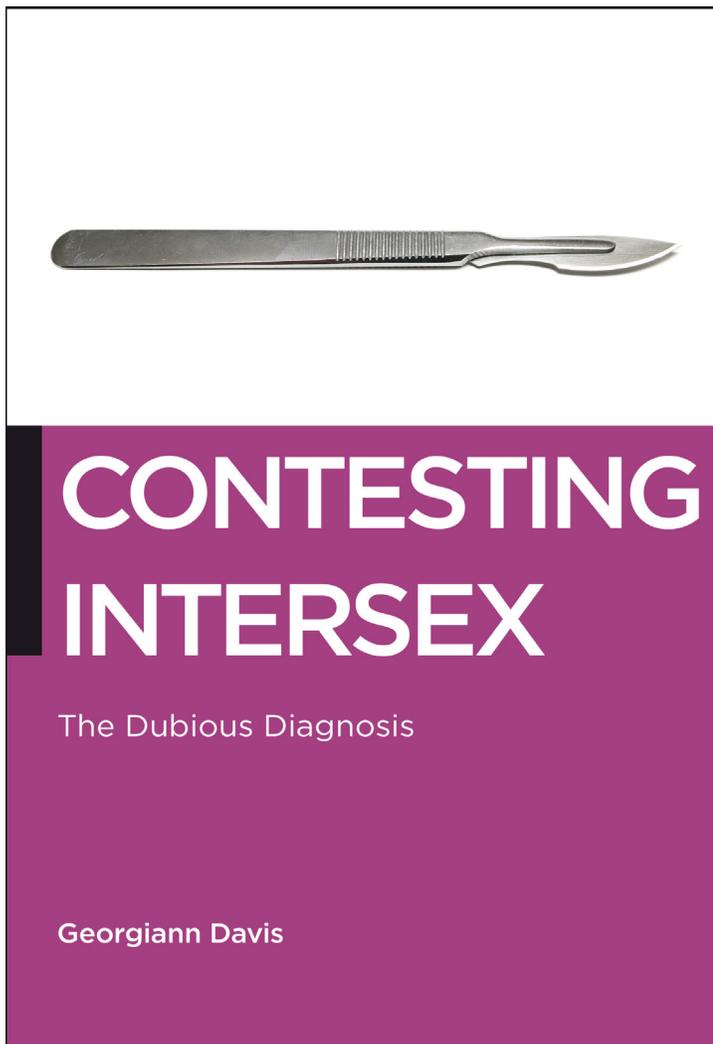


Contesting Intersex

The Dubious Diagnosis

INSTRUCTOR'S GUIDE



Why Consider this Book for Your Class?

- Author is herself intersex, and the book is a very personal campaign for author to avoid surgical “solutions”
- Includes multiple perspectives from the intersex community including intersex people, parents, and medical experts
- Presents the shifting, fluid, and even contradictory definitions of bodies that exist outside the sex binary

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Overview of Supplemental Teaching Guide

I created this guide, geared to the undergraduate classroom, to supplement my book *Contesting Intersex: The Dubious Diagnosis*. While it was written for those who teach undergraduate students, it might also be useful in the graduate seminar.

It contains chapter-by-chapter summaries, discussion questions, links to popular press pieces, blogs, op-eds, etc. on intersex, ideas for small group exercises, and recommended films, documentaries, and YouTube videos—many of these recommendations are available online. Although I've made audio-visual recommendations within each chapter, you will see that the recommendations are applicable with any chapter as one teaches about intersex. I've included approximate runtimes with each recommendation.

My hope is that instructors will find this compilation of resources useful if they use (and I hope they do!) *Contesting Intersex: The Dubious Diagnosis* to teach about sex, gender, medicalization, social movements, body and embodiment, family, and more.

If you have any questions, comments, and/or suggestions for how to improve this guide, please let me know at georgiandavis@gmail.com.

Thank you!



