme in Stage 3 is action. Taking action from a position of clarity (that the BOF is false) can be individual in scope; for example, like reaching out to make an intersex friend. Action under beyond the binary framework does not have to be performed at the high level of activism. Given the activist subjects of the present study, however, the following section emphasizes a high degree of collective action. In other words, the following discussion of action emphasizes very active people who move from clarity about the false nature of the BOF to activities designed to dismantle the BOF and promote a nonpathologized framework of intersex as natural bodily variations. Activists take community-level action in their clarity in order to promote their understanding that intersex people are not disorders to be fixed but rather people deserving of human rights.

### ***Motivations and Need***

The universal theme motivating all of the study participants is to protect intersex children from the nonconsensual surgical, hormonal, and psychological treatments designed to supposedly “fix” them according to the BOF that recognizes only female/girl/heterosexual and male/boy/heterosexual. Angelo expressed his dedication: “It is just my main focus to save the babies and I don’t care if they’re gender variant, transgender, or intersex . . . No child should be taught that they’re in the wrong body. That is wrong.” Val/Valerie stated,

I don’t want other kids to go through what I had to go through. I don’t want all the secrecy, the shame, the genital mutilation that doctors put us through. So, I’m using education and advocacy to help stop that.

Val/Valerie reported fighting for self in the process of fighting for children.

Angelo spoke in some detail regarding his motivations, including his desire to add the

contributions of intersex people to the world, stop myths such as Money's genitals make gender theory, and stop intersex children from being aborted.

Additional motivations held by some of the participants include a spiritual motivation and an opportunity to work on a satisfying issue. Some of the activists described feeling they had a particular talent, skill, or personal attribute to contribute. Two talked about being bridgebuilders. Another thought he served as an example that a high quality of life was possible as an unaltered intersex person.

### ***Prior Conditions***

All of the activists had prior backgrounds or conditions outside of intersex advocacy that set the stage for their activism, including having worked in government relations, policy, and advocacy; organizing a patient group; advocating in the child disability arena; and advocating for gay rights. Three of the activists described some performance experience including radio theater, child entertainment, or church music ministry.

All of the study participants spoke of the significance of having connected with the intersex community as a prior condition of their activism. Learning about the intersex history of medicalized "fixing" fomented their commitment. All four mentioned the influences of the ISNA, the first advocacy organization, and the scholars who revealed the heteronormative ideas behind Money's medicalized treatment protocol, such as Karkazis and Preves.

### ***Activities***

The thrust in activism to date has been publicizing that the intersex community exists, revealing the medicalized harm happening to the intersex community, and taking

legislative action. All of the study participants worked in community education and advocacy to promote the legislative bans of nonconsensual surgeries. They all used the Internet in their outreach, either through their organization's website and/or by being regular commentators on Facebook type groups. They all conducted personal speaking engagements. Three worked only in U.S. activities, one also worked internationally. Three mentioned writing autobiographies, one was being published. One reported building a donor network, lobbying for change, and empowering young activists to let their outrage be even more expressed.

### ***Vision***

In addition to the overall goal of ending nonconsensual "fixing" of children, several activists spoke of other desired improvements. Parents should receive resources and training for raising their intersex children. Insurance coverage would be available for the whole person and not by sex. (Coverage of the whole person would allow, for example, treatment for both a penis and a vagina in one person.) Counseling would be informed and widely available. Several activists longed for the day when physicians and surgeons stopped spending time on unneeded "fixing" and worked on the real medical needs for healthy hormonal treatments for the different variations over their lifespans. One wished for an international website that made connecting with others throughout the world user friendly.

### ***Activist Infighting***

All of the activists noted significant infighting among intersex activists, both in the United States and across national lines. They noticed a variety of issues behind the infighting. Two mentioned opportunity issues such as leadership positions and speaking

opportunities. One observed fighting related to activist strategies. Another observed an issue of race and its representation in leadership positions. The animosities between intersex activists who are “trans” and those who are not was reported as painful. One thought that the degree of medicalized or psychological wounding that a person went through prior to their activism might be a factor in their hostility. Angelo reported several death threats. Marsha considered retiring from activism because of the infighting.

The hardest thing about this work is not communicating or advocating or fighting, whatever you want to call it, against doctors, it’s the conflict and the drama that occurs within the intersex community sometimes. My lowest moments doing this work—the couple of times where I’ve wanted to walk— have been when intersex people are hurting other intersex people. I’ve been in that fray whether it’s around issues of race [or other issues]. Those are the moments when it feels the most hopeless, and I just don’t think I can do it anymore, but somehow, I do.

### ***Intersex Community Subgroups***

Each of the activists discussed the many groups in the intersex community. In other words, any notion that the intersex community is a single harmonious entity is entirely false. The activists’ perceptions of the various subcommunities included formal groups, such as the variation groups that often have their own support group. Other groups are informal, in other words, not organized except in the mind of the activist as a group of people recognizable by a shared viewpoint. The following are descriptions of the many intracommunity groups highlighted by the activists.

**Variation Groups.** All of the activists recognized that each of the intersex variations has an organized or informal group. The medical community approaches each

variation differently. Common medical treatments produce common physical and psychological experiences in persons with that variation. Some groups are heavily influenced by their experiences related to the particular surgical or hormonal efforts to feminize them. A person with CAIS, 46,XY karyotype, for example, might have their testes removed. A person with CAH, 46,XX might have their clitoris recessed or surgically downsized. Some groups may be heavily influenced by medical efforts to masculinize them. For example, a person with hypospadias may have surgeries to urinate like a “real man.”

Val/Valerie observed a wide spectrum of masculine and feminine expression in each variation; for example, herm noted that although AIS groups have a great deal of femininity, there is a spectrum of gender. Some AIS persons seem quite masculine.

Another factor leading to subcommunities is the fact that different intersex variations have a greater or lesser natural alignment with the binary male or female. The privilege that comes from being close to the binary boxes of male or female may lead to political positions that distinguish the variations. For example, in some variation groups that align closely to the binary, there may be a stigma issue related to avoiding being called by the term intersex. If being called intersex can be avoided, then once the “disorder” is fixed, the person is able to think of themselves as a “real male/man” or a “real female/ woman.” Thus, some variation groups may seek an alliance with physicians and surgeons to obtain surgeries and hormonal treatments to fix a disorder and thereby avoid being intersex. One activist observed that the variation groups of Mayer–Rokitansky–Küster–Hauser (MRKH) syndrome and CAH seem to want to distance from being intersex. The activists also noticed that sometimes the stigma of intersex involves

homophobia or transphobia. “Real females/heterosexual women” and “real males/heterosexual men” might want to distance themselves from other intersex people who happen to be gay or trans.

The desire to distance from intersex may be paired with a (faulty) assumption that chromosomes are the determiner of sex and gender. The “chromosomes as determiner” position is clearly false as evidenced, for example, by CAIS 46,XY (male) karyotype persons who identify as girl/woman. Nevertheless by using an erroneous rationale that chromosomes determine gender, a 46,XX karyotype CAH person, who identifies as a woman, for example, can distance from intersex, prefer disorder, and assume that once her clitoris is downsized, she is “fixed.” With her disorder supposedly erased, she became a “real female/woman” and now she can use her “female” chromosomes to “prove” her position. In other words, in a conflation of chromosomes with gender, the person makes the false assumption that their XX chromosomes supposedly justify their belief that they are “real” women.

There are well over a dozen commonly recognized intersex variations. In the next section, activists discussed a few of the more prominent groups related to the variation differences.

***Variation Group MRKH.*** Persons with MRKH have 46,XX karyotype, underdeveloped or absent uteruses and vaginas, but normal ovaries, breasts, and pubic hair. Marsha’s view was that for the most part persons with MRKH do not consider themselves intersex, do not join with legislative groups to oppose surgeries, and do embrace the disordered terminology. Reproductive surgeries for MRKH women are happening with their own adult personal consent (i.e., not in infancy). Marsha reported



that the MRKH group has a “heteronormative feel” as MRKH women are very concerned with maintaining and managing their fertility.

*Variation Group CAH.* CAH individuals with 46,XX karyotype, often distance themselves from the intersex community. Through overexposure to testosterone, CAH female infants often have a large clitoris. The feminizing “fix” procedure involves resecting or otherwise reducing the clitoris size. Such surgery can be disastrous for pain and orgasm potential but also because perhaps 1 in 8 CAH individuals will not grow up to identify as girl/woman. Thus, medical efforts that feminized their supposed clitoris will have worked to normalize their penis in the wrong direction. Marsha reported meeting only one CAH person who was surgically feminized and happy with what had been done.

Marsha held the impression that, unfortunately, CAH people seem to still be in the place of shame and stigma. This may be so because when CAH people hear about intersex variations and issues, they do not think of themselves as intersex. Accordingly, they are not receiving alternative points of view about surgeries or receiving support from the intersex community.

Marsha and Angelo stated that the parent-led CAH support group, CARES, was being led from parent vantage. The group is not being led from the CAH infant or CAH youth vantage. Many parents and physicians put pressure on CAH people to conform to female physical appearance.

CARES members were being inflamed by untruths, namely that intersex organizations supporting the ban are trying to take away all medical care for CAH individuals and all decision-making from CAH parents. These were untruths as intersex organizations supporting the ban are completely in favor of using parent authority to

authorize surgeries to protect life and address adrenal issues. Intersex advocacy organizations are not even against all surgical or hormonal “normalizing” treatments as long as they are chosen by informed adults. Intersex advocacy organizations simply want the individuals to be of sufficient maturity to make their own informed decisions. Since CARES’s claims are so outrageously false, Marsha suspected that the misinformation by CAH parents, CAH physicians, and probably a public relations firm was intentionally inflammatory to influence votes on the proposed legislation to ban intersex infant surgeries.

***Variation Group: Hypospadias/Epispadias.*** Marsha noticed that with the exception of few very vocal advocates like Tiger Devore, hypospadias/epispadias men do not seem very vocal about their outrage at what has been done to them. As a group they seem more akin to the MRKH group. They seem to be more connected to their physicians than to intersex people working on legislative bans of intersex optional sex-related infant surgeries.

**Intersex Heterosexual and LGBTQ+ Groups.** Two other recognized intersex subcommunity groupings pertain to intersex plus heterosexuality and intersex plus **LGBTQ+**. Marsha observed that the intersection of intersex with orientation and/or nonbinary gender is a very significant issue in the intersex community. Some people erroneously assume all intersex are oriented gay or queer. For many intersex individuals such an automatic assumption is offensive due to the inaccuracy of the assumption and a desire to be recognized for the truth of their heterosexuality. Many CAIS women, for example, are heterosexually oriented.

Marsha noticed the issue of intersex groupings related to orientation and/or gender in context of advocacy work. Marsha observed that the intersex plus gay or queer group has particularly strong presence in the intersex advocacy community. According to Marsha, approximately half of the members of the active advocacy group are affiliated with the LGBTQ+ communities. As a practical matter, most of the support to date for advocacy has come from LGBTQ+ rights supporters. The LGBTQ+ intersex youth seemed particularly passionate as activists. The youth seem very clear about their intersex experience as othered and oppressed given their prior experience of being othered and oppressed for their gender and/or orientation. Marsha stated that in advocacy work there is ongoing challenge to balance sexual majority perspectives with sexual minority perspectives since advocacy organizations are not by mission queer ones.

Alternative possibilities for advocacy support might change future orientation dynamics in advocacy organizations. Untapped as of yet are supporters that logically could come from the human justice arenas of reproductive rights, child advocacy rights, and/or disability rights. At present, the active group of intersex people advocating for the legislative bans does include some representation from all of the variations besides MRKH and hypospadias/epispadias.

**Intersex and Race, Religion, and/or Other Intersectionalities.** Several activists reported a hot point associated with the intersection of intersex plus race. Marsha noted that, unfortunately, the majority of activists so far are White, but the landscape is starting to change favorably toward more diverse representation as more and more intersex people are coming out. Other intersex plus intersectionality combinations were noticed such as intersex plus religion and intersex plus nationality. There is an active intersex

Christian group working on educational activities. Val/Valerie noted nationality as a source of intracommunity differences. Intersex people from other countries have different approaches to intersex legal issues.

**Intersex Police.** Two activists used a slang term “the intersex police” for another informal grouping of intersex people defined by a shared viewpoint. Some intersex people strongly believe that all intersex people should be prepared to produce medical documents that verify their biological variance from male or female. Intersex policing might stem from a resentment that some endosex trans people (typical male or female) are claiming to be intersex in order to feel that they have a biological basis for being trans.

Both activists that discussed this topic did not like policing intersex identities, so they did not feel the need for medical record justification. Marsha, however, objects greatly if someone without an intersex variation claims to be intersex and then acts against the mission of banning nonconsensual surgeries or takes money from funders under pretenses of doing intersex advocacy.

**Other Intersex Subgroups.** The above list of intracommunity groups is not exhaustive. The activists identified many other subgroups in the intersex community. Marsha identified a group who are in agreement with their birth assignment and a group who are unhappy with their birth assignment, a group who have been surgically and/or hormonally altered and a group who were left alone, and a group of Fundamentalists and a group of New Agers. Val/Valerie identified U.S.-based organizations and internationally-based organizations. Herm also observed that a group of people who

connect with the intersex community to discover if they too have an intersex variation. The various online groups also have group differences.

### ***Activist Hardships***

All of the activists reported the hardship of having daily contact with the stories of intersex harm. Two activists reported that the difficulty was exacerbated by their own PTS issues from their own intersex trauma. Angelo said,

[The hardest part of activism is] the horrible part of it: the abortions, the genital mutilation, the continued stigma, the homophobia, the transphobia, the intersex phobia, the haters, the judgment, the people that think they're speaking the Word of God and you know they're not, the darkness, the diabolical part of it, the genocide, the eugenics, the torture, the pain, the suffering.

Marsha said that witnessing the hardships in the intersex community daily can trigger her PTS.

I literally can't control as much as I try how I'm going to feel, or the fact that I might get triggered and start crying when you're trying to be really strong and put on a tough face. So that personal emotional triggering piece makes it hard.

Three activists discussed financial sacrifices. Two discussed family as patrons; without family financial support the work could not be performed. A negative of relying on family for financial support was giving up income earned that could have been put to personal retirement or college funding for children. The compensation for the loss of income was personal satisfaction. One activist discussed the significant challenge involved in marshalling the professional legal and fundraising expertise required to grow

a nonprofit advocacy enterprise. One discussed having to work through physical pain and disability.

### ***Activism Changes Over Time***

Val/Valerie reported some progress in that some surgeons are not doing the surgeries. There is concern, however, that some hospitals may be saying they are not doing the surgeries but actually they are. Marsha also reported that the landscape of intersex activism had evolved in her work over almost a decade. Marsha had entered at a dark time of betrayal for many in the intersex community. ISNA, the original unifying group, had been dismantled without input from other intersex people.

With Chase's support, perhaps through the encouragement of Dreger who was a close associate of Chase, the language of disordered (a diagnostic term) instead of intersex (a descriptive term) was adopted by the medical community at the 2006 convention of U.S. and European pediatric urologists in Chicago. Dreger discussed that pivotal time in intersex history and praised herself and Chase for being on the inside of the convention collaborating with physicians. Dreger disparaged the activists who remained outside of the building protesting physicians because she saw them as ineffectual. (Dreger, 2016). Dreger envisions herself as an apologist for scientific objectivity in her book, *Galileo's Middle Finger* (Dreger, 2016). Unfortunately, the scientifically false and damaging language commenced at that point in intersex history. The 2006 medical protocol that came out of that convention represents for many a dark and backwards direction in gaining intersex rights. Marsha noted that the diagnostic term disorder seemingly legitimized placing intersex people under the purview of the medical "normalizing" treatments. Marsha realized the need to move away from using

the term disorder. She worked in her organization to eliminate use of disorder terminology and promote nonpathologizing terminology for people with intersex variations.

### ***Activism Responses***

The activists described mostly positive responses to their activism. Marsha noticed that some conservative friends had gone away. Her family was mostly proud but sometimes wondered when her hard work in activism might end. Marsha appreciated her family's concern but wished that they instead understood the importance of her work and the significant time and sacrifice it required.

### ***Activism Successes***

Marsha stated that the ultimate goal was obtaining legislative bans on infant nonconsensual surgeries. She described also wanting to move the needle by changing practice in legislation, hospitals, and medical associations; raising awareness through the media; and providing advocacy and support for intersex people and their families.

Marsha believes it is important to get varied intersex stories out in the public in order to emphasize the wide differences in the intersex community. Greater public awareness of differences within the community will help new people find a subcommunity they can relate to and gain comfort. Currently, the queer intersex identity or intersex "trans" experience seems to be more represented in the media. Yet, as Marsha noted, not all intersex people are discontent with their birth assignment, and not all have a gender identity that is other than man or woman.

### ***Future in Activism***

All of the activists stated they would remain in intersex activism in one form or another for the remainder of their life. Given the plethora of unaddressed intersex human needs, activists' work will likely just begin when the legislation ban comes to pass. As Angelo said,

[Even when legislation bans “normalizing” infant surgeries] I’d probably end up busier. What I want to do is to help the parents to raise these kids that are in a world where culture is shifting, where the boys can have vaginas and the girls can have penises or have neither . . . [But a break would be in order when legislation comes to pass, for at that point] I see myself taking a nice break in the Bahamas, I see myself on a cruise ship taking a break. No, this is it for life.

### **Self-Actualizing**

Self-actualizing is the third theme in Stage 3. It follows clarity and action. Self-actualizing was evidenced but not thoroughly developed in this study’s data. This theme pertains to the experience in some of the activists of achieving some degree of personally defined self-actualization. Angelo described loving all of his body parts and wanting no surgeries. Mitt described getting over his fear of being seen naked by intentionally experiencing a nudist camp to do so and, over time, gaining self-acceptance of his body through that public experience.

Given the wide diversity of experiences in the intersex community, strong caution to counselors is made about assuming what the nature of self-actualizing is or should be for an individual intersex person. In their self-actualizing, one intersex person might embrace all their body parts, both those traditionally thought of as male as well as those traditionally thought of as female. Another who was misassigned and had body parts



removed may feel horrible as an adult and want fully informed consensual surgery to restore a sense of their original intersex body. Another might have wanted their testes removed but just wanted the dignity of being able to make the decision for themselves. Another might have never wanted their testes removed. Variance in self-actualizing should be expected. People differ from each other and people change their own goals over time. Self-determination is the key.

### **Activists' Perspectives on Positive Intersex Counseling**

#### **Overview**

The study participants experienced a range of counseling services. One participant experienced over 20 inpatient and outpatient counseling experiences and viewed all but one as horrifically damaging. Psychologists and psychiatrists damaged their intersex clients by thwarting atypical gender identity/expression and by reinforcing inaccurate birth assignments. Psychiatrists made inaccurate diagnoses and overmedicated with addictive, brain damaging drugs. Two participants also experienced gender “brainwashing” counseling.

On the other hand, one participant reported a 12-year positive, life-changing, and life-affirming experience. The sex therapist helped his client undo a sense of the intersex body as monstrous. The counselor then spent time working to help his client learn to follow his own pleasurable endeavors. Two participants described positive experiences with counselors when seeing them for specific issues of anxiety and depression. One stated that twelve-step programs were important in his life. The availability of knowledgeable counselors trained to address intersex needs was reported as essentially nonexistent.

## **Current Status: Needed, Low Availability, Uninformed**

Mitt described the need for and deficit of trained counselors: “The need for counseling help for us, it is almost unexplainable. It’s so big. It’s so deep, it’s abyssal.” Angelo commented similarly, “I can’t guide them (intersex contacts) to counselors . . . There is no referral.” Marsha also emphasized the need for competent counselors:

There aren’t enough counselors with knowledge or experience. I mean even the same thing with doctors, because they’re not getting education . . . mental health is similar . . . we need more counselors who have competency in this area, and know what it means, and have read case studies or ideally met, and worked with other intersex people.

In terms of counselor education and training, the activists warned that empathy alone is insufficient. Mitt said,

[The following] is a sentence you can write down that no counselor should ever say to an intersex person: “I can’t imagine what it would be like to be you.” I should say, “Then why am I paying you?” You [as counselor are] supposed to be able to figure out what it’s like to be me so that you can help me cope with the problems I’m having with being me. If you can’t even imagine it, I am not here to be your entertainer!

Counselors would be erroneous to think that LGBTQ+ counseling experience is all that is needed for competent intersex counseling. Angelo commented on the inadvertent errors that counselors are likely to make without specialized intersex training, especially by those who hold prejudice against sexual minorities.

Counselors themselves don’t have enough training around just gay, lesbian, and bisexual let alone transgender issues and intersex. They’re not trained. So [my

experience with counselors] was a disaster. You [counselors] are going to do harm without even knowing it. Especially if you are homophobic or transphobic and haven't . . . had sensitivity training.

Counselors should expect to encounter people with grave emotional wounding due to irreversible surgical and hormonal medical treatments. Intersex emotional wounding often relates to being told that their very existence is insufferable. Positive counseling for intersex people, therefore, can mean life or death. Mitt said,

Some of them are going to be living with something horrible that can never be healed. Physical amputation can never be healed, that's why [ethical medical practitioners do not perform surgeries] unless we absolutely have to . . . An intersex baby does not need to have its clit or penis sliced off. It is not gangrenous; it [their intersex trait] is not going to kill them . . . Leave it the fuck alone, damn it. Put the knife down, there's no help in that. But you will be counseling people this has happened to, it's still happening at the rate of five a day in this country. You're going to run into them if you start counseling intersex people. But just as bad, there are people who have been psychologically mutilated by being told that they are only being suffered to exist; and they've been told this through example and body language.

Mitt described the benefit of long-term counseling with a sex therapist who took the time to understand intersex experiences:

My counseling and the fact that I received counseling, 12 years of it, at least once a week, made it possible for me to function as an intersex person in a cisgender

society. Without adequate counseling, I could not have been sitting here talking to you.

### **Connects Clients With the Intersex Community**

All participants spoke of the life-changing experience that happened when they connected with other intersex people. Given the major impact of connecting intersex people with like others, counselors should connect clients to support groups as a matter of priority. Marsha observed, “After I had found out the truth, [about my having an intersex variation], and I got to the support group, I learned that there was such a thing [as an intersex variation], then there were options.” The Interface Project was especially helpful to Angelo, who said, “Interface Project, that project helped me more than you could ever imagine because they had people literally sharing their story about how they’ve been mutilated and how their lives have been destroyed.” Counselors should support intersex people connecting with other intersex people as a fundamental key to their moving beyond the BOF.

### **Comprehends the Unique Intersex Experience of Nonexistence**

All of the activists described the intersex experience of not being allowed to exist, which included related terms of annihilation, erasure, unnatural, and eugenics. According to cisgender heteronormative society, intersex is a phenomenon that does not exist, only disorders of male or female exist. The erasure is created first by definition, by defining intersex as a disorder. The erasure is then enacted in medical settings through surgical and hormonal treatments designed to erase parts of the body that do not look male or female. Mitt stated that counselors have never dealt with anything similar: “You have never dealt with somebody who has been told from infancy through adulthood that they are not natural. That their very body and therefore their entire existence goes against

every other living being on the planet.” Counselors who counsel intersex people are taking on clients who have been told from birth that they are so unnatural their mere presence is an affront and must be undone.

### **Proficient in Intersex Variation Differences and Implications**

Counselors should be proficient with the various types of intersex variations and their likely psychological, medical, and social experiences in order to help their clients learn how to be intersex persons in a binary world. These intersex individuals may not understand their own variations or the likely physical and emotional issues ahead. Mitt said,

You’ve got to know what the various intersex traits are because the patients may not know. They may be experiencing [unusual body changes] and are saying “Oh my god, what’s happening to me?” And the doctors may not be able to answer the question. Or they [doctors] may be able to answer the [medical] question but they haven’t the first idea how to help them cope with the physical realities ahead [Even if the doctors are able to help with the physical changes, they] haven’t the first idea what kind of issues this causes emotionally.

Intersex-informed counselors must be sensitive regarding how the variations differ physically. The differences cannot be ignored as they lead to surgical and hormonal treatments designed for those variations. Accordingly, the degree and type of interaction an individual will have with the medical community will vary significantly. A helpful question is to ask the individual how their variation is impacting their life. As Mitt stated,

There’s difference[s] [among intersex people]. If you take an intersex person who has an almost completely developed phallus so that it’s damn near a penis, maybe a little hypospadias at most, they’re having erection experiences like me that

females are not having. Yet there they are with a uterus and vagina . . .

[Counseling] has to [have] sensitivity toward asking each individual what is going on with their own body. How is it impacting their life?

Puberty is a particularly volatile time when additional or completely new atypicality may occur. As Mitt said, “You literally wake up and discover that you’re in a man’s body instead of a woman’s body. This happens to some intersex people. How are you going to counsel that?”

All of these issues—the variation, its medical treatment, the discovery, and the coping process—will impact psychological development and possibly lead to the sociological ethos of an intersex subgroup that exists to support similar others.

Val/Valerie said,

I want to tell counselors: Don’t think that just because you’ve met one intersex person you know what the community is. If you don’t understand what the community relationships are, then you’re not really yet ready to work with intersex people.

Mitt stated that psychological, sociological, bioethics, medical history, gender studies, and feminism are important for counseling as well:

You have to understand what they’re going through from a physical point of view, from a psychological point, from a sociological point of view, you cannot isolate these different types of study. You cannot be ignorant in all of these things.

In other words, multiple interdisciplinary perspectives are required for a full understanding of intersex experiences.

## **Holds the Monstrous, Exterminated, Alien Self**

Mitt provided a comprehensive image of successful counseling. The counselor undid years of shame, fear, secrecy, and lies in Mitt. As a start, the counselor mirrored that Mitt did not have low self-esteem; he had no self-esteem. Mitt had been brainwashed into thinking that he did not have a right to his own life.

They [intersex people] believe they're not real, they believe they don't exist, they believe this so deeply. It's screwed on so tight. If counselors can help them [be real people], even if they've had [physical] parts of them amputated, at least they become real to themselves. Real experiences will teach them that they're real to others, that they're not the exception to absolutely everything everyone says which was my problem. I believed I was the exception [to humanity].

Mitt observed that some of the shaming an intersex person feels may come from religion.

There are a lot of intersex people who had [the BOF in which only man and woman exist] screwed onto them by a lot of different religions. You're going to have to tackle religion too because it's ugly, it's mean-spirited, and it's politically controlled right now.

PTSD storms may be involved. Angelo was retraumatized while watching the love scenes between a transwoman who retained her penis and a cisgender heterosexual male in the movie *The Crying Game*:

You just saw the truth [genitals do not make gender]. You realize how you were deceived and lied to. How you were psychically mutilated comes back like a storm. You're like: Why do we do this to people? Why did it happen to me too? Me too! And it takes you over 10 days to get over it and there is no suicide phone line because you couldn't even explain what you just experienced because they

don't even speak the same language. There is no counselor, they don't speak the same language. There is no one unless you have a friend like (name deleted) or other intersex people. . . then out of the grace of God they speak your language, and they could ground you, and even they don't know what to do if [substance abuse is involved].

*The Crying Game* mirrored to Angelo the degree of his own trauma from his psychic mutilation under the BOF. He also saw the hopeful reality that love is hardly out of range for intersex people. There are worthy people who know how to love, and they fall in love with intersex people. People who know how to love, fall in love with people, not with their genitals.

### **Reflects and Strengthens the Lovable, Human Self**

A therapists' ability to reflect the loveable intersex person requires an unusually supportive environment as intersex clients may not think they have the right to exist. Mitt's counselor gave Mitt permission to exist. Mitt described his counseling success as validating him as a human being who is real and deserves to exist: "I now have the permission to love others, to love myself, and the courage to say I'm not an abomination. I'm a person. I'm a human being. I'm a man. I'm valid."

In route to the goal of Mitt's self-acceptance, Mitt's counselor taught him that danger from haters was real but trying to earn sufferance of one's existence by being "a good boy and a jack of all trades did not work; gay people had already learned that." Instead, Mitt was advised to get a gun to keep under his pillow and to go be his intersex self and gay self while living his life in happiness. The counselor also provided Mitt with the message to get away from what was causing pain and choose pleasure. Mitt counseled counselors with the knowledge he learned from his own counselor.



If you want to help them unscrew those horrible dysfunctional things that are weighing them down like cement, you have to find out what gives them pleasure, and pain, and you have to know ways to help them get around it.

Marsha, emphasized the importance of age-appropriate truth in counseling:

I know how important the truth is and knowing the truth . . . it would have been better for me to have been told at age-appropriate times in age appropriate ways when I was 15 and supported with . . . psychosocial support.

Specialized support will be needed for those who were misassigned their gender.

Angelo hoped counselors would help intersex people undergoing transition to understand that surgeries are optional. Additionally, counselors should serve as family educators and moderators during transition. Transitioning is difficult enough without having to protect oneself from family rejection. Furthermore, so much loss is involved with transitioning. Counselors should help the individual find new safe spaces, because, as Angelo stated, “When you become a visibly out minority, it’s a landslide of losing a church, losing your friends, losing your family, losing even your pharmacist.” The anecdote to the massive loss is finding safe spaces and resources. Angelo said,

Helping people find those safe circles, those safe resources, those safe doctors, of safe counselors, those safe friends, safe schools, safe states, the list goes on. And they are proof that yeah, there is a frickin’ stigma out there but it’s not theirs, it’s society’s. And when you do find your safe circle these kids, and these families are thriving, and they’re not chopping on their genitals.

Val/Valerie described the importance of counselors providing safe space to help the person work out gender expression and gender identity:

A counselor should help the person explore to see what they like and do not like in clothes, behavior, and makeup. The person should be allowed autonomy and time to work through all of the different possible expressions [that may change over time] so they can be the best person they can be.

### **Supports Parents and Ensures Comprehensive Informed Consent**

Activist empathized about how new parents are shocked. Parents' whole knowledge of what is male and female has just exploded. This is the optimal time for counselors to normalize an intersex birth. Counselors should be able to describe the intersex variation and how parents will be able to successfully raise their child with appropriate support. If parents are overwhelmed, counselors should reassure by introducing them to the variation's support group and by providing referrals for more intense emotional needs, as Mitt detailed:

[When medical staff hands parents] an infant with a penis and a vagina . . . their entire knowledge of what is male and female, what is boy, and what is girl, explodes. Their whole existence is suddenly mush. And this is a woman who just pushed a baby out! Are you fucking kidding me? How could anybody cope with that. You see? [Counselors] have to come into it going "Oh, it's one of those [name of intersex variation]. Not a problem. We have a parent support group. You can start up with them, and if you have trouble with family members, and you feel like you need more intensive counseling, hey, we've got people.

One activist stated that a useful alternative to surgeries is providing parents with the opportunity to meet other parents whose children have unexpected birth outcomes. Intersex parents have been fed lies that they will never meet other intersex parents.

Isolation serves to promote the surgeries. Mitt suggested that a parent group would not have to be restricted to intersex parents alone:

It would have been just as good to meet with other parents with other unexpected outcomes . . . If [parents] hadn't been fed the lie that there was no other intersex person, [parents] could have gotten support from a host of other people.

Until a legislative ban is achieved, counselors should be vigilant to ensure that a proper informed consent process is followed. Counselors can look to guidance from interACT regarding proper informed consent components that should be used in hospitals (InterACT Advocates for Youth, 2020). An improper informed consent process is one that is rushed or otherwise pressured. As Mitt stated,

A service that should be happening is not to send parents in to be ganged up on [by a team of DSD MT doctors]. The first thing that should happen is that they should be referred to physicians who do not gang up on them with a timer running, you have to make a decision now, now, now, now.

According to Mitt, the reality is that physicians may not know what the variation is or how development outside the womb is going to unfold.

[Intersex education should be provided in a broad way] because nobody knows exactly what's going on with the baby . . . education [is needed] first on the physical end of it. Then they need to be connected to other parents at different stages of raising their children . . . There's nothing more important than that. They should hear our stories, they should be able to get at our stories, they should know what it's like to grow up with different genitals. They should stop lying to these

parents that their child is so fucking rare that they will never run into another person like that.

In summary, parents need comprehensive support, education, a fully informed consent process, and the opportunity to connect with other parents of children with unexpected birth outcomes.

### **Addresses Transitional Care**

Marsha observed that current counseling focuses on parents making infant surgical decisions. In other words, there is a major deficit in transitional counseling and transitional medical care for youth and adults. Counseling should develop transitional support to address the concerns Marsha expresses:

There's no transitional care for adults [whether] physical or mental health. You fall off a cliff. There's a focus on pediatrics. There's no real follow up, nor is there any place for a young adult or any adult to go for competent care around hormones or just understanding the body. It's a huge health disparity, generally.

Activist Mx. Anunnaki Ray Marquez developed a counseling intake form (see Appendix J) that will be useful to counselors. It identifies many counseling-relevant issues for supporting intersex people after they leave DSD MT care.

### **Conclusion**

The experiences of four intersex activists were presented in this chapter. The content provided by the activists answered the research questions: What has it been like having an intersex variation? What led to becoming an intersex activist? What is your life like now as an intersex activist? How has the 2006 change in medical protocol impacted intersex people? What has any personal experience with intersex counseling been like? And what would improve counseling for intersex individuals and families?

The activists differed in their variation-related experiences. Angelo was misassigned as girl, underwent hormonal and extreme psychological normalizing experiences, and later decided to reassign as a man for physical health reasons. Mitt underwent a harsh psychological evaluation by a John Money collaborator, Anke Ehrhardt, but his family left Ehrhardt's clinic and resisted genital surgeries. Marsha did not know she had an intersex variation until later in life when she learned she had been surgically "normalized" without her permission. Val/Valerie was assigned boy but always knew herm was both girl and boy. Val/Valerie experienced many unnecessary penis surgeries and ultimately amputated herms penis due to surgical harm.

The activists shared having had some degree of intersex medicalized experiences involving diagnoses, hormonal and surgical treatments, and/or counseling. The medicalized experiences were largely based on a binary-only conceptualization of sex biology. The medicalized experiences were conducted or enforced by the medical community, the professional mental health community, and by society in general. The treatments conceptualized each of the activists as disordered due to having an intersex variation.

Both the varied and the similar experiences of the activists were developed into themes in this study. The themes consisted of intersex internal processes, experiences, or states of being. The themes were then organized into three overarching social contexts. The result produced a three-stage identity development model specifically designed to explain: first, a context in which being born other than male or female is not considered acceptable; second, a context of breaking away from that binary framework, and third, a

context in which intersex variations are understood as a natural and acceptable human sex development occurrences.

## CHAPTER 5: DISCUSSION

This final chapter begins with a review of the purposes behind this study, which led to my emphasizing Preves's sociological work. I next compare Preves's findings with the findings in the present study. Comparing Preves's work with these findings led to my developing a new intersex identity development model. I explain the new model and its justifications. I conclude the chapter with a discussion of the study's implications for counselor practice, training, and research and with my final observations.

This study's primary purpose was to provide a window into the complex needs and concerns of the intersex community for the field of professional counseling. Six research questions were used to address this purpose by exploring intersex experiences, activists' perspectives, and counseling implications. The findings that answered the research questions were presented in Chapter 4.

While I focused on the research questions, I also worked on additional tactical goals to improve the state of intersex counseling. One goal was to present content that was underrepresented in the existing literature, namely the complex diversity of intersex experiences by variation. This goal was accomplished by presenting four narratives from individuals who differed from each other by variation and by the medical treatment they received for the variation.

Another problem tackled was how to depict the fact that the binary-only framework (BOF) is not a universal anathema for all intersex people. Some variations align better than others with the privileged boxes of male/man/heterosexual and female/woman/heterosexual. The privilege may be desired by some and pursued through allegiances with the medical profession. In therapy practice situations, therefore, counselors should not assume that all

intersex clients will value a ban on intersex infant surgeries. My goal of depicting the political diversity that exists in the intersex community was hopefully accomplished through the activists sharing their lenses on the subgroups in the intersex community.