Georgiann Davis, PhD
Assistant Professor of Sociology
University of Nevada, Las Vegas

Georgiann Davis Biography

I was born just outside of Chicago in October of 1980, and after a turbulent educational history (I dropped out of the seventh grade to help my financially struggling family), I eventually earned my GED (1998), AA in General Studies (College of Lake County (2002), BA in Sociology (Northeastern Illinois University 2004), MA in Sociology (University of Wisconsin, Milwaukee, 2006), and PhD in Sociology (University of Illinois at Chicago).

After finishing my PhD, I joined the Department of Sociology and Criminal Justice Studies at Southern Illinois University Edwardsville where I was on the tenure track from 2011-2014. In 2014, I joined the Department of Sociology at the University of Nevada, Las Vegas.

I am also the former president of the [AIS-DSD Support Group](#) (2014-2015), and a current board member for [InterACT: Advocates for Intersex Youth](#) (2016-present).

In addition to [Contesting Intersex: The Dubious Diagnosis](#) (2015, NYU Press), I have written numerous articles on intersex in various outlets ranging from *Ms. Magazine* to the *American Journal of Bioethics*.

You can read more about my work, including my teaching and mentorship, at www.georgiannDavis.com.



Resources for Ch. 1:

Introduction: “You’re in the Monkey Cage with Me”

In chapter 1, I explain my definition of intersex is the state of being born with a combination of characteristics (e.g., genital, gonadal, and/or chromosomal) that are typically presumed to be exclusively male or female. I also describe how the term “intersex” is itself contested, but explain that I prefer such term over the pathologizing “disorder of sex development” terminology.

I explain in this chapter that I rely on gender structure theory to analyze intersex at the institutional, individual, and interactional levels. I find it to be a useful empirical tool, and one that allowed me to integrate other theories at each of these levels, including biological citizenship, perspectives on medicalization, and more.

I also describe my methodology. I describe that my study is based on 65 in-depth interviews with intersex people, their parents, and medical professionals who “treat” intersex people. This number also includes a few past intersex board members who do not have a personal connection with intersex nor are medical professionals.

While methodology is important in any empirical project, it is at the heart of *Contesting Intersex* given I’m not only studying the intersex community, I’m in it as an out intersex person. However, I wasn’t connected to the intersex community when I started this project, thus I maintain the project started from an insider/outside perspective.

I also turn the methodological lens on myself to theorize why I subconsciously altered my hairstyle and clothing depending upon who I was interviewing. I trying to make sense of the fact that I was altering my presentation of self based on how I believed my participants would perceive me—not necessarily how I was being perceived.

Chapter 1 Discussion Questions

1. How is intersex strong evidence that sex and gender binary ideologies are flawed? Begin your answer by defining intersex and what is meant by binary ideologies. Then, drawing on intersex, identify and explain three ways that the sex and gender binary ideologies are flawed.

Resources for Ch. 1:

Introduction: “You’re in the Monkey Cage with Me”

2. Davis acknowledges that the intersex community is mostly white and college educated. She also notes that the cultural capital gained from educational attainment may explain, at least partially, why she didn’t observe a relationship between race/ethnicity and experience with intersexuality. What is meant by cultural capital, and how might it shape or influence one’s experience with intersex?
3. Davis anticipates some readers will view *Contesting Intersex* as methodologically biased given her personal experience with intersex and activist role in the intersex community. Is all research biased? Why or why not?

Chapter 1 Ideas for Small Group Exercises

1. Ask students to get into small groups and create a short video about intersex aimed at raising public awareness. These videos could draw on chapter 1 as well as any of the suggested popular press pieces, blogs, and op-eds shared below.

Have students write a hypothetical letter to Pidgeon Pagonis’s childhood medical providers based on sociological understandings of intersex and Pagonis’s piece [9 Damaging Lies Doctors Told Me When I Was Growing Up Intersex](#).