Another goal was to figure out how to introduce the field of counseling to the prior texts of intersex scholars from outside of counseling. I addressed this goal by referencing in detail the prior texts of intersex scholars from other fields. The landscape of intersex community issues is complex and dynamic. Journal articles or chapters in multicultural texts are too cursory in length to capture the complexity involved in the why, what, and how of intersex medicalization. I built my own foundation of knowledge on comprehensive texts outside of the field of counseling that addressed in great depth (a) intersex biology, (b) former historical, nonmedicalized treatment approaches to intersex births, (c) the first medicalized approach popularized by Money, (d) social construction of sex as binary and heteronormative, and (e) the psychological and physical harm experienced by intersex individuals from parents, physicians, and surgeons who enforce the binary rule on intersex bodies. The two primary scholars that I built this foundation on are Karkazis (2008) and Preves (2003). Bioethicist Karkazis (2008), with her unique access to hospitals, provided in-depth information from physicians, surgeons, intersex individuals, and their parents. Sociologist Preves (2003) analyzing adult intersex individuals emphasizing psychological data using the Cass sexual minority identity model. As Preves wrote before the change in 2006 protocol, I also turned to Davis (2015) for content that emphasized the change in landscape since the 2006 protocol.

Of all of the scholars, I emphasized Preves for her sociological intersex adult findings. My desire was, first, to compare Preves's results with my results for validity. I



had determined to go deep with a small sample for this study, so I assumed that an opportunity to compare the four in-depth stories in this study with the breadth in Preves's study of over 20 adult intersex individuals would be interesting and useful. Second, Preves's findings represented the only major intersex work that organized findings in a format recognizable to counselors, namely Cass's sexual minority identity model. In other words, Preves's findings would likely be the most valuable foundation for counselors.

Both Karkazis (2008) and Preves (2003) remain relevant today. Karkazis's work provides a more current perspective about intersex medicalized experiences, and, as mentioned, she does so from multiple perspectives. Preves's work, however, remains particularly relevant for counselors for her in-depth interviews that emphasize the psychological effects in intersex people. Furthermore, researchers will find Preves interesting for her detail about the counselor-relevant qualitative research methodology that undergirds her writing.

Both authors have historical relevance for depicting intersex medicalized history prior to any major influence from the 2006 Chicago protocol. As a point of reference and contrast, the present study's time frame overlaps with both the Money protocol and the 2006 protocol. All of the present study's participants were youthful during the time of the Money protocol but their work as activists involves working with people who are interacting with medical professionals after the 2006 change in protocol.

Another reason I valued Preves's use of a minority identity development model is because a model is a useful tool for counselors in charting client progress. Minority identity development models identify common growth stages for individuals as they

evolve from a disvalued minority identity into an identity that no longer pathologizes self as inferior to the majority. These models are not all meant to be viewed as invariable, completely linear in time, and/or composed of a fixed set of steps that every member goes through in lockstep order. A stage framework, however, aids counselors in predicting a generally linear growth path and in preparing interventions accordingly. My hope was that by comparing the present study's results with the Preves/Cass findings, counselors seeking intersex counseling competency would feel on familiar ground. Counselors would be primed to think of intersex identity development processes given the widely known Cass identity development model. I address my goal of introducing Preves's intersex findings according to the Cass model into counseling literature in detail in the following section.

An additional goal was pedagogical. As a counselor educator, I was interested in presenting the complex intersex material in as simple yet thorough a manner as possible. I remember well the barrage of new concepts and terms as I first approached the subjects of intersex biology and intersex history. I wondered how I could make the subjects easier for others. My goal was to benefit students and motivate others to become intersex counselors. Hopefully, if the complex intersex material was organized elegantly, then more counselors might be interested in approaching the material, thereby increasing the number of competent intersex counselors. I hoped that a comprehensive, easy-to-print, and easy-to-file list of themes would provide an easily accessible resource for future counselors. Striving for pedagogical simplicity led to the new model. I compared two lists side by side—the Preves/Cass stages and themes and this study's themes. The three-stage

intersex identity development model emerged from that comparison exercise. The model is addressed next in more detail.

### **Intersex Identity Development Model Compared to Preves's Sexual Minority Identity Model**

Before comparing the two models, it may be helpful to review two assumptions about the new model. First, as has been mentioned, the three stages in the new model are social contexts. This is in contrast to other identity models. Other models use an individual's processes (such as acknowledging one's difference) or states of being such as (identity tolerance) at their highest level. This model places things that individuals do (processes) or are (states of being) at a lower tier. My rationale is that contexts explain why individuals do the things they do and achieve certain states of being. Reality is not generally the other way around. (For example, a first grader pledges allegiance [individual process] because of the classroom [social context] expectations; the youth does not perform pledging behavior in [a different social context] of a theme park.) Second, this study is idiographic. Not all themes are will apply to all individuals.

Turning now to both models, the detail in the previous section indicated that Preves and I have described essentially the same phenomenon, namely the intersex experience from 1950s through the first part of the 21st century. The present study's data in no way contradict Preves's data. Additional data were added in this study: (a) four in-depth narratives revealing intersex variation differences, (b) activism experiences, (c) counseling experiences, (d) intracommunity groups, (e) detail regarding intersex "trans" experiences, and (f) activist perspectives on a host of topics.

In general, Preves's Stage 1. Recognizing one's nonconformity, corresponds with the intersex identity development model's Stage 1. Binary-only framework: intersex as a

medical disorder. Preves's Stage 2. Acknowledging one's difference and her Stage 3. Validation of self correspond to this study's Stage 2. Breaking the binary-only framework. Preves's Stage 4. Pride in the marginal identity, corresponds to this study's Stage 3. Beyond the binary-only framework: intersex as a natural bodily variation.

Some minor differences are present. Preves's Stage 5. Identity synthesis and integration does not correspond directly with the data about activists. Activists do not "move on" and lessen the salience of their intersex identity in the same way that other intersex people may. Activists determine to stay present with their marginalized identity and keep it at the forefront of their lives. The present study's findings do not contradict Preves's Stage 5 findings; rather, the data for synthesis and integration were simply not present in this sample. Future researchers could explore the relationship between the Preves's Stage 5. Synthesis and integration (lessening the salience of the intersex identity) and this study's theme of individual self-actualization. The intersex identity development model also does not address the following Stage 2 theme in Preves's model: self according to biological logic. In another study, self according to biological logic could be included in this model's theme of discovering one's variation later in life. See Table 5 for more detail comparing this study's model and Preves's model.

**Table 5**

*Comparison: Intersex Identity Development Model Themes and Preves's Sexual Minority Identity Model Themes*

| Intersex identity development model themes   | Preves's sexual minority identity themes             |
|--|--|
| <b>Stage 1. Binary-only framework: Intersex as a medical disorder</b>  | <b>Stage 1 (S1). Recognizing one's nonconformity</b> |
| <ul style="list-style-type: none"> <li>• Born under the binary-only framework</li> <li>• Being “fixed” or “normalized” as “disorder”</li> <li>• Not knowing about an alternate framework to binary-only</li> <li>• Experiencing confusing discrepancies</li> <li>• The binary-only influences of culture or religion</li> <li>• Not allowed to exist: exterminated, annihilated, eugenics</li> <li>• Discovering one's variation later in life</li> <li>• Harm from all social sources               <ul style="list-style-type: none"> <li>○ Abuse: physical, verbal, and sexual</li> <li>○ Force-fitting: body and behavior</li> <li>○ Toxic labeling</li> <li>○ Family rejection and scapegoating</li> <li>○ Isolated, secrecy, lies, and stigma</li> <li>○ Pity</li> </ul> </li> </ul> | Performing (fit in/ease/stress/please; S1)           |

| Intersex identity development model themes  | Preves's sexual minority identity themes                    |
|---|---|
| <ul style="list-style-type: none"> <li>• Harm from mental health professionals               <ul style="list-style-type: none"> <li>○ Psychiatric false diagnoses and drugs</li> <li>○ Gender brainwashing</li> <li>○ Erasure through invisibility</li> <li>○ World Professional Association for Transgender Health (WPATH) standards misapplied</li> </ul> </li> </ul>   |   |
| <ul style="list-style-type: none"> <li>• Harm from medical professionals               <ul style="list-style-type: none"> <li>○ Medically induced “trans”</li> <li>○ Surgically erasing intersex</li> <li>○ Hormonally erasing intersex</li> <li>○ Loss of their natural intersex body</li> <li>○ Robbed of normal quality of life</li> <li>○ Lies and/or secrecy</li> <li>○ Objectified as a medical “thing”</li> <li>○ Neglected or unaddressed medical needs</li> <li>○ Iatrogenic harm</li> </ul> </li> </ul> | Erasing difference (S1)                                     |
| <ul style="list-style-type: none"> <li>• Harmed responses               <ul style="list-style-type: none"> <li>○ Shame internalized: Sex-related phobias</li> <li>○ Emotional castration, psychic mutilation</li> <li>○ Freak, monster, alien</li> <li>○ Genital exposure trauma</li> <li>○ Fear of doctors</li> </ul> </li> </ul>  | Being an object of study (shame, stigma, and isolation; S1) |
|   | Fearing the unknown (monstrosity; S1)                       |

| Intersex identity development model themes   | Preves's sexual minority identity themes  |
|--|---|
| <ul style="list-style-type: none"> <li>○ Survivor guilt</li> <li>○ Other emotional disturbance</li> </ul>  |   |
| <b>Stage 2. Breaking the binary-only framework</b>   |   |
| <ul style="list-style-type: none"> <li>● Discovering and investigating</li> </ul>  | Personal archeology (locating personal history) (S2)  |
| <ul style="list-style-type: none"> <li>● Connecting with the intersex community</li> </ul>   | <b>Stage 3. Validation of self (S3)</b>   |
| <ul style="list-style-type: none"> <li>● Realizing intersex exists and I have an intersex variation</li> </ul>   |   |
| <ul style="list-style-type: none"> <li>● Being affirmed (external support) <ul style="list-style-type: none"> <li>○ Support from intersex people</li> <li>○ Support from close family and friends</li> <li>○ Positive counseling</li> </ul> </li> </ul>                      | Telling others (breaking secrecy and isolation; S2)   |
| <ul style="list-style-type: none"> <li>● Adaptive responses (internal support) <ul style="list-style-type: none"> <li>○ Self as superhero or powerful alien</li> <li>○ Defensive faking or lying</li> <li>○ Ending secrecy, accessing medical records</li> </ul> </li> </ul> | Reclaiming the (destroyed) self (S2)  |
| <ul style="list-style-type: none"> <li>● Self-soothing: Self-protection, self-care, humor, spirituality</li> </ul>   | Doing gender (empowered performance; S1)<br>From shame to anger to empowerment (S2)<br>Humor to transform stigma (S4) |

| Intersex identity development model themes  | Preves's sexual minority identity themes  |
|---|---|
| <b>Stage 3. Beyond the binary-only framework: Intersex as a natural bodily variation</b>  |   |
| <ul style="list-style-type: none"> <li>• Clarity</li> <li>• Action: Activism or individual empowerment</li> <li>• Self-actualizing</li> </ul> | Supporting others (S3)<br><b>Stage 4. Pride in the marginal identity (S4)</b><br>Humor to transform stigma (S4) |

The major difference between the two models is organizational and conceptual emphasis, not a contradiction of data. First, I endeavored to organize this study's content in a way that supports the work of counselors. Toward this goal, I organized the content by more explicit and detailed lists of harms, sources of the harms, harmed responses, and adaptations. Preves's similar content was provided in her chapter descriptions, and hence she provided a fewer number of themes. Hopefully this study's counselor-relevant organization will be useful as easy to scan and thus lead to improved intersex counselor competency training.

Second, as mentioned, the key conceptual difference between the two models is that the Preves/Cass model's emphasis is on the level of an individual's experiences in identity development. The Preves/Cass model emphasizes an individual's coping processes or states of awareness as the highest order of organization. The data are essentially the same in the two models.

Conversely, the intersex identity development model emphasizes the social framework first and the individual as second tier. Social context is at the highest level in this model because social context drives/explains the second-tier level of an individual's



processes and states of being. Contexts emphasized are Stage 1. Binary-only framework: intersex as a medical disorder, Stage 2. Breaking the binary-only framework, and Stage 3. Beyond the binary-only framework: intersex as a natural bodily variation.

The intersex identity development model highlights that contexts propel process. Growth from Stage 1 to Stage 2 happens because the facts stop adding up in Stage 1, leading to breaking. The facts do not fit reality because an intersex person is not in actuality a disorder to be fixed/exterminated. The discrepancies that crop up demand exploration, exploration leads to like others, and new information arrives that disproves Stage 1. The title of Stage 2 may sound like an individual process given the term breaking, but the context is a social context of flux. The identity reorganizing that takes place in Stage 2, the context-in-flux, leads to Stage 3, a new framework of nonpathologized intersex identity. Below the level of contexts, what gets emphasized are the purpose-driven processes native to human intentional endeavor that are derived from the social contexts in which they occur. These human processes are captured in the new model as themes. Besides human processes, other germane elements are included such as context-defining ideas.

The stage titles in the intersex identity development model emerged from thinking about Preves/Cass stage titles. To me, the titles of the Preves/Cass stages seemed to describe individual processes not instantly recognizable by the contexts that produced those processes. (This is a statement about pedagogical presentation of high-level concepts for the sake of faster absorption of material, not a critique of Preves's content. As can be seen Chapter 2, Preves provided thick, rich detail in her chapters about the same contexts described in the intersex identity development model's stage titles, namely

Money's medicalized intersex treatment, reorganizing self-concept, and arriving at a new, nonpathologizing framework.)

Third, making a distinction in this study between context and process was important in terms of the judgements about where human problems are located and therefore how counselors treat them. Are they problems in society or in the person? Treatment to fix society is political; treatment to fix an individual is personal. This model makes the distinction between individual processes and social context for the same reason that feminism counseling uses a social systems approach and contrasts itself with psychological or medical treatment models. If an individual comes in upset, a therapist using a psychological approach might target a change in the person's internal thoughts. A medical model clinician might look at medicating the person's apparent depression. In other words, those models place the problem inside the individual. A feminist counselor instead would look at a higher level than the individual's processes and examine the social context of the depression. The feminist counselor might explore whether in that person's work or home life was there a context of that person being repeatedly oppressed. If so, the feminist counselor would want the person to recognize the oppressive social context, not place the blame within themselves, and work on changing or extricating from a context that is the cause of the depression due to its unfairness and/or abuse. Intersex people are constantly "blamed" as having disorders in themselves and are then treated by therapy and surgeries as if the problem is in them, when actually the binary context is the source of the problems and an alternative context is the source of solutions. In the new model, I wanted to emphasize that the problems intersex people experience do not originate in them but instead in the harming binary context. Alternative helpful intersex

contexts can be found and lived in as defined, made, and maintained by the individual and their supportive network.

Fourth, and most important, Preves putting her intersex data into the Cass model did not seem to do justice to the unique horror we both documented in our respective intersex studies. The intersex stories we both collected seemed qualitatively different to me than anything I had experienced in counseling sessions or anywhere else for that matter. Placing intersex people into the Preves/Cass sexual minority identity model seemed to imply that once you understand the Cass model, you understand the intersex medicalized experience. This idea did not seem to do true justice to the unique intersex physical and psychological horror in which infants are denied self-determination by socially endorsed surgical, hormonal and behavioral treatments. All of the present study's participants used the same extreme terms that I did not witness in other social contexts: freak, monstrosity, superhero, alien, extermination, annihilation, not allowed to exist, and the most shocking, eugenics. The very existence of intersex people is not allowed, whether by definition (only male or female exist) or by the actual surgical or hormonal forces working to make the intersex body disappear. A different intersex identity development model seemed necessary to represent the horror that distinguishes intersex social and medical treatment from other minorities. An intersex identity development model should highlight the context that produces intersex harm in the first place as its Stage 1. Binary-only framework: intersex as a medical disorder.

As I worked out the reality of a three-stage model in my own mind, I could perceive the difference in the two model's relative ability to describe intersex horror by my using a lens of narrative comparison. I told myself a story using Preves/Cass model

titles and themes below them and then did the same with this study's model for comparison. In the Preves/Cass model that emphasizes an individual's "story," the intersex person goes through five stages. In Stage 1. Recognizing one's nonconformity, the person is pathologized, erased, shamed, isolated, and feels stress to fit in. In Stage 2. Acknowledging one's difference, the person develops some agency, puts an end to secrecy, learns about self through medical records, and begins to reclaim a destroyed self, moving from shame to anger and then empowerment. In Stage 3. Validation of self, the person affirms self in the process of developing a supportive community. In Stage 4. Pride in the marginal identity, the person is clear and proud and engages in political action to advance the interests of the community. In Stage 5. Identity synthesis and integration, the individual has absorbed the marginalized identity into self in peaceful balance with other identities.

The Preves/Cass stages in that story seemed coherent about a path of growth but they also seemed somewhat independent of one another. Why do those stages happen? What drives the movement of those stages? In contrast, the following is the story I endeavored to tell about the same data with the intersex identity development model, differently presented in a way that focuses on the social context as influencer/driver of the movement through the three stages. The social context drives/influences growth due to its horrific impact upon intersex lives. In Stage 1. Binary-only framework: intersex as a medical disorder, intersex people are born into a social framework that only recognizes male and female. Intersex people are therefore only allowed to be a disorder that gets fixed by surgeries and hormones. The person is confused and endeavors to fit in, but the methods do not work to make the intersex person fit in. The "fixing" produces harm

because intersex bodies are not exactly like male and female. The “fixing” harm comes from social, medical, and mental health sources. The harm is physical and psychological. In the Stage 2. Breaking the binary-only framework, the individual’s discrepant physical and emotional experiences that are outside the BOF have begun to challenge the BOF framework. The individual reaches out, connects with similar others, and begins to learn over time that there is a different, nonpathologizing way to think about self. In Stage 3. Beyond the binary-only framework: intersex as a natural bodily variation, the individual is clear about the harm that was done in Stage 1 and has a clear nonpathologized way to think about self. Enlightened action is taken at various levels. An individual-level action may involve, for example, not putting one’s self in a situation that brings medical harm. A community level of action is seen in the work of some individuals in the form of activism. The person selects nonpathologizing personal goals in pursuit of individualized self-actualizing. A far personal distance has been traversed from the original and horrific BOF context.