2. Pair students up and ask one student to play the role of an intersex person who is disclosing their diagnosis to the other student playing the role of a good friend. Have each student reflect on this process of diagnosis disclosure.
3. Most intersex people learn about intersex by doing their own searches about their respective intersex trait, not by the medical doctors who imposed the diagnosis. Ask students to work in groups to search for information about a specific intersex trait. What did they find and learn by their search? You might want to group students up and assign each group a different intersex trait to work with such as androgen insensitivity syndrome, MRKH, Swyer Syndrome, Turner Syndrome, congenital adrenal hyperplasia, etc.

Resources for Ch. 1:

Introduction: “You’re in the Monkey Cage with Me”

Chapter 1 Suggested Popular Press Pieces, Blogs, and Op-Eds

[5 Things I Wish You Knew About Intersex People](#) by Georgiann Davis, UNLV News Center

[Fact Sheet: Intersex](#) by Free and Equal United Nations for LGBT Equality

[Defining: Intersex](#) by Georgiann Davis, The Parents Project

[Brief Guidelines for Intersex Allies](#) by Claudia Astorino and Hida Viloria, OII United States

[Standing Up For The Rights of Intersex People—How Can You Help?](#) by Dan Christian Ghattas, ILGA Europe

[9 Damaging Lies Doctors Told Me When I Was Growing Up Intersex](#) by Pidgeon Pagonis, Everyday Feminism

Chapter 1 Audio-Visual Recommendations

[What It’s Like To Be Intersex](#)

3 minutes

[This Girl Has Balls](#) a TEDx Talk by Georgiann Davis

11 minutes

(Recorded April 2016—link will be available at www.georgianndavis.com when ready)

[Is Anatomy Destiny?](#) a TEDx Talk by Alice Dreger

18 minutes

[Gender Bound](#) a TEDx Talk by Judi Herring

13 minutes

[A Mini-Lecture from Georgiann Davis](#)

5 minutes

Resources for Ch. 2:

The Transformation of Intersex Advocacy

In chapter 2, I explore the institutional level of gender structure by focusing on key social movement organizations—Intersex Society of North America (ISNA), Accord Alliance, Androgen Insensitivity Syndrome Support Group-USA (AISSG-USA), and Organisation Intersex International (OII)—in the intersex rights movement and the transformation of intersex rights advocacy from what I label “collective confrontation” to what I conceptualize as “contested collaboration.”

I draw on Nikolas Rose and Carlos Novas’s definitions of rights biocitizenship (activism for change), digital biocitizenship (employment of electronic media in connecting people across the intersex community), and informational biocitizenship (specialized knowledge about one’s trait) in this chapter.

I also describe in this chapter the birth of DSD language and the community conflict about terminology that followed. This conflict marks the current period, which I label “contested collaboration.” Today’s intersex advocacy reflects disagreements and disputes exacerbated by DSD language, as some members of the community want to work with medical professionals to change intersex medical care, while others resist such collaboration. Although the intersex community and its social movement organizations were never monolithic, I show that the introduction of DSD nomenclature heightened differences across the community and the intersex social movement organizations (ISMOs) in ways that further divided individuals with intersex traits.

I maintain ISMOs are especially important in intersex advocacy because they serve as vehicles for influencing public ideologies about intersex and ultimately changing medical care.

Chapter 2 Discussion Questions

1. Describe the workings of what Davis conceptualizes as “collective confrontation” and “contested collaboration.” How are these two periods in intersex advocacy different from one another? How are they similar?
2. Compare and contrast rights biocitizenship, digital biocitizenship, and informational biocitizenship. Might one be more powerful in promoting change in the intersex community? Why or why not?

Resources for Ch. 2:

The Transformation of Intersex Advocacy

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3. Davis argues that DSD nomenclature created new divides in the intersex community. Is it possible that these new divides could have been avoided even with the introduction of the DSD terminology? Why or why not?

Chapter 2 Ideas for Small Group Exercises

1. Ask students to construct a timeline of intersex advocacy, beginning with Anne Fausto-Sterling's 1993 essay "The Five Sexes," and Cheryl Chase's response to that piece, up to and including the year that disorder of sex development terminology was formally introduced (2006).
2. Have students put together a chart of the four ISMO in this study that includes the year they were formed, their mission statements, strategies for change, key founder(s), and if applicable the year they ceased operations.
3. This study involves four ISMOs. Have students search the Internet for other ISMOs in order to compile a list of resources for newly diagnosed intersex people and their families. How is this process enacting digital biocitizenship?

Chapter 2 Suggested Popular Press Pieces, Blogs, and Op-Eds

[Is The World Finally Waking Up To Intersex Rights?](#) by Naomi Larsson, The Guardian

[A Good Day For Intersex Human Rights?](#) by StopIGM.org

[OII Calls For Greater Support For Intersex Rights Ahead of the Federal Election](#) by Cee Busby, Gay News Network

[My Life As An Intersex Advocate](#) by Kay Cairns, Advocate

Chapter 2 Audio-Visual Recommendations

[Hermaphrodites Speak!](#)

35 minutes

Resources for Ch. 3: Medical Jurisdiction and the Intersex Body

In chapter 3, I continue to address the institutional level of gender structure, but rather than focus on the intersex social movement organizations, I focus on the medical management of intersex traits beginning with a historical discussion of John Money's model for treating intersex, which dominated intersex medical care for much of the second half of the twentieth century. Although Money was once a highly regarded psychologist at The Johns Hopkins Hospital, I revisit the events that led to the discrediting of his research and the collapse of his reputation as the leading expert on intersex (The John/Joan Case).

I argue that insights from the sociology of diagnosis—specifically Annemarie Jutel's theoretical insights about diagnostic naming—can help us understand the contemporary medical management of intersex, specifically why and how medical experts so quickly embraced DSD language.

I show how contemporary U.S. medical experts on intersex, like much of society, tend to hold narrow, essentialist understandings of sex, gender, and sexuality. The danger in medical professionals holding these views is that they often are used to justify medically unnecessary and irreversible surgical interventions on intersex bodies, which have long-lasting implications for intersex people. Taking into account these two realities alongside 1990s intersex activism (discussed in chapter 2), I argue that medical professionals took so quickly to the new DSD nomenclature because it allowed them to escape their tainted history of intersex medical care. Today, it is rare to find a medical expert who speaks or writes about intersex without using DSD terminology.

I conclude this chapter suggesting that with medical authority and jurisdiction over the intersex body in jeopardy, the new language allowed medical professionals to reassert their power over intersex. Medical professionals no longer treat intersex traits; they treat DSDs and in doing so maintain their authority.

Chapter 3 Discussion Questions

1. Describe John Money's gender socialization thesis, and explain whether or not Davis feels the John/Joan Case successfully refutes it.

Resources for Ch. 3:

Medical Jurisdiction and the Intersex Body

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2. According to Davis, what factors led to medical professionals taking so quickly to disorder of sex development terminology?
 3. Davis describes the majority of medical professionals she spoke with as “white coat gender essentialists.” Describe what she means by such, and explain how such essentialist ideology is related to intersex medical treatment.
 4. A few of the doctors Davis interviewed were critical of the ways in which their peers treated intersex people. Explain the dominant medical approach to intersex, and then explain the critiques of this approach that a few of the medical professionals Davis interviewed raised during their interviews.
 5. What are “DSD Teams” and why is Davis critical of them when enacted in the field of intersex medicine?

Chapter 3 Ideas for Small Group Exercises

1. Ask students to describe how a progressive doctor, one who respected intersex people’s bodily autonomy, would diagnose and address a person’s intersex trait.
2. Place students in groups of 3-4 and ask them to develop a short handout that teaches medical professionals the difference between sex, gender, and sexuality.
3. Have students trace the history of a specific diagnosis (for example, fetal alcohol syndrome, obesity, restless leg syndrome, chronic fatigue syndrome, etc.), including the birth of the diagnosis and, if applicable, community disputes about how medical professionals approach the diagnosis.