Fifth, it may be remembered that a goal in this study was to present in deep narrative form, a few intersex stories illustrating variation differences. For what seemed missing from all the multidisciplinary research literature to date was in-depth stories to reveal just how different the narratives of intersex people can be from each other. However, I initially experienced this goal as being uncomfortably at odds with my other desire of encouraging more counselors to develop proficiency in a complex area. Given a goal of increasing the number of trained counselors, an endeavor that added narrative complexity to the literature seemed to be heading in the wrong direction. I thusly valued the new model as a solution to that problem. The simplicity of three stages, not five, is

easier to remember and seems to capture the essence of context-driven intersex growth processes regardless of intersex variation differences.

In summary, the present study's findings provide justifications for this new model, including the simplicity of a three-stage model compared to the five or six stages in other identity models. The new model is offered as "an easier to remember" type of identity development model because this model emphasizes social context at its highest level. There are fewer social contexts to remember than the stages in models that promote individual processes or themes to their highest level. Below the level of stages, themes in the new model are listed with their own dedicated title to provide counselors with an easy-to-scan list of possible issues.

The model's primary justification, however, is its explanatory power. The horror of intersex medicalized treatment is not adequately represented by models that place individual processes and states of being at their highest level. The highest level of an intersex identity model's organization should emphasize the social context that produces intersex harm in the first place, namely the social context of a binary-only conceptualization of sex biology.

### **Limitations**

This study provided in-depth interviews of four people with different intersex variations. As there are well over a dozen different intersex variations, additional interviews reflecting different variations might have yielded additional insights. Two of the four individuals had "trans" intersex experiences. In the intersex population, a "trans" plus intersex experience occurs in less than 50% of the population; thus, the study's findings were skewed in the direction of the complex intersex "trans" experiences.

Though I was willing to go anywhere in North America to achieve the targeted number of interviews for a small population, the participants were all located in the eastern United States. None were in rural settings; all had experienced medical care through major hospitals. Thus, rural, nonmedicalized, economically disadvantaged, intersex experiences were not represented. As previously mentioned, especially disappointing to me was the fact that persons of color were not represented in this study. A very helpful and important study would focus exclusively on the intersex experiences of activists who are also persons of color. The sample size was small according to IPA recommendations for proper attention to idiographic detail. Obviously, more interviews would have provided more idiographic perspectives.

Two participants requested three interview sessions; two others requested only two sessions. The three session interviews were deeper in depth; hence one intersex “trans” person and one person who was not intersex “trans” received greater representation in the study content. All participants were over 40 years of age; thus, younger experiences were not represented. I do not possess an intersex variation. Insider status might have led to deeper disclosure although I did not perceive that the participants held back information given the graphic detail provided in the interviews.

The intersex identity development model is a reflection of my findings. It is a model of the identity development of the participants in this study of intersex activists. To the degree that their experiences represent the experience of others in the population of intersex, the model may apply more broadly. However, I did not survey the intersex population as a whole, and any generalizations must be qualified. It is possible that there are intersex cases where an individual was treated by medical professionals, was satisfied

with the results, and essentially lived a life without the need to become independent from a pathologizing framework. However, given the nature of the intersex experience of daily exclusion from a binary-only world and the implications of that at social and personal levels, it may be unlikely that an intersex person simply adapts to the binary world and lives a life without complications or consequences. Therefore, given that activists often have a highly developed consciousness about their experiences and the experience of other people like them, it is possible that their experience has credibility as representing the intersex medicalized experience in general. Future research will be necessary to determine the degree to which the intersex activists' experiences are representative of some portion of the larger population of people with intersex variations.

### **Delimitations**

It is especially germane to place the Preves model, its participants, and its findings and this study's model, its participants, and its findings in context of key historical events for the intersex community. Preves wrote 3 years before the 2006 Chicago Consensus in which Money's optimum gender of rearing model/concealment model/genitals make gender model was replaced by the new 2006 model involving disorders of sex development multidisciplinary team clinics (DSD MT clinics). The present study's participants, just as Preves's participants, were all born during the time Money's concealment model predominated. In contrast to Preves's study, participants in this study have lived for over a decade since the advent of the 2006 protocol.

As mentioned, a key 2006 Chicago Consensus recommendation was that DSD MT clinics are supposed to reveal the variation diagnosis and the actual nature of any surgeries to the parents as a part of informed consent. In other words, there has been a protocol shift away from the extreme secrecy and lies operant when Preves wrote. As time has moved



on, the medical profession's ability to maintain the extreme secrecy and lies detailed by Preves has been impacted by activist protest and by wide access to information through the Internet. The secrecy and overt lies about the nature of removed body parts and the lies about there being no others, as revealed by Preves and in this study, are perhaps lessening somewhat.

In summary of a historical placement for this study, there has been some improvement in secrecy since Preves documented her findings. Hopefully, more is coming sooner than later. The framework lie of 2006 protocol conceptualizing intersex as disorder is new since 2006. The most salient fact related to ongoing harm to the intersex community remains the same pre and post 2006. Nonconsensual optional intersex infant sex-related surgeries are continuing.

A few other delimitation observations follow. The three stages in this study deemphasized the Preves/Cass final stage of synthesis and integration. (Preves herself did not focus in great detail on her final two stages of pride and synthesis and integration but her discussing them somewhat served a benefit of demonstrating applicability of all of the Cass stages.) Preves's synthesis and integration data were not contradicted in the present study; rather, similar data were just not found because the activists did not deemphasize their intersex identity. They appeared to demonstrate a super strong version of pride. The activists in this study are all determined to remain active for a lifetime. If results from this study had not led to a new model, I might have suggested a sixth stage for the Preves/Cass model, on the other side of synthesis and integration, for activists because they are willing to take on the challenges of their community for a lifetime, selflessly sacrificing their own emotions by reexposing themselves daily to the same

horrors that trigger their own PTS for the sake of children like themselves. Intersex activists remind me of other dedicated social servants who have been recognized nationally and internationally with peace awards. Such a degree of life-time community devotion strikes me as beyond both the fourth stage of pride and the fifth stage of synthesis and integration.

The following remark concerns the intersex identity development model's Stage 3 theme of action. The three-stage intersex identity development model is proposed to work for intersex people who come to see themselves as having an intersex natural bodily variation, not a disorder, but who are less committed to action than the activists interviewed in this study. I discerned no compelling need to differentiate how much action follows clarity. The activists in this study demonstrated an extraordinarily high level of action, but in another study other intersex people might demonstrate less action and perhaps, over time, a lessening of importance of being intersex to their identity; that is, Preves/Cass fifth stage of synthesis and integration.

As previously noted, individuals with different variations may have different perspectives regarding whether intersex variations should be "fixed." If the individual embraces the notion of being disordered because when medical "fixed," they see themselves as either male or female, then the two stages after the binary-only framework would not transpire. Second, this study's model may have a partial exception regarding intersex individuals who do not see themselves as disordered yet who sometimes wish to remain under the medical model of disorder. This can be for a practical consideration of wanting to avail one's self of needed medical care and thus tolerating, but not believing, the disorder framework. Finally, even though the I presented a new model to describe the

unique horror of medicalized intersex experiences, it occurred to me that the model very well may apply, with adaptations, to other sexual minority or race minority populations. However, considering such extended application of the model is beyond the scope of this study.

### **Implications: Counselor Practice, Training, and Research**

#### **Avoiding Common Terminological Errors**

Mixing terms related to gender (identity) with biological sex terms is a very common error. The errors are common because they are embedded in society (i.e., the BOF, in which all boys are male and all girls are female). In other words, avoiding common errors means making intentional effort to resist the gravitational force of social assumptions. The activists in this study strongly preferred that intersex be restricted to biology only; intersex variations involve sex biology that is physically different from male and female. Intersex variations are not the contrast to boy and girl, which are gender terms. Mixing gender and biology weakens the political focus on the harm happening to intersex people because of their intersex biology. Accordingly, it is a significant error to say intersex identity because intersex identity is a gender term. Intersex biological variations and intersex natural bodily variations are the correct terms.

Distinguishing intersex “trans” from endosex trans is important for the goal of not erasing anyone’s differences, intersex or trans. The surgical and political issues are different. One place this occurs is in counseling texts. Placing all intersex information in a counseling chapter with all endosex trans information is a mix of focus on a subject (intersex) that primarily emphasizes biology and medical issues with a subject (endosex trans) that emphasizes gender and medical issues. For textbook space reasons, it might seem logical to combine intersex people who are intersex “trans” with endosex trans, but

doing so can be viewed as offensive given that most intersex people are not trans. Placing the two subjects in the same book chapter can perpetuate the notion that counselor educators do not realize that most intersex individuals are not intersex “trans.” The subset of intersex persons who are intersex “trans” and endosex trans do overlap many issues but they are distinct as well. If those two groups are combined in one chapter, then there should be a separate chapter for the bulk of intersex content that in fact does not pertain to trans.

### **Addressing the Counseling Training and Research Vacuum**

There is no comprehensive intersex training program available for counselors compared with training available for other multicultural issues. Professionals in mental health are regarded by many in the intersex community with suspicion if not outright disdain. This is not surprising even apart from John Money’s legacy as the originator of medicalized harm. Intersex counseling needs remain largely unaddressed.

It is very disturbing to think that intersex individuals and families are going to counselors who have not been trained in the unique and complex needs of the intersex population. It is unethical for counselors to treat clients without adequate training. Unfortunately, there seems to be a “Catch 22.” It is unethical for counselors to treat individuals when untrained, yet there is no comprehensive training available to teach counselor competency in intersex issues. All participants in this study indicated that counselors are not trained to provide for the counseling needs of intersex people. There were several stories of how an intersex person or parent went to a counselor and paid for an hour only to spend the hour educating the counselor. If over 50% of a counseling session is devoted to counselor education, then the counselor should consider not charging the client for some portion of the session. This issue may seem small to a

counselor, but the activists' stories indicated that the single practice of counselors taking payment from intersex people for counselor education is a barrier to seeking treatment.

The intersex population is relatively small compared to the population as a whole. The number of trained counselors will likely remain small. Client numbers in any one practice are likely to be few, which is a disincentive to gaining competency in those counseling needs. Furthermore, the issues are complex, which serves as another disincentive to develop competency.

Technology and the online world will hopefully address these issues by opening up specialized training and outreach opportunities for a geographically diverse population of both intersex people and their trained counselors. Technology could also be helpful in developing longitudinal studies of quality of life. Longitudinal studies of quality of life, long absent in intersex medicalized history (Human Rights Watch & interACT Advocates for Youth, 2017; Lee, 2016) are needed to sample not only patients who are accessible through physician and surgeon medical records and also those who have left or do not enter the medical sphere for the harm it produced or for lack of access to medical care.

Autobiographies of intersex activists are increasing. Counselors can receive helpful training by reading firsthand accounts and joining intersex support and/or Facebook groups to listen and learn. Counselor educators could develop intersex counseling training programs and require students to read texts by authors outside the field of counseling until the counseling field has adequate texts in its own right.

Counseling education cannot be competent without sufficient research. The primary psychological literature published to date references psychosocial support for parents as provided by DSD clinics according to the Chicago 2006 Consensus

recommendation. However, the details on the counseling in DSD clinics are not clear. What is a clinic's master plan for psychosocial support? Is a counselor on staff or available through referral only? How many times do parents see the counselor? Is the emphasis on facilitating surgeries? Is psychosocial support only on clinic days? What are the treatment plans? What are the measures of success? How many sessions are included? What are the plans for long-term follow up? A comparative study regarding counseling being provided in the various DSD clinics would be informative. It is disturbing to wonder if the counseling being provided is promoting infant surgeries instead of providing fully informed consent processes. As mentioned, one participant wondered whether parents are being told during the informed consent process that nonconsensual infant genital surgeries have been deemed torture by the United Nations.

Counseling needs pertaining to the first few years of life are very important. Also unaddressed, however, are the lifetime and transitional counseling needs beyond the clinic years of youth. Counselors should develop quantitative studies to document impacts over the lifespan of the medical approaches that pathologize and "fix." In summary, counselor education, counseling research, and trained counseling for intersex individuals and their families are underdeveloped services.

### **Trauma, Grief, and Other Avenues for Needed Research**

Consider a true story relayed by Val/Valerie. This one story could occupy a counselor researcher for a long time, shed insight, and lead to training on important needed topics. A recently married woman who did not know she had the complete androgen insensitivity syndrome (CAIS) variation went to a medical doctor to find out why she could not conceive. The physician "explained" that she could not conceive because she was "really a boy," thereby traumatizing her with language that implied

falsely that her chromosomes made her gender. In fact, she was just as much a woman as she had always been. She just happened to learn now that she had XY chromosomes that impacted her fertility. Neither she nor her husband coped with the news. He divorced her. She never absorbed that chromosomes do not make gender. Homophobic and transphobic, she could not cope with feeling that she was now “one of those” as she had always put down gay and trans people.

Sadly, her self-assessment was false, even on her own homophobic and transphobic terms, as she never became a gay or trans person. Gender is not biology. Gender is in the brain “between the ears.” Intersex is sex development biology. The woman remained the same heterosexual woman she was before learning that she had XY chromosomes. Unable to cope, she tragically committed suicide. The needed set of research topics to be mined in just this one single story include intersex medical provider communication training, intersex trauma, intersex infertility grief, intersex variations overlap with homophobia and transphobia, XY woman and XY man heterosexual marriage issues, and intersex infertility counseling.

### **Develop Intersex Counseling Competency by Variation**

As discussed several times, through conducting this study, I explicitly intended to point to the importance of counselors developing a nuanced understanding of intersex experiences by variation. For, as covered, intersex variations vary in their biology and their medical treatment for that variation. Thus, the physical and psychological harms also differ by variation. Given the numbers of the variations, variation-specific knowledge of well over a dozen types might seem an insurmountable obstacle; however, a minimum bar of counseling competence could be obtained by becoming familiar with perhaps six common variations: congenital adrenal hyperplasia, complete androgen

insensitivity, partial androgen insensitivity syndrome, hypospadias, Klinefelter syndrome, and Turner syndrome. For each variation, the counselor could become familiar with its general sex development path, physical projections for secondary sex characteristics, general hormonal needs, common long-term health issues, typical “fixing” approaches, possible fertility issues, possible learning issues, names of variation specific support groups, name of the primary activist organization, interACT, and knowledge about whether members of that variation tend to see themselves as having an intersex variation or not. Activist Mx. Anunnaki Ray Marquez created a valuable set of intake questions for intersex client intake titled Suggestions for Intake Forms for Intersex Clients (see Appendix J).

### **Final Observations**

#### **Using Medicine Appropriately to Address Actual, Not Imagined Intersex Medical Needs**

The appropriate use of medicine is to address real and underresearched medical needs of intersex people. All of the activists described complex hormone needs related to intersex bodily variations, and they all stated that intersex people are medically underserved. Unfortunately, having more endocrinologists and internists research and support intersex hormonal and medical needs is not going to make surgeons stop operating unnecessarily.

#### **Operant Quantum Physics Observation Principle and the Binary-Only Prison**

Findings from this study evidence the quantum physics principle that the act of observation is not static: observation affects the reality observed. This study evidenced the interactive change of researcher and reality observed. For example, after many talks with the activists, the term nonbinary made less and less sense to me. In its place, I



thought “beyond the binary” seemed more appropriate, and I shared this insight with the mentor activist. I said,

The more I think about all of this, nonbinary does not make sense to me in context of biology. The term seems to say, binary biology is real and then there is something other, nonbinary. If, however, binary biology is not real, only continuum is real, then the term nonbinary seems to pivot from a category that is not real in the first place.

The activist responded by changing his perspective. He began using the term beyond the binary in his writings.

My family changed in the process of their observing me observing. Early on in the research process, I was shocked when my heterosexual husband of almost 40 years asked me if my research interest meant I was going to come out as lesbian. I was similarly shocked when both of my adult endosex children independently asked if they were intersex and had just not yet been told. As I observed my own family’s disequilibrium at learning about exceptions to the binary, my own sensitivity grew regarding challenges other families encounter when incorporating their child’s intersex variation into their family dynamics. The new sensitivity no doubt affected the interviews through deeper probing about family adjustment, which in turn may have contributed to some change in intersex activist reality about whether counselors can be sensitive to intersex family issues.

My perceptions about my own gender changed. After decades of thinking these issues were completely stable as female, woman, heterosexual, my personal changes were at first unsettling. Heterosexuality did not shift, but my gender identity did in small but

significant ways. I noticed growing more and more comfortable with myself when I interacted with my activist mentor who had lived as both man and woman and now lived as man. I experienced the mentor's gender identity, though man, as broader than what I was used to as man in the man/woman binary. The mentor's gender breadth highlighted a tension in me that I sometimes felt wondering if I was fitting (my own idea) of the woman gender box. Worries of sometimes being too dominant, too goal driven, or not having much to say in a group of women had long produced internal tension in me. Over time, I noticed less internal judgement about my own gender identity and gender expression.

My experience was one Preves (2003) pointed out. Preves observed that given the centrality of sexual identity, when some aspect of sexuality shifts, be it gender, physical sex, or orientation, other aspects of the self may go into a period of unsettled reshuffling. By breaking some of my own binary box, I gained a new measure of personal comfort after an initial phase of discomfort. The point being made is that the binary-only box imprisons heteronormative people too, and acts of stretching to appreciate diversity increases freedom for all.

No diminished value in this study was perceived as a result of the unavoidable change that occurred through qualitative researcher–interviewee interaction. Rather, the specifics of the interaction were to be recognized and acknowledged. My ethical duty was to attempt to separate self from subject (i.e., phenomenological bracketing) during data analysis but also to present how influence likely occurred to help the reader more fully appreciate the findings. Findings from this study hopefully serve as an example of how

the mutual influence between researcher and participant in some measure benefited the study, the researcher, and the participants.

### **Descartes Has Something to Say**

Perhaps Descartes has something to say regarding why intersex discrepancies start to stack up, resulting in wider and wider cracks in the BOF until the framework finally breaks. Descartes came to the conclusion that the one undoubtable thing is one's own existence, for to doubt that, one would have to have an existence to do the doubting. The BOF runs headlong into Descartes's "Cogito, Ergo Sum" (I think, therefore I am) when it tries to tell an intersex person they do not exist when in fact they do. Intersex people ultimately fight/reject/move from the BOF because they in fact exist. For intersex people to willfully comply forever with erasure/eugenics means that what exists would have to agree that it does not exist. For a while, society can get away with a sort of reverse "Emperor's New Clothes" illusion in which we say over and over, "Intersex does not exist! Intersex does not exist!" Making that claim over and over, with hormones and surgeries, however, does not change the fact of intersex existence. The emperor claimed over and over he had clothes, doing so did not make it so. In these stories, intersex activists live in ignorance for a time regarding BOF in which they were not supposed to exist. Intersex people can for a time try to fit the binary boxes but trying does not work well because intersex people do exist, and so the cracks of discrepancies start to appear. The one thing that does not stand much chance of lasting is asking a person who exists to deny that they exist, for at some point they likely feel, if not say, "Cogito, Ergo Sum."

### **This is Eugenics**

During early days of data analysis, I internally flinched when the activists used the term eugenics. The term is terrifying, not usual in conversation, and reserved for the very

worst that humans do to each other. Were these activists overstating, prone to drama, and/or unaware of clear eugenic contexts like the Holocaust? After immersion in the data, and hearing terms like extermination, annihilation, and not allowed to exist over and over, and then trying to imagine what it must feel like to use those terms, I no longer resisted eugenics as an exaggerated expression, and not just because some intersex fetuses are actually being aborted.

It is absolutely true that eugenics to describe intersex has to be distinguished from eugenics that leaves mass graves and skeletons that bear witness to horrific crimes. Except in cases of abortion, there is no tangible connection to cessation of brain activity, etc., by what intersex surgeons and other professionals are doing. However, what other English words are available to describe “You are not allowed to exist as intersex, you are nothing if not boy or girl, and social, medical, and mental health professional forces will do everything to make sure you are fixed because ‘disorders’ must be fixed?”

The truth seems to be that current language usage struggles with what is happening to intersex people. Typical language such grief, shame, isolation, and oppression seem tremendously watered down and not at all representative of the depth of intersex emotional pain from being annihilated as a disorder. I came to the conclusion that intersex eugenics is not the same as the Holocaust eugenics, but it is closer than not.

### **Medical Hubris and Law of Unintended Consequences: Stigma Created, Not Prevented**

The previous discussion begs the question, how can good medical intent go so wrong? The gap between the physician/parent communication, “I’m going to surgically alter your genitals without giving you a choice because this really for your own good,” to the receiver’s adult meaning, “This is eugenics!” reflects a huge gap in sender–receiver

communication. Surgeons may think that making a baby's genitals prettier for mom and dad and society is a good thing. Tragically and ironically, medicalization creates the very stigma it seeks to prevent. Physicians and surgeons themselves are the ones creating the very first and lasting stigma, not the bullies on the playground.

The stigma that physicians and surgeons create does not get erased. Scars in the mirror last a lifetime. According to one participant, the psychological scarring is even worse. The human hubris of "I am a surgeon, I can fix" meets the law of unintended consequences, resulting in tragic, horrific toll to intersex people.

I am baffled by the following. Medical minds somehow find it logical to create a first stigma (being born so unacceptable that one is surgically altered in infancy) as a way to prevent a second stigma (i.e., playground bullying or family rejection). Is the first stigma imagined to magically disappear in pursuit of ameliorating the second stigma? Can it be that medical minds really do not see the first stigma? The activists more logically connected a social need with a social solution, finding a supportive community.

### **AND Thinking Is a Muscle**

Mitt said either/or thinking is the problem and that AND thinking is the actual way of the universe. "We (intersex people) are not complicated, but we are complex. This isn't nature or nurture, that was a fallacy, it's another binary, it's another either/or, it's another black or white, when the whole universe is AND." Angelo said pity (about disorder) leads to the surgeries. The two notions of either/or (absolutist) mind set and pity are connected.

Intersex people suffer because of either/or, black or white thinking, in other words, male/female OR disorder instead of male/female AND intersex. In absolutist thinking, after a mental division is made of either/or, then one side is judged negatively.

Since intersex is on the “wrong” side, next comes the evidence of the negative judgement—pity. Intersex people happen to have atypical genitals in a world where the majority have male or female genitals. Black or white (absolutist) thinking leads to “I pity you because you didn’t land on the “right” side of what sex development is supposed to be. I pity you because you are not in the majority.” Mitt described pity as “Sucks to be you! We’ve all heard that ‘sucks to be you’ in one way or another in one form or another. [It means] you should never have been born.”

Intersex (wrong)/typical genitals (right)—is this just the way the world has to work? Do we have to accept that those of any minority who happen to land on the “wrong” side of either/or thinking should just be pitied because “It sucks to be them?” Is this absolutely necessary? For chickens and their pecking order, mostly likely yes, but perhaps not for humans with consciousness and conscience.

Maybe there is training that fosters AND thinking. What is the difference between the thinking that is reductionist, (either/or, black or white, right or wrong) and thinking that is expansive? What if either/or thinking is a helpful skill and there is more of it around because it is an easier skill to learn, and AND thinking is also just another skill, but more complex and therefore more in need of instruction? What if AND thinking came to the forefront of education? What if half of a course focused on black or white thinking native to that field and half of the course emphasized AND thinking possibilities for that course, so much so that graduates were automatically aware when they were wearing their either/or thinking hats and when they were wearing their AND hats. What if the graduates became so trained in knowing which was which that when they thought of

using one hat, doing so automatically begged the question of what do I now need to do to look at the data from the other hat?

The AND thinking in this study was honed through training. Counselors are trained, for example, to think AND through the requirements related to mastering various counseling theories, including, for example, knowing how to think and treat using psychodynamic, person centered, family systems, etc. Training in the various theories of counseling helps to create the awareness there are many different systems or ways to look at human thought, emotions, and behaviors, each with different principles and different powers of explanation relative to different populations. The training of every first-year counseling student is therefore not just either/or.

Cottone's (2012) *Paradigms of Counseling and Psychotherapy* raised counseling's AND training to a whole other level by organizing the various theories of counseling into four paradigms or meta theories of counseling: the organic medical paradigm, the psychological paradigm, the systematic-relational paradigm, and the social constructivism paradigm. It was that training that helped to create my awareness that intersex people are being treated according to the organic medical model with its disease orientation to human suffering. Under this model, an individual's problems are treated as illnesses and therefore in need of treatment. The AND training I received in counseling helped me see that intersex people are now engaging in socially constructing an alternative paradigm in which intersex is not a disorder but a natural bodily variation. Finally, it was that social constructivist and paradigm training that lead me to ask, "What is at the next higher level (similar to a paradigm) 'located' higher than the individual responses evidenced in the data?" That AND thinking question led to the higher,

framework (i.e., context) levels of the binary-only, breaking the binary-only, and beyond the binary.

A benefit of “up and out” AND thinking training in any field is that the problems that occur at one level of thinking open up to new possibilities for new solutions at a next higher level. If intersex surgeons were not occupied with thinking either/or, right or wrong, “Sucks to be you, but in my pity I will fix you with my knives,” then possibilities for researching the unique hormonal needs of intersex people might lead to discoveries about hormones that benefit the majority, not just the minority. As one participant discussed, hormones are not just sex hormones. They impact every cell, not just reproductive organs.

In *Lessons From the Intersexed*, Kessler (1998) provided up-and-out thinking for the fields of sociology, feminism, and gender studies with her book’s focus on intersex issues and her explicating the systemic assumptions behind heteronormativity. In other words, AND thinking can be taught in any field just as much as either/or rules-based thinking is taught. AND thinking, when exercised, grows like a muscle. With AND thinking comes the awareness of just how prevalent reductionist thinking is. Thinking in binaries with only two options (i.e., right/wrong, either/or, black or white, male or female only, etc.) is artificially reassuring as a mentality for its simplicity but it is an infertile mentality for ideas. More importantly, either/or thinking is often scientifically erroneous as it is in when sex biology is viewed as male or female only. New worlds of opportunity and solutions open up beyond binaries, where diversity is cherished and explored, not just judged and “fixed” out of pity.



## **Ethical “Con” Argument Trumps A Surgical Prowess “Pro” Argument: Infants Should Have A Right of Self-Determination**

Time is a factor that unfortunately tends to result in medical dismissal of intersex adult claims about their harmed experiences during infancy. Surgeons can claim that all harm is in the past. The infant is never in a position to complain, and it takes approximately 30 years before infants grow to be intersex adults capable of speaking out about damage that began in infancy. In other words, complaints from an adult years after the surgeries were conducted have a built-in way to be dismissed. Surgeons can always say that their surgical skill has improved since the person’s infancy.

A way to address this problem is to raise the level of the argument. The most important issue is not surgical but ethical. Perfect surgical technique cannot undo the ethical violation of denying an individual their right to self-determination over their own body and gender when there was no health-based reason for doing so. The profession of counseling through its counseling advocacy is in a strong position to help make ethical claims in support of intersex infants’ right of self-determination over their own bodies. Counselors are frontline witnesses to the long-term damage that results when people experience loss of autonomy over their bodies, for example, as in cases of domestic violence.

### **Counselors Should Be Involved With interACT**

Counselors are now increasingly involved in the story of medicalized harm to intersex people whether they realize it or not. As counselors, we are associated by virtue of our profession with Money and Ehrhardt, who were psychologists. Even more important, counselors are now associated with the new 2006 Chicago Consensus protocol

of treating intersex infants as disordered in DSD MT clinics. Counseling is supposed to be happening in clinics that provide intersex infant optional sex-related surgeries.

There is a window of time before counselors will likely hear from activists. The year can be estimated based on how long it took for the first wave of activists to get old enough to protest (about 30 years). Subtract some years (estimate of 5) because now the Internet makes information readily available and provides the opportunity to connect with and learn from like others sooner. Add a couple of years for an estimate of how long it took to get the DSD MT clinics operational. Add 25 years to 2006 (the year of the Chicago Consensus) and 2 more years. The estimated year the world will likely start hearing from U.S. (and European) intersex people who were harmed and only treated under the 2006 DSD MT protocol is approximately 2033 (2006 plus 27). From that point forward until the legislative bans are achieved, counselors will be implicated in harm to those whose self-determination was taken under DSD MT care. Ideally the bans will happen well before that date.

Our voices as counselors opposing infant sex-related surgeries need to be heard in the public sphere to distinguish ourselves from therapists who are willing to participate in clinics that provide ongoing optional infant sex-related surgeries. interACT's website has a section with instruction for how to support its efforts (interACT Advocates for Youth, 2019a). At a minimum, individual counselors and the ACA should write letters in support of interACT's efforts to achieve legislative bans on infant optional sex-related surgeries designed to fit them as "disordered" into the binary boxes of male or female.

## **Counselors: Erase Pity, Pity Kills, Cherish Diversity Instead**

In conclusion, I am reminded of what one activist pointed to as the fundamental cause of all this harm to intersex infants. In tears, Angelo discussed how pity is what leads to intersex mutilation:

Often times when I see a doctor or counselor—not just counselors, even people who I have educated like a gay man for instance—they are really sad to find out I don't have a typical penis. They almost have this grief for me that's really uncalled for. I get the same sympathy and empathy from some counselors and doctors. You all do not understand.

Angelo then quoted from Herculine Barbin, a famous intersex person of the 1800s who was tortured by society and ultimately committed suicide:

You are to be pitied more than I, perhaps. I soar above all your innumerable miseries, partaking of the nature of the angel. For as you have said, my place is not in your narrow sphere. You have earth, I have boundless space. Enchained here below by the thousand bonds of your gross material senses, your spirits cannot plunge into that limpid Ocean of the Infinite, where lost for a day upon your arid shores, my soul drinks deep. Don't pity me, I pity you. My empathy and sympathy are for you because when they erased me they took away your ability to see the beauty of human diversity.

The horrors of intersex erasure and eugenics flow from pity. Pity, in turn, flows from either/or thinking. Intersex harm occurs when we falsely, in either/or, right or wrong thinking, assume that surely everyone needs to be male or female and have a “normal” appearing penis and vagina. Our pity then flows toward those who do not fit our either/or thinking. Surgeons then surgically “fix” those intersex genitals out of our collective pity.

Every single counselor has a role to play from home and office in changing the horror of intersex “fixing.” In our imaginations, we can call up images of intersex genitals and erase any pity (or rejection) that arises in our hearts and minds. See those diverse images and overlay them with thoughts about the genuine beauty of diversity. Say as mantra: intersex natural bodily variations.

## References

- Accord Alliance. (n.d.). *Welcome to Accord Alliance*. <http://www.accordalliance.org>
- Alderson, K. (2013). *Counseling LGBTI clients*. Sage Publications.  
<https://doi.org/10.4135/9781452244068>
- ALGBTIC LGBQQA Competencies Taskforce, Harper, A., Finnerty, P., Martinez, M.,  
Brace, A., Crethar, H. C., Loos, B., Harper, B., Graham, S., Singh, A., Kocet, M.,  
Travis, L., Lambert, S., Burnes, T., Dickey, L. M., & Hammer, T. R. (2013).  
Association for Lesbian, Gay, Bisexual, and Transgender Issues in Counseling  
competencies for counseling with lesbian, gay, bisexual, queer, questioning,  
intersex, and ally individuals. *Journal of LGBT Issues in Counseling*, 7(1), 2–43.  
<https://doi.org/10.1080/15538605.2013.755444>
- American Counseling Association. (2004). *ACA Governing Council resolution to protect  
intersex children from unwanted surgery, secrecy and shame*.  
<https://www.counseling.org/news/updates/2006/01/16/resolutions-adopted-by-governing-council>
- American Counseling Association. (2014). *ACA code of ethics*.  
<https://www.counseling.org/resources/aca-code-of-ethics.pdf>
- American Jewish World Service, Astraea Lesbian Foundation for Justice, & Global  
Action for TransEquality. (2017). *The state of intersex organizing* (2nd ed.).  
<https://transactivists.org/the-state-of-intersex-organizing-report-2017/>
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental  
disorders* (5th ed.). <https://doi.org/10.1176/appi.books.9780890425596>

Androgen Insensitivity Syndrome-Differences of Sex Development Support Group.

(2017). *Home*. <http://aisdsd.org>

Astorino, C., & Vilorio, H. (2012). *Brief guidelines for intersex allies*. Intersex Campaign for Equality. <http://www.intersexequality.com/wp-content/uploads/2012/10/Brief-Guidelines-for-Intersex-Allies.pdf>

Bennecke, E., Werner-Rosen, K., Thyen, U., Kleinemeier, E., Lux, A., Jürgensen, M., Grüters, A., & Köhler, B. (2015). Subjective need for psychological support (PsySupp) in parents of children and adolescents with disorders of sex development (dsd). *European Journal of Pediatrics*, *174*(10), 1287–1297. <https://doi.org/10.1007/s00431-015-2530-8>

Blair, K. (2016). When doctors get it wrong. In J. DuBois & A. Iltis (Eds.), *Normalizing intersex. VOICES: Personal stories from the pages of narrative inquiry in bioethics* (pp. 5–6). Johns Hopkins University Press. <https://doi.org/10.13140/RG.2.2.24391.70569>

Brinkmann, L., Schuetzmann, K., & Richter-Appelt, H. (2007). Gender assignment and medical history of individuals with different forms of intersexuality: Evaluation of medical records and the patients' perspective. *Journal of Sexual Medicine*, *4*(4i), 964–980. <https://doi.org/10.1111/j.1743-6109.2007.00524.x>

Burnes, T. R., & Richmond, K. (2012). Counseling strategies with intersex clients: A process-based approach. In S. H. Dworkin & M. Pope (Eds.), *Casebook for counseling lesbian, gay, bisexual, and transgendered persons and their families* (pp. 35–44). American Counseling Association.

- Cass, V. (1979). Homosexual identity formation: A theoretical model. *Journal of Homosexuality*, 4(3), 219–235. [https://doi.org/10.1300/J082v04n03\\_01](https://doi.org/10.1300/J082v04n03_01)
- Colapinto, J. (2000). *As nature made him; The boy who was raised as a girl*. HarperCollins Publishers.
- Consortium on the Management of Disorders of Sex Development. (2006a). *Clinical guidelines for the management of disorders of sex development in childhood*. Intersex Society of North America. <http://www.dsdguidelines.org>
- Consortium on the Management of Disorders of Sex Development. (2006b). *Handbook for parents*. Intersex Society of North America. <https://dsdguidelines.org/htdocs/parents/>
- Corbin, J., & Strauss, A. (2015). *Basics of qualitative research: Techniques and procedures for developing grounded theory* (4th ed.). Sage Publications.
- Costello, C. (n.d.). *Dr. Cary Gabriel Costello*. <https://www.blogger.com/profile/14478058791195474381>
- Cottone, R. R. (2012). *Paradigms of counseling and psychotherapy*. Cottone Publishing.
- Cottone, R. R. (2017). *Theories of counseling and psychotherapy: Individual and relational approaches*. Springer.
- Crissman, H. P., Warner, L., Gardner, M., Carr, M., Schast, A., Quittner, A. L., Kogan, B., & Sandberg, D. E. (2011). Children with disorders of sex development: A qualitative study of early parental experience. *International Journal of Pediatric Endocrinology*, 2011, Article 10. <https://doi.org/10.1186/1687-9856-2011-10>

- D'Andrea, W., Ford, J., Stolbach, B., Spinazzola, J., & van der Kolk, B. A. (2012). Understanding interpersonal trauma in children: Why we need a developmentally appropriate trauma diagnosis. *American Journal of Orthopsychiatry*, 82(2), 187–200. <https://doi.org/10.1111/j.1939-0025.2012.01154.x>
- Davis, G. (2015). *Contesting intersex: The dubious diagnosis*. New York University Press.
- Davis, G. (2016). Introduction: Normalizing intersex: The transformative power of stories. In J. M. DuBois & A. Iltis (Eds.), *Normalizing intersex. VOICES: Personal stories from the pages of narrative inquiry in bioethics* (pp. 1–3). Johns Hopkins University Press. <https://doi.org/10.13140/RG.2.2.24391.70569>.
- Dayner, J. E., Lee, P. A., & Houk, C. P. (2004). Medical treatment of intersex: Parental perspectives. *The Journal of Urology*, 172(4, Pt. 2), 1762–1765. <https://doi.org/10.1097/01.ju.0000138519.12573.3a>
- della Porta, D. (2000). Activists who persist. [Review of the book *The persistent activist: How peace commitment develops and survives* by J. Downton & P. Wehr]. *Peace and Conflict: Journal of Peace Psychology*, 6(3), 273–276. [https://doi.org/10.1207/S15327949PAC0603\\_11](https://doi.org/10.1207/S15327949PAC0603_11)
- Devore, T. (n.d.). *Curriculum vitae*. <https://www.nvpsychology.org/wp-content/uploads/2015/06/Tiger-Devore-PhD-CV.pdf>
- Devore, T. (1999). Growing up in the surgical maelstrom. In A. D. Dreger (Ed.), *Intersex in the age of ethics* (pp. 79–81). University Publishing Group.
- Devore, T. (2013, July 12). *Tiger Devore, PhD.—Las Vegas, NV*. [Video]. YouTube. <https://www.youtube.com/watch?v=Uli3tZO9InA>