Resources for Ch. 3: Medical Jurisdiction and the Intersex Body

Chapter 3 Suggested Popular Press Pieces, Blogs, and Op-Eds

[The Modern Master of Sex](#) by Melissa Pandika, OZY

[The Spectrum of Sex Development: Eric Vilain and the Intersex Controversy](#) by Sara Reardon, Nature News Feature

[Born In Between: Should Doctors Operate On Intersex Babies](#) by Azeen Ghorayshi, BuzzFeed

Chapter 3 Audio-Visual Recommendations

[Intersex Children: A Journey Between Genders](#)

9 minutes

Resources for Ch. 4: The Power in a Name

In chapter 4, I highlight the individual level of gender structure by focusing on intersex people, themselves, including the emotional and sexual struggles many in our community, regardless of surgical status have faced, which I maintain serves as evidence that our struggles do not reside exclusively from the scalpel but rather reside within the broader medicalization process, including the pathologization of the intersex body. For this reason, I fear that DSD terminology, if not approached carefully, is potentially dangerous to the intersex community. *Disorder of sex development* implies that one has an abnormality or, worse, is abnormal.

I also discuss intersex people's terminological preferences (which I note seem to be shaped by one's understanding of gender), ultimately contending that it is most powerful to be flexible with terminological preference because each term offers benefits and challenges. However, being flexible with the employment of terminology requires that one acknowledge that diagnostic terminology—like sex, gender, and sexuality—are socially constructed phenomena.

To support these arguments, I rely on Rose and Novas's discussion of biological citizenship, which they conceptualize as "both individualizing and collectivizing" (2005, 441). Biological citizenship at the individual level is particularly concerned with how individuals use biomedical language to describe aspects of the self. Because *DSD* was formally introduced by the powerful institution of medicine, the intersex community has no choice but to engage with it—even if such engagement is to critique it.

Chapter 4 Discussion Questions

1. Describe intersex people's terminological preferences, and explain the advantages and disadvantages of each preference. Why does Davis suggest that it is useful for intersex people to be flexible with their terminological preference?
2. Davis argues many of the emotional and sexual struggles intersex people face result not only from the scalpel but from the broader medicalization process. What does she mean by "broader medicalization process"? Be sure to clearly define and explain medicalization, including its processes, in your answer.
3. Are there other so-called medical "conditions" where terminological tensions exist? Explain these tensions.

Resources for Ch. 4:
The Power in a Name

4. What is biological citizenship, and how, according to Davis, does it interact with terminological preferences? Explain your answer.

Chapter 4 Ideas for Small Group Exercises

1. Place students into four groups and ask each group to create a short 5-minute skit for the general public where they explain that sex, gender, sexuality, or diagnoses are socially constructed.
2. Have students create a conceptual map of intersex people's terminological tensions. This can include advantages and disadvantages of respective terms, access to biological citizenship, etc. This should help students visibly understand the utility of being flexible with terminological preferences.
3. Organize students into three groups: those who prefer intersex, those who prefer disorder of sex development, and those who are flexible. Stage a debate where each group makes arguments for their terminological preference.

Chapter 4 Suggested Popular Press Pieces, Blogs, and Op-Eds

[Not All Intersex People Are the Same](#) by Arti, InterACT blog

[American Surgeons Are Still Mutilating Children Who Don't Look "Normal"](#) by Sean Saifa Wall, Quartz

[Are Intersex People Inherently Part of the Queer Community?](#) by Claudia Astorino, Everyone Is Gay

[My Intersex Body: More Than an Object of Fascination or Repulsion to be 'Fixed'](#) by Phoebe Hart, Independent

Resources for Ch. 4:
The Power in a Name

Chapter 4 Audio-Visual Recommendations

[Discovering One's Intersex Self—a Personal Story](#) by Gina Wilson
4 minutes

[36 Revolutions of Change](#) by Sean Saifa Wall
14 minutes

[Growing Up Intersex](#) featuring Claudia Astorino
7 minutes

[The Spectrum: Intersex](#)
25 minutes

[Collected Stories, The Interface Project](#)
A number of 3-4 minute narratives from a diverse group of intersex people

Resources for Ch. 5: A Different Kind of Information

In chapter 5, I turn to the interactional level of gender structure to investigate how parents of intersex children reach decisions about medical intervention.

I show how medical professionals present intersex as a medical emergency to parents of newly diagnosed intersex children. This framing creates what Giorgio Agamben describes as a state of exception—a framing that allows them, I argue, to abandon medical ethics that warn against performing medically unnecessary surgery on children.

Once the intersex trait is presented as an emergency and the state of exception is established, medical providers tend to inundate parents with information about intersex. However, the information they present focuses on the alignment of sex, gender, and sexuality as essentialist characteristics of the body, laying the groundwork for justifying medically unnecessary interventions, notably irreversible surgical procedures that many doctors continue to, even today, recommend without any hesitation to parents of newly diagnosed children.

Relying once again on Nikolas Rose and Carlos Novas, I show how medical professionals place the responsibility for the medical interventions they perform entirely on parents, thereby avoiding responsibility for questionable interventions. Most important, I argue that when parents are exposed to a different kind of information—that is, information which originates in the intersex community rather than in the medical profession—they are more likely to delay or even refuse medical recommendations. Such questioning of medical recommendations directly challenges medical authority and changes the standard course of intersex medical care. Those who obtain information from the intersex community after consenting to medical procedures tend to report a tremendous amount of guilt, but they too challenge medical authority by advising other parents in the intersex community to question the necessity of medical interventions.

I end the chapter showing how parents of intersex children are not as divided over DSD terminology as intersex adults. In fact, their children's intersex traits challenged many parents to adopt more socially constructed views of gender, making conceptualizations of gender less relevant to their positions on nomenclature than such is for intersex adults' terminological preference. Parents' terminological preferences seemed to have more to do with their acceptance of

Resources for Ch. 5: A Different Kind of Information

LGBT communities. Parents who embraced DSD language tended to be critical of the move to include an *I* for *intersex* on the LGBT abbreviation, leading me to believe that homophobia fueled at least some of their terminological preference.

Chapter 5 Discussion Questions

1. Describe, in detail, how medical professionals typically present the intersex diagnosis to parents of newly diagnosed intersex children.
2. Davis claims that doctors present intersex as an emergency thereby establishing a state of exception. Define state of emergency and state of exception, and then explain why, according to Davis, this theoretical framing is useful in understanding parental decision making and the processes behind these medically unnecessary interventions.
3. If many parents of intersex children end up expressing decisional regret for consenting to their children's medically unnecessary and irreversible interventions, why don't more parents refuse to consent to such procedures?
4. What factors shape parents' terminological preferences, and how do these factors differ from the factors shaping intersex people's terminological preferences? In your answer, be sure to explain, in detail, parents' and intersex adults' terminological preferences.

Chapter 5 Ideas for Small Group Exercises

1. Organize students into small groups and ask them to imagine an obstetrician hired them to create a supplement on intersex that she could give to her pregnant patients to accompany the ever so popular—albeit problematic—book, [What To Expect When You're Expecting](#). Have each group discuss what such a supplement would look like and what information it should contain. Then, ask the students to create the supplement and share it with the class.

Resources for Ch. 5:
A Different Kind of Information

2. Ask students to imagine that they are the parents of a newly diagnosed intersex infant. They've never heard of intersex before, and doctors are coming in and out of the new parents' hospital room using language the parents don't understand—disorder of sex development, chromosomes, biomarkers, etc. The doctors, one after another, are also repeatedly looking at their new baby's genitals. Scared and confused, the parents decide to search for information about "disorders of sex development" on their smart phones. List all of the resources that are easily accessible on the internet. How do these resources frame intersex?