- Devore, T. (2017, January 27). *Tiger with Oprah Winfrey* [Video]. YouTube.  
<https://www.youtube.com/watch?v=tmXIG8E4EIE>
- Douglas, G., Axelrad, M. E., Brandt, M. L., Crabtree, E., Dietrich, J. E., French, S., Gunn, S., Karaviti, L., Lopez, M. E., Macias, C. G., McCullough, L. B., Suresh, D., Austin, E., & Reid Sutton, V. (2012). Guidelines for evaluating and managing children born with disorders of sexual development. *Pediatric Annals*, *41*(4), e1–e7. <https://doi.org/10.3928/00904481-20120307-09>
- Dreger, A. (1998). *Hermaphrodites and the medical invention of sex*. Harvard University Press.
- Dreger, A. (1999). *Intersex in the age of ethics*. University Publishing Group.
- Dreger, A. (2015, November 21). *Tiger Devore's statement*. Alice Domurat Dreger.  
[http://alicedreger.com/Tiger\\_Devore](http://alicedreger.com/Tiger_Devore)
- Dreger, A. D. (2016). *Galileo's middle finger: Heretics, activists, and one scholar's search for justice*. Penguin Books.
- Dutt, A., & Grabe, S. (2014). Lifetime activism, marginality, and psychology: Narratives of lifelong feminist activists committed to social change. *Qualitative Psychology*, *1*(2), 107–122. <https://doi.org/http://dx.doi.org/10.1037/qup0000010>
- Dworkin, S. H., & Pope, M. (Eds.). (2012). *Casebook for counseling lesbian, gay, bisexual, and transgender persons and their families*. American Counseling Association.
- Easton, K. L., McCornish, J. F., & Greenberg, R. (2000). Avoiding common pitfalls in qualitative data collection and transcription. *Qualitative Health Research*, *10*(5), 703–707. <https://doi.org/10.1177/104973200129118651>

- Fausto-Sterling, A. (2000). *Sexing the body: Gender politics and the construction of sexuality*. Basic Books.
- Feder, E. (2014). *Making sense of intersex: Changing ethical perspectives in biomedicine*. Indiana University Press.
- Feder, E., & Karkazis, K. (2008). What's in a name?: The controversy over disorders of sex development. *Hastings Center Report*, 38(5), 33–36.  
<https://doi.org/10.1353/hcr.0.0062>
- Ford, K. (2000). “First, do no harm”—The fiction of legal parental consent to genital-normalizing surgery on on intersexed infants. *Yale Law and Policy Review*, 19(2).  
<https://digitalcommons.law.yale.edu/ylpr/vol19/iss2/7>
- Ginicola, M. M. (2017). Counseling intersex clients. In M. M. Ginicola, C. Smith, & J. M. Filmore (Eds.), *Affirmative counseling with LGBTQI+ people* (pp. 241–250). American Counseling Association. <https://doi.org/10.1002/9781119375517.ch14>
- Ginicola, M. M., Smith, C., & Filmore, J. M. (Eds.). (2017). *Affirmative counseling with LGBTQI+ people*. American Counseling Association.  
<https://doi.org/10.1002/9781119375517>
- Gomez-Lobo, V. (2014). Multidisciplinary care for individuals with disorders of sex development. *Current Opinion in Obstetrics & Gynecology*, 26(5), 366–371.  
<https://doi.org/10.1097/GCO.0000000000000101>
- Goodrich, K. M., & Luke, M. (2015). *Group counseling with LGBTQI persons*. American Counseling Association.

- Gough, B., Weyman, N., Alderson, J., Butler, G., & Stoner, M. (2008). 'They did not have a word': The parental quest to locate a 'true sex' for their intersex children. *Psychology & Health, 23*(4), 493–507.  
<https://doi.org/10.1080/14768320601176170>
- Greenberg, J. (2012). *Intersexuality and the law: Why sex matters*. New York University Press.
- Griffiths, M. R. (2009). *Parent and child experiences of childhood cancer: An interpretative phenomenological analysis approach* [Doctoral dissertation, Queensland University of Technology]. QUT ePrints.  
<https://eprints.qut.edu.au/29174/>
- Guilbert, K. (2018). *Portugal approves law to boost transgender rights, protect intersex*. Reuters. <https://www.reuters.com/article/us-portugal-lgbt-lawmaking-idUSKBN1HK22Q>
- Harper, C. (2007). *Intersex*. Berg Publishers.
- Hays, P. A. (2001). *Addressing cultural complexities in practice: A framework for clinicians and counselors*. American Psychological Association.
- Hind, R. A. (2014). *An exploration of parents' experiences of having an infant who requires surgery using interpretative phenomenological analysis* (Publication No. U620445) [Doctoral dissertation, University of Glasgow]. ProQuest Dissertations and Theses Global.

Hiort, O., Birnbaum, W., Marshall, L., Wunsch, L., Werner, R., Schröder, T., Döhnert, U., & Holterhus, P.-M. (2014). Management of disorders of sex development.

*Nature Reviews Endocrinology*, *10*(9), 520–529.

<https://doi.org/10.1038/nrendo.2014.108>

Holmes, M. (2008). *Intersex: A perilous difference*. Susquehanna University Press.

Human Rights Watch & interACT Advocates for Youth. (2017). “*I want to be like nature made me*”: Medically unnecessary surgeries on intersex children in the U.S.

Human Rights Watch.

[https://www.hrw.org/sites/default/files/report\\_pdf/lgbtintersex0717\\_web\\_0.pdf](https://www.hrw.org/sites/default/files/report_pdf/lgbtintersex0717_web_0.pdf)

Hyena, H. (1999, October 12). *The inbetween sex: An interview with intersexual Howard*

*Devore, Ph.D.* SFGate. [https://www.sfgate.com/music/article/The-Inbetween-](https://www.sfgate.com/music/article/The-Inbetween-Sex-An-interview-with-intersexual-2904027.php)

[Sex-An-interview-with-intersexual-2904027.php](https://www.sfgate.com/music/article/The-Inbetween-Sex-An-interview-with-intersexual-2904027.php)

interACT Advocates for Youth. (2018, August 28). Victory: California is the first state in the U.S. to pass legislation on intersex rights.

<https://interactadvocates.org/intersex-legislation-california-blog/>

interACT Advocates for Youth. (2019a). *FAQ: What is intersex?*

<https://interactadvocates.org/faq/>

interACT Advocates for Youth. (2019b). *interACT law and policy*.

<https://interactadvocates.org/intersex-law-and-policy/#>

interACT Advocates for Youth. (2019c). *What we wish our doctors knew*.

[https://interactadvocates.org/wp-content/uploads/2015/12/BROCHURE-](https://interactadvocates.org/wp-content/uploads/2015/12/BROCHURE-interACT-Doctors-final-web.pdf)

[interACT-Doctors-final-web.pdf](https://interactadvocates.org/wp-content/uploads/2015/12/BROCHURE-interACT-Doctors-final-web.pdf)

- interACT Advocates for Youth. (2019d). *What we wish our friends knew*.  
<https://interactadvocates.org/wp-content/uploads/2015/12/BROCHURE-interACT-Friends-final-web.pdf>
- interACT Advocates for Youth. (2019e). *What we wish our parents knew*.  
<https://interactadvocates.org/wp-content/uploads/2015/12/BROCHURE-interACT-Parents-final-web.pdf>
- interACT Advocates for Youth. (2019f). *What we wish our teachers knew*.  
<https://interactadvocates.org/wp-content/uploads/2018/07/BROCHURE-interACT-Teachers-final.pdf>
- interACT Advocates for Youth. (2020). *Providing ethical and compassionate healthcare to intersex patients*. <https://interactadvocates.org/wp-content/uploads/2018/09/interACT-Lambda-Legal-intersex-hospital-policies.pdf>
- Interface Project. (2012). *About*. <https://www.interfaceproject.org/about/>
- Hida. (2015, April 1). *How common is intersex? An explanation of the stats*. Intersex Campaign for Equality. <https://www.intersexequality.com/how-common-is-intersex-in-humans/>
- Intersex Initiative Portland. (2003). *Introduction to activism: A guide for allies* (2nd ed.).  
<http://www.intersexinitiative.org/publications/pdf/intersex-activism2.pdf>
- Intersex Society of North America. (2008). *Our mission*. <http://www.isna.org>
- Karkazis, K. (2008). *Fixing sex: Intersex, medical authority, and lived experience*. Duke University Press.
- Kessler, S. (1998). *Lessons from the intersexed*. Rutgers University Press.

- Laverty, S. M. (2003). Hermeneutic phenomenology and phenomenology: A comparison of historical and methodological considerations. *International Journal of Qualitative Methods*, 2(3), 21–29. <https://doi.org/10.1177/160940690300200303>
- Lee, P. A., Houk, C. P., Ahmed, S. F., & Hughes, I. A. (2006). Consensus statement on management of intersex disorders. International Consensus Conference on Intersex. *Pediatrics*, 118(2), e488–e500. <https://doi.org/10.1542/peds.2006-0738>
- Lee, P. A., Nordenström, A., Houk, C. P., Faisal Ahmed, S., Auchus, R., Baratz, A., Dalke, K. B., Lih-Mei, L., Lin-Su, K., Looijenga, L. H. J., Mazur, T., Meyer-Bahlburg, H. F. L., Mouriquand, P., Quigley, C. A., Sandberg, D. E., Vilain, E., & Witchel, S. (2016). Global disorders of sex development update since 2006: Perceptions, approach and care. *Hormone Research In Paediatrics*, 85(3), 158–180. <https://doi.org/10.1159/000442975>
- Leiner, B., Cerf, V., Clark, D. A., Kahn, R., Kleinrock, L., Lynch, D., Postel, J., Roberts, L., & Wolff, S. (1997). *Brief history of the Internet*. Internet Society. <https://www.internetsociety.org/internet/history-internet/brief-history-internet/>
- Lev, A. I. (2006). Intersexuality in the family: An unacknowledged trauma. *Journal of Gay & Lesbian Psychotherapy*, 10(2), 27–56. [https://doi.org/10.1300/J236v10n02\\_03](https://doi.org/10.1300/J236v10n02_03)
- Liao, L. (2016). Commentary: Stonewalling emotion. In J. DuBois & A. Iltis (Eds.), *Normalizing intersex. VOICES: Personal stories from the pages of narrative inquiry in bioethics* (pp. 57–64). Johns Hopkins University Press.

- Liao, L.-M., & Roen, K. (2014). Intersex/DSD post-Chicago: New developments and challenges for psychologists. *Psychology & Sexuality*, 5(1), 1–4.  
<https://doi.org/10.1080/19419899.2013.831210>
- Liao, L.-M., & Simmonds, M. (2014). A values-driven and evidence-based health care psychology for diverse sex development. *Psychology & Sexuality*, 5(1), 83–101.  
<https://doi.org/10.1080/19419899.2013.831217>
- Macrotrends. (n.d.). *U.S. population 1950–2020*.  
<https://www.macrotrends.net/countries/USA/united-states/population>
- Marquez, A. (n.d.). About Mx. Anunnaki Ray Marquez. *Mx. Anunnaki Ray Marquez—Gender/INTERSEX Activist: Educator, Writer & Visionary*.  
<https://anunnakiray.com/about/>
- Marquez, A. R. (2016, July 3). Doctors call us a disorder, defect, or syndrome when we are born. We are simply intersex. *Mx. Anunnaki Ray Marquez—Gender/INTERSEX Activist: Educator, Writer & Visionary*.  
<https://anunnakiray.com/2016/07/03/doctors-call-us-a-disorder-defect-or-syndrome-when-we-are-born-we-are-simply-intersex/>
- Marquez, A. R. (2018, September 20). I am proudly the first in Colorado to get an intersex birth certificate. *Mx. Anunnaki Ray Marquez—Gender/INTERSEX Activist: Educator, Writer & Visionary*. <https://anunnakiray.com/2018/09/20/i-am-proudly-the-first-in-colorado-to-get-an-intersex-birth-certificate/>
- Marquez, A. (2019, July 23). Cultural dysphoria: Stop conflating biological sex with gender identity. *Mx. Anunnaki Ray Marquez—Gender/INTERSEX Activist: Educator, Writer & Visionary* <https://anunnakiray.com/?s=Cultural+dysphoria>

- Marshall, M. N. (1996). Sampling for qualitative research. *Family Practice*, 13(6), 522–525. <https://doi.org/10.1093/fampra/13.6.522>
- McLellan, E., MacQueen, K. M., & Neidig, J. L. (2003). Beyond the qualitative interview: Data preparation and transcription. *Field Methods*, 15(1), 63–84. <https://doi.org/10.1177/1525822X02239573>
- Mellin, E. A., Hunt, B., & Nichols, L. M. (2011). Counselor professional identity: Findings and implications for counseling and interprofessional collaboration. *Journal of Counseling & Development*, 89(2), 140–147. <https://doi.org/10.1002/j.1556-6678.2011.tb00071.x>
- Merriam, S. B. (2016). *Qualitative research: A guide of design and implementation* (4th ed.). Jossey-Bass.
- Money, J., & Ehrhardt, A. A. (1973). *Man & woman, boy & girl: Gender identity from conception to maturity*. Johns Hopkins University Press.
- Moran, M. E., & Karkazis, K. (2012). Developing a multidisciplinary team for disorders of sex development: Planning, implementation, and operation tools for care providers. *Advances in Urology*, 2012, Article 604135. <https://doi.org/10.1155/2012/604135>
- Morris, E. (2004, February 2). The self I will never know. *New internationalist*. <https://newint.org/features/2004/02/01/self>
- Moshiri, M., Chapman, T., Fechner, P. Y., Dubinsky, T. J., Shnorhavorian, M., Osman, S., Bhargava, P., & Katz, D. S. (2012). Evaluation and management of disorders of sex development: Multidisciplinary approach to a complex diagnosis. *Radiographics*, 32(6), 1599–1618. <https://doi.org/10.1148/rg.326125507>



- Motta, C. (2011). *Interviews: Dr. Tiger Howard Devore, PhD. We Who Feel Differently*.  
<https://wewhofeeldifferently.info/interview.php?interview=108>
- O'Hara, M. (2016, December 29). *Nation's first known intersex birth certificate issued in NYC*. NBC News. <https://www.nbcnews.com/feature/nbc-out/nation-s-first-known-intersex-birth-certificate-issued-nyc-n701186>
- Organisation Intersex International. (n.d.). *FAQ*.  
<https://oiiinternational.com/category/faqs/page/2/>
- Pasterski, V., Prentice, P., & Hughes, I. A. (2010). Consequences of the Chicago consensus on disorders of sex development (DSD): Current practices in Europe. *Archives of Disease in Childhood*, 95(8), 618–623.  
<https://doi.org/10.1136/adc.2009.163840>
- Patten, M., & Newhart, M. (2018). *Understanding research methods: An overview of the essentials* (10th ed.). Routledge.
- Patton, M. Q. (2002). *Qualitative research and evaluation methods* (3rd ed.). Sage Publications.
- Pope, M. (2015). History and philosophy of the counseling profession. In V. F. Sangganjanavanich & C. Reynolds (Eds.), *Introduction to professional counseling* (pp. 25–46). Sage Publications.
- Preves, S. (2003). *Intersex and identity: The contested self*. Rutgers University Press.
- Reis, E. (2009). *Bodies in doubt: An American history of intersex*. Johns Hopkins University Press.

- Roen, K. (2009). Clinical interventions and embodied subjectivity: Atypically sexed children and their parents. In M. Holmes (Ed.), *Critical intersex* (pp. 15–40). Ashgate Publishing.
- Rolston, A. M., Gardner, M., Vilain, E., & Sandberg, D. E. (2015). Parental reports of stigma associated with child's disorder of sex development. *International Journal of Endocrinology*, 2015, Article 980121. <https://doi.org/10.1155/2015/980121>
- Sandberg, D. E., Gardner, M., Callens, N., & Mazur, T. (2017). Interdisciplinary care in disorders/differences of sex development (DSD): The psychosocial component of the DSD-translational research network. *American Journal of Medical Genetics, Part C, Seminars in Medical Genetics*, 175(2), 279–292. <https://doi.org/10.1002/ajmg.c.31561>
- Sanders, C., Carter, B., & Goodacre, L. (2008). Parents' narratives about their experiences of their child's reconstructive genital surgeries for ambiguous genitalia. *Journal of Clinical Nursing*, 17(23), 3187–3195. <https://doi.org/10.1111/j.1365-2702.2007.02006.x>
- Savas, O., & Stewart, A. J. (2018). Alternative pathways to activism: Intersections of social and personal pasts in the narratives of women's rights activists. *Qualitative Psychology*, 6(1), 27–46. <https://doi.org/10.1037/qup0000117>
- Schweizer, K., Brunner, F., Gedrose, B., Handford, C., & Richter-Appelt, H. (2017). Coping with diverse sex development: Treatment experiences and psychosocial support during childhood and adolescence and adult well-being. *Journal of Pediatric Psychology*, 42(5), 504–519. <https://doi.org/10.1093/jpepsy/jsw058>

- Schweizer, K., Brunner, F., Schützmann, K., Schönbucher, V., & Richter-Appelt, H. (2009). Gender identity and coping in female 46, XY adults with androgen biosynthesis deficiency (intersexuality/DSD). *Journal of Counseling Psychology*, 56(1), 189–201. <https://doi.org/10.1037/a0013575>
- Singh, A. A., Boyd, C. J., & Whitman, J. S. (2010). Counseling competency with transgender and intersex persons. In J. A. E. Cornish, B. A. Schreier, L. I. Nadkarni, L. H. Metzger, & E. R. Rodolfa (Eds.), *Handbook of multicultural counseling competencies* (pp. 415–441). John Wiley & Sons.
- Smith, J. A., Flowers, P., & Larkin, M. H. (2013). *Interpretative phenomenological analysis: Theory, method and research*. Sage Publications.
- Sterling, B. (1993). *Short history of the Internet*. Internet Society.  
<https://www.internetsociety.org/internet/history-internet/short-history-of-the-internet/>
- TED. (2018, November 29). *Mx. Anunnaki Ray Marquex: Born intersex: We are human!* [Video]. YouTube. <https://www.youtube.com/watch?v=WpPTf-00ab0>
- Turner Syndrome Society. (n.d.). *About Turner syndrome*.  
<https://www.turnersyndrome.org/about-turnersyndrome>
- United Nations Office of the High Commissioner for Human Rights. (2015). *Fact sheet: Intersex*.  
[https://www.ohchr.org/Documents/Issues/Discrimination/LGBT/FactSheets/UNF\\_E\\_FactSheet\\_Intersex\\_EN.pdf](https://www.ohchr.org/Documents/Issues/Discrimination/LGBT/FactSheets/UNF_E_FactSheet_Intersex_EN.pdf)
- Urology Care Foundation. (2018). *What is hypospadias?*  
<http://www.urologyhealth.org/urologic-conditions/hypospadias?article=130>

- van der Kolk, B. A., & d'Andrea, W. (2010). Towards a developmental trauma disorder diagnosis for childhood interpersonal trauma. In R. A. Lanius, E. Vermetten, & C. Pain (Eds.), *The impact of early life trauma on health and disease: The hidden epidemic* (pp. 57–68). Cambridge University Press.
- Viloria, H. (2017). *Born both: An intersex life*. Hachette Books.
- Wertz, F., Charmaz, K., McMullen, L., Josselson, R., Anderson, A., & McSadden, E. (2011). *Five ways of doing qualitative analysis: Phenomenological psychology, grounded theory, discourse analysis, narrative research, and intuitive inquiry*. Guilford Press.
- Williamson, R. (2013). *Exploring the therapeutic self* (Publication No. 10018243) [Doctoral dissertation, City University London]. ProQuest Dissertations and Theses Global.
- Wilson, J. D., Rivarola, M. A., Mendonca, B. B., Warne, G. L., Josso, N., Drop, S. L. S., & Grumbach, M. M. (2012). Advice on the management of ambiguous genitalia to a young endocrinologist from experienced clinicians. *Seminars in Reproductive Medicine*, 30(5), 339–350. <https://doi.org/10.1055/s-0032-1324717>
- Wisniewski, A. B., Chernausek, S. D., & Kropp, B. H. (2012). *Disorders of sex development; A guide for parents and physicians*. Johns Hopkins University Press.
- Wit, J., Ranke, M., & Kelnar, C. J. H. (Eds.) (2007). Disorders of sex development (DSD). *Hormone Research in Paediatrics*, 68(Suppl. 2), 21–26. <https://doi.org/10.1159/000112055>

World Health Organization. (2015). *Sexual health, human rights and the law*.

[https://apps.who.int/iris/bitstream/handle/10665/175556/9789241564984\\_eng.pdf;jsessionid=49FE1347542E3C12426EA3D378C6E73F?sequence=1](https://apps.who.int/iris/bitstream/handle/10665/175556/9789241564984_eng.pdf;jsessionid=49FE1347542E3C12426EA3D378C6E73F?sequence=1)

Zieselman, K. (2020). *XOXY*. Kingsley.

## APPENDIX A

### U.S. Hospitals With Intersex/DSD Multidisciplinary Clinics

Ann & Robert H. Lurie Chicago Hospital, Chicago, IL

Boston Children's Hospital, MA

Children's Hospital Michigan, Detroit, MI

Children's Hospital of Philadelphia, PA

Children's Mercy Hospital, Kansas City, KA

Cincinnati Children's Hospital Medical Center (CCHMC), Cincinnati, OH

Cohen Children's Hospital, North Shore, Long Island, NY

Lenox Baker Children's Hospital, Duke University School of Medicine, Durham, NC

National Children's Hospital, Washington D.C.

Nationwide Children's Ohio, Columbus, OH

Rady Children's Hospital, San Diego

Riley's Children's Hospital, Indianapolis, IN

Phoenix Children's Hospital, Phoenix, AZ

St. Louis Children's Hospital, St. Louis, MO

Seattle Children's Hospital, WA

Texas Children's Hospital, Houston, TX

University of California Pediatric Departments in San Francisco, Los Angeles and San

Diego

University of Minnesota Department of Pediatrics, Minneapolis, MN

The University of Oklahoma Health Sciences Center, Oklahoma City, OK

## APPENDIX B

### Participant Demographic Information

Participant ID: \_\_\_\_\_

#### Research Study Title

*Intersex Experiences, Activists' Perspectives, and Counseling Implications*

#### Demographics (Circle One)

##### 1. Age

- 17 or younger
- 18-20
- 21-29
- 30-39
- 40-49
- 50-59
- 60 or older

##### 2. Economic status (Yearly income)

- \$0 – \$9,999
- \$10,000 – \$19,999
- \$20,000 – \$29,999
- \$30,000 – \$39,999
- \$40,000 – \$49,999
- \$50,000 – \$59,999
- \$60,000 – \$69,999
- \$70,000 – \$79,999
- \$80,000 – \$89,999
- \$90,000 – \$99,999
- \$100,000 or more

##### 3. Race/ Ethnic background

- White
- Black or African-American
- American Indian or Alaskan Native
- Asian
- Native Hawaiian or another Pacific islander population
- From another race: (specify) \_\_\_\_\_
- From multiple races (specify) \_\_\_\_\_

##### 4. Biology

- Male
- Female
- Intersex

A biology descriptor you prefer (specify) \_\_\_\_\_

**5. Gender**

Man/boy

Woman/girl

Intersex

A gender descriptor you prefer (please specify) \_\_\_\_\_

**6. Sexual orientation**

Asexual

Bisexual

Gay

Lesbian

Heterosexual

Pansexual

Polyamorous

A sexual orientation you prefer (please specify) \_\_\_\_\_

**7. Marital status**

Never married

Married

Divorced

Committed relationship/Not married

Separated

Widowed

A marital status you prefer (specify) \_\_\_\_\_

**8. Citizenship (Please circle all that apply)**

North American (U.S.)

North American (Canada)

Central American

**9. Employment**

Employed, working 1-39 hours per week

Employed, working 40 or more hours per week

Not employed, looking for work

Not employed, NOT looking for work

Retired

Disabled not able to work

**10. Education**

Less than high school equivalence

High school equivalence (e.g. GED)

Some college/no degree

Associate degree

Bachelor degree

Graduate degree



**Activism Demographics**

11. Years in intersex activism \_\_\_\_\_

12. Hours per week in paid activism (please circle one)

0-10

10-20

15-20

20-30

30-40

More than 40

13. Hours per week in voluntary activism (please circle one)

0-10

10-20

15-20

20-30

30-40

More than 40

(For the questions below, please circle either Yes or No)

14. Received medically necessary surgeries Yes/ No

15. Received medically unnecessary surgeries Yes/ No

16. Affiliated with one or more intersex support group? Yes/ No

17. Affiliated with one or more intersex activist organization? Yes/ No

## APPENDIX C

### Quality Rubric

#### Yardley’s (2000) Recommendations for Appraising Qualitative Research Adapted to IPA by Smith, Flowers and Larkin (2013)

Scoring: 0=Not Satisfied, 1=Partially Satisfied, 2 =Fully Addressed

Note: Smith states that some evidence is equally suited to more than one principle, for example, ‘putting participant at ease’ reflects principles I. and II.

| <b>Principles</b>   | <b>Core Component</b>                                       | <b>Possible Evidence</b>   | <b>Score</b> |
|---|---|--|--------------|
| <b>I. Sensitivity to Context</b>  | in early study activities prior to data collection          | Socio-cultural<br>Choice of data requested<br>Introduction literature<br>Choice of IPA<br>Rapport with gatekeepers   |              |
|   | in data collection  | Empathy<br>Putting participant at ease<br>Negotiating power<br>Design of interview schedule<br>Protection of data  |              |
|   | in analysis   | Grounding claims in the data<br>Liberal quantity of quotes<br>Claims appropriate to sample<br>Claims made cautiously<br>Appropriate topic (substantive) literature<br>Appropriate theoretical literature (IPA)           |              |
| <b>II. Commitment (attentiveness) &amp; Rigor (thoroughness of study)</b> | in data collection  | Attentiveness to participant comfort and protections<br>Attentiveness toward participant communication<br>Rigor in sample selection<br>Rigor in interview processes (balance between closeness/distance; digging deeper) |              |
|   | in analysis<br>“good IPA says something important about the | Rigor in systematic analysis<br>Rigor in idiographic approach<br>Rigor in interpretation   |              |

|  |  |  |  |
|--|--|--|--|
|  | individuals and something important about the themes they share” |  |  |
| <b>III. Transparency and Coherency</b> | Making the research processes evident                            | Clearly stated sample<br>Clearly stated interview construction<br>Clearly stated transcription format  |  |
|  | Making the study hang together as a whole                        | Phenomenological<br>(Significant experiences described)<br><br>Idiographic<br>(individual is important; nuanced; claims are cautious)<br><br>Hermeneutic<br>(clearly interpretive; coherent argument; themes hang together logically; ambiguities explained; reader is positioned to see researcher making sense of the participant) |  |
| <b>IV. Impact and Importance</b>       | Something interesting or useful is provided to the reader        |  |  |

## APPENDIX D

### Participant Information Sheet

#### Research Study Title

*Intersex Experiences, Activists' Perspectives, and Counseling Implications*

#### Who is conducting this study?

My name is Cynthia Mulit and I am a doctoral candidate in Counseling at the University of Missouri – St. Louis. As a part of my doctoral training, I am conducting a research study about the motivations and emotional experiences of intersex activists. I invite you to look over this information sheet. The information you read will help you decide if you wish to take part in the study. This information sheet is intended to address any questions you have. If, however, you feel there is something else you would like to discuss, please call me. Your call will be confidential.

#### Who has reviewed this study?

First, this study was reviewed and approved by my dissertation committee comprised of Dr. Rocco Cottone, Ph.D., Dr. Mark Pope, Ed.D., Dr. Mary Nelson, Ph.D., and Dr. Ruxandra Ritter, Ph.D. Then the University of Missouri – St. Louis Institutional Review Board reviewed my study and determined it met the standards for ethical research.

#### How do I contact the researcher, Cynthia Mulit, MA, LAC, NCC?

My phone number: [REDACTED]. My email: [cjm2yf@mail.umsl.edu](mailto:cjm2yf@mail.umsl.edu)

#### Is there an intersex activist advising this study?

Yes. Mx. Anunnaki Ray Marquez. An interACT staff member reviewed the first draft of the proposal.

#### What is the aim of the study?

To understand the experiences of intersex people, in general, and intersex activists, in particular, so that affirming and well-informed counseling education programs can be developed.

#### Why am I being asked to take part?

I have identified you as an intersex activist. I located potential participants through (a) published materials, in print or online, (b) videos on the Interface Project, (c) public involvement in activist organizations and/or (d) referral by other activists.

#### To participate in this study, do I have to have received a formal intersex medical diagnosis?

No. Your word is accepted.

#### What if I never had medically unnecessary surgeries?

Having had medically unnecessary surgeries is *not* a criterion for participation in this study.

**What if I was active as an activist but now I am not?**

To participate in this study, you are required to have been public in your activism for at least one year in your life but you are not required to be active at the present.

**Do any emotional experiences that I went through as an intersex person and an intersex activist have to be experiences that I saw a professional counselor for?**

No. You are not required to have discussed your experiences with any other person, professional or private.

**Do any emotional experiences have to be negative?**

No. The emotional experiences can be positive or negative or both.

**Who will know I was taking part in the study?**

Your participation will be anonymous. Your name will be known only to me, Cynthia Mulit, the researcher for the study.

**If I specifically request in writing to be identified in the dissertation, may I be identified by name?** No, anonymity will be observed in this study. You may be referenced by name regarding content you have already made public, for example, through blogs on your website. Your public content, however, will not be linked to your anonymous content in this study.

**Will I need to provide any identifying records, for example, medical records?**

No. You will not be asked to provide any identifying information or personal records.

**May I provide you with written materials too?**

You may provide written materials that you think would be helpful for the researcher.

**Will I be asked general information about myself for demographic purposes?**

Yes, you will be asked general information about yourself such as age, gender, education, etc. but that information will be summarized/aggregated and presented anonymously. In other words, the information will be not connected to you by name or in a way that you could be identified.

**What do you expect from me?**

The interview will take approximately 1.5 hours of your time, in 2 or 3 sessions according to your preference. The interviews will be conducted by Cynthia Mulit, the researcher. If an in-person interview cannot be arranged, an interview using online technology may be offered. At the beginning of the interview, you will have an opportunity to ask questions before signing the consent form. Then you will be asked what having an intersex variation was like in youth and adulthood. You will be asked what led you becoming an activist and what your life is like now as an activist. You will also be asked about your impressions about the quality of any intersex counseling you received. Finally you will be asked for any ideas about how intersex counseling can be improved in the future.

**What will happen to the information I provide?**

The information will be recorded and then transcribed. After the researcher has checked to make sure that the written transcript accurately reflects the audio, the recorded content will be destroyed. The written transcript will be identified by a number not a name. The transcript will be made into two copies for researcher use only. (The two copies give the researcher plenty of space to take two rounds of notes.) Both copies will be kept locked until after the dissertation is approved. For researcher use only, a list that matches participant name to a transcript numbers will be kept in a bank lock box, in a location separate from the locked transcripts.

The anonymous information will be summarized, analyzed and then presented to the dissertation committee in partial fulfillment for a doctorate in Counseling at University of Missouri – St. Louis. Some of the dissertation may be submitted to scientific journals or to book publishers that have an interest in intersex counseling. Portions of your anonymous information may be quoted verbatim in the report but the anonymous information will not be linked to your name.

**Do I have to take part?**

No, you are not required to participate in this study. Participation is voluntary only.

**May I withdraw from the interview?**

You may withdraw at any time. You are not required to state your reason if you wish to withdraw.

**May I review the transcript of my comments?** At your request, you will be given a chance to review the full transcript of your comments.

**How will I know that the study adequately represents what I meant to say?** If you feel your words in the transcript did not reflect your meaning, you will be given an opportunity to send Cynthia Mulit a memo reflecting any clarifications or corrections.

**How will I know about the study findings?** At your request, a copy of the dissertation will be sent to you. On the form that you sign to consent to being interviewed there is space to fill in your address.

**Do I have to pay anything in order to participate in this study?**

Absolutely not. There is no fee for participating in this study.

**What are the benefits for participating in this study?**

Each participant will receive a \$25 Amazon gift card. The other benefit a participant will receive is indirect, namely the benefit of contributing to research that may help future intersex individuals and their families.

**Will the researcher provide counseling, consulting, or other treatments during this study?** No. This study is for research purposes only. The researcher will function as a researcher only. No counseling, consulting, or other treatments will be provided as a part

of this study. Should the discussion bring up uncomfortable feelings that you need to process immediately, you will be provided with a hotline number to call. At your request, the researcher can provide a referral to an affirming mental health professional near you.

**What are the risks in participating in this study?**

It is unlikely that you will experience any difficulties due to being interviewed in this study. For by its focus, intersex activism involves being able to discuss sensitive sexual topics. Should you feel uncomfortable with any question, you are free to decline to answer. If you need a break, that is perfectly acceptable. As mentioned above, should the discussion bring up uncomfortable feelings that you need to process immediately, you will be provided with a hotline number to call. At your request, the researcher can provide a referral to an affirming mental health professional near you.

**Who may I contact for more information or to express any concerns or complaints about this study?**

| <b>Name</b>   | <b>Role</b>      | <b>Contact Information</b> |
|---|------------------|----------------------------|
| Cynthia Mulit, MA, LAC, NCC                                     | Researcher       | ██████████                 |
| Dr. Rocco Cottone, Ph.D. University of Missouri-St. Louis       | Academic Advisor | (314) 516-6094             |
| Dr. Susan Kashubeck-West Ph.D. University of Missouri-St. Louis | Department Chair | (314) 516-6091             |

**What do I do now?**

If you are interested, please call the researcher, Cynthia Mulit at ██████████ or email [cjm2yf@mail.umsl.edu](mailto:cjm2yf@mail.umsl.edu). Please provide your phone number, a best time to call you, and your permission to me to leave a message on your phone.

## APPENDIX E

### Participant Consent Form

Page 1 of 3



Department of Education Sciences and Professional Programs  
College of Education  
University of Missouri – St. Louis

One University Boulevard  
St. Louis, Missouri 63121-4499  
Telephone: 314-516-6094

### **Informed Consent for Participation in Research Activities**

Study Title: *Intersex Experiences, Activists' Perspectives, and Counseling Implications*

Participant \_\_\_\_\_ HSC Approval Number \_\_\_\_\_

Principal Investigator (PI): Cynthia Mult, MA, LAC, NCC, Phone Number [REDACTED]

#### **Summary of the Study**

The purpose of this study to understand life experiences of intersex activist individuals so as to improve counseling services. You will be asked what having an intersex variation has been like and what prompted your intersex activism. You will be asked what life has been like as an intersex activist. You will be asked about any experiences you may have had with counseling that was related to your intersex variation. You will also be asked for any ideas about how to make counseling for the intersex community better.

1. You are invited to participate in a research study conducted by Cynthia Mult, MA, LAC, NCC and Faculty Advisor, Dr. R. Rocco Cottone, Ph.D.

2. a) Your participation will involve:

Answering interview questions in a private, safe and comfortable location selected by you. You will have ample opportunity to ask the researcher any questions before signing a consent form to be interviewed. The interview session will be audio recorded. The recorded audio content will be destroyed immediately after verifying that the written transcript matches the audio content.

b) The amount of time involved in your participation will consist of a 1.5-hour interview session. Two additional 1.5 hour sessions will be provided upon request for a maximum of 4.5 hours.



3. There are no known risks associated with this research. At the interview, a list of resources will be provided for counseling should you have any emotional concerns.
4. There are no direct benefits for you for participating in this study.
5. No clinical assessments of participants will be made during this study.
6. Your participation is voluntary. You may choose not to participate in this research study. You may withdraw your consent at any time. You will NOT be penalized in any way should you choose not to participate or withdraw. You have the option to not answer any specific question.
7. We will do everything we can to protect your privacy. As part of this effort, your identity will not be revealed in any publication that may result from this study. In rare instances, a researcher's study must undergo an audit or program evaluation by an oversight agency (such as the Office for Human Research Protection) that would lead to disclosure of your data as well as any other information collected by the researcher.
8. If you have any questions or concerns regarding this study, or if any problems arise, you may call the Investigator, Cynthia Mult, MA, LAC, NCC [REDACTED] or the Faculty Advisor, R. Rocco Cottone, Ph.D., (314) 516-6094. You may also ask questions or state concerns regarding your rights as a research participant to the Office of Research, at (314) 516-5897.

**I have read this consent form and have been given the opportunity to ask questions. I will also be given a copy of this consent form for my records. I hereby consent to my participation in the research described above.**

\_\_\_\_\_  
Participant's Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Researcher Signature

\_\_\_\_\_  
Date

**Page 2 of 3 Participant Initials:** \_\_\_\_\_

If you have any questions or concerns about any aspect of your participation, please contact the researcher, research supervisor or independent contact below:

**Primary Researcher**

Cynthia J. Mulit, MA, LAC, NCC  
Doctoral Candidate - Counseling  
University of Missouri—St. Louis  
Department of Education Sciences and Professional Programs  
1 University Boulevard (469 MH)  
St. Louis, Missouri (MO) 63121  
[REDACTED]

**Research Supervisor**

R. Rocco Cottone, Ph.D.  
Professor  
Fellow of the American Counseling Association  
University of Missouri—St. Louis  
Department of Education Sciences and Professional Programs  
1 University Boulevard (469 MH)  
St. Louis, Missouri (MO) 63121  
Phone: 314.516.6094. Fax: 314.516.5784. Department Phone: 314.516.5782  
Email: [cottone@umsl.edu](mailto:cottone@umsl.edu)

**Independent Contact**

Susan Kashubeck-West, Ph.D.  
Professor and Associate Chair  
Dept. of Education Sciences and Professional Programs  
University of Missouri – St. Louis  
455 Marillac Hall  
314-516-6091  
[SusanKW@umsl.edu](mailto:SusanKW@umsl.edu)

**Page 3 of 3 Participant Initials:** \_\_\_\_\_

**APPENDIX F**

**Participant Debrief**

Participant ID Code: \_\_\_\_\_

**A. Debrief.** Thank you for taking part in this research. We can spend a bit of time talking about your interview experience now.

**B. Your Participation Protections.** To reiterate information provided to you at the beginning of this interview, I will make your data anonymous and confidential. Your participation is voluntary. At your request, you may have a copy of your transcript. You may provide corrections to clarify your meaning.

**Request for copy of your transcript**

I would like you to send me a copy of my transcript. Yes \_\_\_ No \_\_\_

If you selected a Yes response, please provide your address:

---

**C. Further Processing of this Interview.** As a research interviewer, I am unable to provide counseling or consulting support to you. Should difficult feelings or memories come up for you, I recommend that you contact your personal therapist or use the following contacts. If you request, I can assist you in finding an affirming therapist who lives locally.

**Find A Therapist**

<https://www.psychologytoday.com/us/therapists>

**GriefShare**

1-800-395-5755

**United Way Crisis Helpline**

1-800-233-HELP

**D. Your Declaration of Ethical Treatment in This Interview**

This interview was conducted by the interviewer in a sensitive, ethical and professional manner. The interviewer took care to make sure I was in no distress when leaving. The interviewer provided me with the above sources of support should I need further care. I am authorizing the research to proceed with transcribing my words.

Signature: \_\_\_\_\_

Printed name: \_\_\_\_\_

Date \_\_\_\_\_

If you have any questions or concerns about any aspect of your participation, please contact the researcher, research supervisor or independent contact below:

**Researcher**

Cynthia J. Mulit, MA, LAC, NCC  
Doctoral Candidate - Counseling  
University of Missouri—St. Louis  
Department of Education Sciences and Professional Programs  
1 University Boulevard (469 MH)  
St. Louis, Missouri (MO) 63121  
[REDACTED]

**Research Supervisor**

R. Rocco Cottone, Ph.D.  
Professor  
Fellow of the American Counseling Association  
University of Missouri—St. Louis  
Department of Education Sciences and Professional Programs  
1 University Boulevard (469 MH)  
St. Louis, Missouri (MO) 63121  
Phone: 314.516.6094. Fax: 314.516.5784. Department Phone: 314.516.5782  
Email: [cottone@umsl.edu](mailto:cottone@umsl.edu)

**Independent Contact**

Susan Kashubeck-West, Ph.D.  
Professor and Associate Chair  
Dept. of Education Sciences and Professional Programs  
University of Missouri – St. Louis  
455 Marillac Hall  
314-516-6091  
[SusanKW@umsl.edu](mailto:SusanKW@umsl.edu)

## APPENDIX G

### Modified Participant Debrief Per Activist Hotline Suggestions

Participant ID Code: \_\_\_\_\_

**A. Debrief.** Thank you for taking part in this research. We can spend a bit of time talking about your interview experience now.

**B. Your Participation Protections.** To reiterate information provided to you at the beginning of this interview, I will make your data anonymous and confidential. Your participation is voluntary. At your request, you may have a copy of your transcript. You may provide corrections to clarify your meaning.

**Request for copy of your transcript**

I would like you to send me a copy of my transcript. Yes \_\_\_ No \_\_\_

If you selected a Yes response, please provide your address:

---

**C. Further Processing of this Interview.** As a research interviewer, I am unable to provide counseling or consulting support to you. Should difficult feelings or memories come up for you, I recommend that you contact your personal therapist or use the following contacts. If you request, I can assist you in finding an affirming therapist who lives locally.

**Trans Lifeline**  
1-877-565-8860

**Trever Project**  
[thetrevorproject.org/get-help-now](http://thetrevorproject.org/get-help-now)

**LGBT Suicide**  
1-866-488-7386

**Sage LGBT Elder Hotline**  
1-888-234-SAGE

**National Suicide Line (qualify the person as affirming and safe)**  
1-800-273-TALK

**National Sexual Assault Hotline**  
1-800-656-HOPE

**D. Your Declaration of Ethical Treatment in This Interview**

This interview was conducted by the interviewer in a sensitive, ethical and professional manner. The interviewer took care to make sure I was in no distress when leaving. The interviewer provided me with the above sources of support should I need further care. I am authorizing the research to proceed with transcribing my words.

Signature: \_\_\_\_\_

Printed name: \_\_\_\_\_

Date \_\_\_\_\_

If you have any questions or concerns about any aspect of your participation, please contact the researcher, research supervisor or independent contact below:

**Researcher**

Cynthia J. Mulit, MA, LAC, NCC  
Doctoral Candidate - Counseling  
University of Missouri—St. Louis  
Department of Education Sciences and Professional Programs  
1 University Boulevard (469 MH)  
St. Louis, Missouri (MO) 63121  
[REDACTED]

**Research Supervisor**

R. Rocco Cottone, Ph.D.  
Professor  
Fellow of the American Counseling Association  
University of Missouri—St. Louis  
Department of Education Sciences and Professional Programs  
1 University Boulevard (469 MH)  
St. Louis, Missouri (MO) 63121  
Phone: 314.516.6094. Fax: 314.516.5784. Department Phone: 314.516.5782  
Email: [cottone@umsl.edu](mailto:cottone@umsl.edu)

**Independent Contact**

Susan Kashubeck-West, Ph.D.  
Professor and Associate Chair  
Dept. of Education Sciences and Professional Programs  
University of Missouri – St. Louis  
455 Marillac Hall  
314-516-6091  
[SusanKW@umsl.edu](mailto:SusanKW@umsl.edu)

## APPENDIX H

### Interview Schedule

#### WARM UP

Make sure the person is relaxed and hears that their work is protected. Repeat protections of anonymity, confidentiality, permission to not answer, stop anytime, or clarify later. State why I care about the topic and what I'm doing to help.

#### FOUNDATION

**(1) PLEASE TELL ME WHAT IT HAS BEEN LIKE IT HAVING AN INTERSEX VARIATION?**

*Birth story?*

*What was diagnosis (variation)/ sex assignment like?*

*Who made choices for you?*

*Medical experiences?*

medical personnel

surgeries

other medical treatments

access to medical records

*Social responses?*

parents, siblings, extended family

school and work

friends

*Negative Emotions*

*What helped you most in addressing them?*

*What message was most helpful in addressing them?*

(Listen for suicide.)

*Emotional Adjustment*

*What message harmed the most?*

*What message helped the most?*

(Toddler, youth, adolescent)

Shock/Indifference

Confusion/Clarity

Fear/Confidence

Depression/Anxiety/ Suicidality/ Other mental health issues

Shame/ Pride

Self-acceptance/ Self-rejection

Joy at others' acceptance/ Pain from others' rejection

(2) ***WHAT LED TO BECOMING AN INTERSEX ACTIVIST?***

Events  
Emotions  
Motivations

(3) ***WHAT IS YOUR LIFE LIKE NOW AS AN INTERSEX ACTIVIST?***

**Activities**

**Controversies**

Other activists  
Legal documents  
Legislative ban/Judicial challenges  
CARES parents  
Alliances with other sexual minorities  
Conflation of intersex variation with transgender experience  
Long term health care  
Violence and discrimination

**Events**

**Emotions**

**Motivations**

(4) ***HOW HAS THE 2006 CHANGE IN MEDICAL PROTOCOL IMPACTED INTERSEX PEOPLE?***

Comment on: “Bad things are just artifacts of 30 years ago”

(5) ***WHAT HAS ANY COUNSELING FOR INTERSEX INDIVIDUALS AND THEIR FAMILIES BEEN LIKE?***

At hospitals  
Other counseling venues

(6) ***WHAT COULD IMPROVE COUNSELING FOR INTERSEX INDIVIDUALS AND FAMILIES?***

At hospitals  
Other counseling venues

**REFLECTION/ WIND DOWN**

Challenges, Mistakes, Successes  
Future picture of success/ Barriers



## APPENDIX I

### Quality Report

#### *Intersex Experiences, Activist's Perspectives, and Counseling Implications*

Self-Graded With Yardley's (2000) Recommendations for Appraising Qualitative Research

Adapted to IPA by Smith, Flowers and Larkin (2013)

#### **I. Sensitivity to Context – Score 6 out of 6.**

This study demonstrated sensitivity to context during study set up by selecting IPA that gives intersex people individual voice to their unique stories by variation. Data Collection was sensitive by collecting input from interviewees about the research questions, putting subjects at ease and protecting the data. Analysis was sensitive by being grounded in the data, providing liberal use of quotes, and using appropriate literature

#### **II. Commitment (attentiveness) & Rigor (thoroughness of study) – Score 4 out of 4**

In data collection, this study demonstrated commitment to participants through strong commitment to doing justice to the participants content as evidenced by time and effort. The study demonstrated rigor in interview process by advance preparation and time and effort during collection. This study demonstrated rigor in data analysis by providing the important things individuals wanted to say as individuals and the important things they wanted to say in common.

#### **III. Transparency and Coherency – Score 3 out of 4.**

This study made the research processes evident and the study hung together as a whole. This study was (a) phenomenological in that significant experiences were described, (b) idiographic in that the individual was important and individual nuance was captured, (c) hermeneutic in that it was clearly interpretive, coherent in argument, the themes hung together logically, ambiguities were explained, and the reader was positioned to see researcher making sense of the participant. One half of a point was docked because IPA makes its interpretations cautiously. While this study is cautious by recognizing that it will not apply to those who do not want to see themselves as intersex, its act of presenting a model evidences a spirit of boldness rather than a spirit of IPA cautious interpretation.

**IV. Impact and Importance – 2 out of 2 plus a bonus point.**

This study presents an Intersex Identity Development Model. Identity models are highly useful for counselors as they organize client experience and serve to bring next steps for growth into focus.

**Total 16 out of 16**

## **APPENDIX J**

### **Activist-Prepared Intake Questions for Intersex Clients**

**By Mx. Anunnaki Ray Marquez, <https://anunnakiray.com>  
Copyright 2020. Reprinted with permission.**

#### **What is Intersex?**

Intersex people are born with sex characteristics (including genitals, gonads and chromosome patterns) that do not fit typical binary notions of male or female bodies.

Intersex is an umbrella term used to describe a wide range of natural bodily variations. In some cases, intersex traits are visible at birth while in others, they are not apparent until puberty. Some chromosomal intersex variations may not be physically apparent at all.

According to experts, between 0.05% and 1.7% of the population is born with intersex traits – the upper estimate is similar to the number of red-haired people. Being intersex relates to biological sex characteristics and is distinct from a person's sexual orientation or gender identity. An intersex person may be straight, gay, lesbian, bisexual or asexual, and may identify as female, male, both or neither.

Because their bodies are seen as different, intersex children and adults are often stigmatized and subjected to multiple human rights violations, including violations of their rights to health and physical integrity, to be free from torture and ill-treatment, and to equality and nondiscrimination." United Nations Intersex Fact Sheet

## Questions about Bodily Autonomy and Chromosomes

For the sake of these intake questions, I will use "intersex bodily variation" or "intersex trait(s)" to describe being born outside the norms of an endosex male or female body.

Note: Endosex means born within the definition of male and female bodily anatomy.

### Which would you consider yourself: (Select one)

- A. I am aware that I am intersex and accept the word "intersex" to describe myself.
- B. I am aware that I am not endosex but reject the word "intersex" to describe myself.
- C. I am aware I am not endosex but use a different word to describe "intersex," "intersex traits," or "intersex bodily variations." Please share what terms you feel comfortable with.
- D. I am questioning if I have an intersex trait(s) and would like to investigate.

Now please explain more:

1. How did you figure out you were not born endosex?
2. Please describe your intersex traits(s). They can be chromosomal, hormonal, or involve your genitals or reproductive system.
3. Do you have a formal medical report or diagnosis describing your variation of intersex from a physician, and if so, what does it say?
4. Are you okay calling your bodily variations "intersex," or "intersex traits," or do you prefer a different language to be used?
5. Do you feel that you have had sex assigning surgery as a non-consenting child?  
How did you find out you did?
6. Are you happy with the medical treatment you have received at birth and so far?  
Please share why you are unhappy.

### **Questions about Gender Identity and Anatomical Sex**

1. Do you look at *anatomical sex* and *gender identity* as separate or the same?
2. Do you agree with your birth assignment, and does your gender identity match it?
3. Are you happy with your birth certificate, or would you like it changed?
4. If you do not agree, have you considered emancipating your true gender identity through social and/or medical transition?
5. If you disagree with your birth assignment, do you feel you were medically, surgically or psychiatrically violated when assigned the wrong sex and gender?
6. How do you feel about the label *transgender* if you need to go against your birth assignment in emancipating your authentic self?
7. Would you like to change your legal documents (birth certificate, passport, and social security)?
8. How do you feel about *intersex* being considered your sex?
9. Would you want an intersex birth certificate?

### **Questions about Sexual Orientation, Gender identity and Gender Expression**

1. What is your sexual orientation? Heterosexual, Gay, Lesbian, Bisexual, Pansexual, Asexual, or any other ways to describe this.
2. Are you a part of LGBTQIA+ Pride Groups, or do you consider yourself a "Straight" outsider?
3. If you are a heterosexual and agree with your birth assignment, do you consider yourself an LGBTQIA+ Ally?

4. Do you have bias or prejudice against LGBTQIA+ people?
5. Have you ever suffered from genital exposure trauma or body shame, due to being born intersex? This genital exposure trauma could include past sex partners, or even harm brought to you by medical professionals.
6. How would you describe your real lived gender: Man/boy, Woman/girl, Both or neither?
7. Please share your label to describe your gender identity if you have one.
8. Please share how you would describe your gender expression: How you dress, act, or appear as man/boy, woman/girl, both or neither.
9. Do you like what you see in the mirror, or would you like to change things?

#### **Questions about Medical and Psychological Professionals**

1. Do you feel unhappy in any way with the way professionals in the medical complex or psychological complex have treated you?
2. Do you feel medically violated, sexually harassed, or disrespected by any medical or psychological professionals?
3. Have you ever find someone that understood you in the medical or psychological complex?
4. Do you have ongoing health concerns that are related to being born with an intersex bodily variation or intersex traits(s)?
5. Do you have a doctor that taking care of your medical needs?
6. Do you need a reproductive endocrinologist to transition from one gender to the other?

**Questions about Family Dysfunction, Past Self Harm, Societal Harms,  
and Substance Abuse**

1. Do you feel you were raised in a dysfunctional family? If yes, please explain how.
2. Did/do you ever self-harm in the form of eating disorders or cutting?
3. Are you the survivor of incest? Are you the survivor of rape?
4. Are you the survivor of a hate crime due to your sexual orientation, gender identity, or gender expression?
5. Did/do you feel you depend or (ever have depended) on prescription drugs, street drugs, or alcohol to make it through the day?
6. Do you consider yourself an alcoholic or an addict?
7. If you do consider yourself an alcoholic or addict, are you in recovery? If so, explain what type.
8. Did you ever run away from home or became homeless? If yes, please explain at what age and why.
9. Have you ever worked as a sex worker?
10. Have you ever been forced into the sex trade or child pornography?
11. Have you ever attempted suicide? If so, how many times, and why?
12. Do you ever suffer from anxiety, depression or other mental health difficulties?

**Questions about Family and Peer Support Questions**

1. Do you have family support? or do you feel isolated and alone?
2. Do you have peer/friend support?
3. Do you feel isolated and alone?

4. Are you married or in a steady relationship?
5. Are you the parent of children biological or adopted?
6. Have you ever suffered prejudice for being born different?
7. Were you ever kicked out of a school, church, or organization for being different?
8. Do you belong to a formal church or fellowship?
9. Do you belong to any support groups?
10. What helps you most cope with challenges in life?

By Mx. Anunnaki Ray Marquez, March 6, 2020  
Published: [www.anunnakiray.com](http://www.anunnakiray.com)