Chapter 5 Suggested Popular Press Pieces, Blogs, and Op-Eds

[Five Things You Can Do For Your Intersex Child](#) by Georgiann Davis, The Parents Project

[Intersex Conditions: Is There An Ultimate Best?](#) by Nita Whelan, The Medically Modified Human

['We Don't Know If Your Baby's a Boy or a Girl': Growing Up Intersex](#) by Jenny Kleeman, The Guardian

Chapter 5 Audio-Visual Recommendations

[The Challenges of Raising an Intersex Child](#)
23 minutes

Resources for Ch. 6:

Conclusion: The Dubious Diagnosis

Chapter 6 concludes *Contesting Intersex*. It begins with the public attention intersex has recently received. I focus specifically on a groundbreaking 2013 lawsuit filed in both federal and state courts against “South Carolina Department of Social Services (SCDSS), Greenville Hospital System, Medical University of South Carolina and individual employees” by parents who adopted a child with an intersex trait. I then turn to the possibility for positive social change in the form of practical actions that intersex activists and allies can take to decrease intersex stigma and the shame and secrecy that surround it. These actions include: (1) continuing to fight for the elimination of medically unnecessary surgeries; (2) collaborating with medical allies; (3) forging connections across groups in the intersex rights movement with a goal of increasing gender, racial, and class diversity across and within intersex organizations; (4) overcoming the fear of public exposure; (5) engaging with formal and informal feminist scholarship; (6) recognizing that social constructions—most notably sex, gender, sexuality, and medical diagnoses—drive inequalities in our community; and, most important, (7) recognizing the importance of the voices of intersex children in the evaluation of intersex medical care.

Chapter 6 Discussion Questions

1. What is the #Justice4MC case, and why is it important in intersex advocacy?
2. Davis identifies seven practical actions that intersex activists and allies can take to decrease intersex stigma and the shame and secrecy that surround it. Explain each of these actions, and then, after considering each of them, add one or two actions to her list that you think might also be helpful.

Chapter 6 Ideas for Small Group Exercises

1. The #Justice4MC case was filed in both federal and state courts. As described in *Contesting Intersex*, the federal court case was eventually dismissed. But, at the time *Contesting Intersex* went to press, the state case was still active. Ask students to get into small groups to search the internet for updates on the case.

Resources for Ch. 6:

Conclusion: The Dubious Diagnosis

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2. Ask students to get into small groups to find and describe the International Olympic Committee and International Association of Athletics Federations current stance on hyperandrogenism as it pertains to participating in elite completion.

Chapter 6 Suggested Popular Press Pieces, Blogs, and Op-Eds

[Intersex Inclusion in Popular Media](#) by Amanda Saenz, InterACT blog

[Are We Witnessing The Birth of TV's Intersex Liberation](#) by Diane Anderson-Minshall, Advocate

[Intersex Buzz: To Avoid \(or engage with\) 'Disorder of Sex Development' Terminology?](#) By Georgiann Davis, From the Square

[6 Things Intersex Folks Should Know About How We Perpetuate Anti-Black Racism](#) by Pidgeon Pagonis, Everyday Feminism

[Dutee Chand, Female Sprinter With High Testosterone Level, Wins Right to Compete](#) by John Branch, New York Times

[Carter Covington Explains Why MTV Is Ending "Faking It" With Season 3 \(Exclusive\)](#) by Lesley Goldberg, The Hollywood Reporter

[Sex vs Gender: Doctors Change Their Approach With Intersex Kids](#) by Molly Reed, WKBN First News (also a video news story)

[Intersex Person Who Was Denied a Passport Over Gender Designation Sues U.S. Government](#) by Hailey Branson-Potts, LA Times

Chapter 6 Audio-Visual Recommendations

[Intersexion](#)

1 hour 8 minutes

[XXY](#)

1 hour 26 minutes

Resources for Ch. 6:

Conclusion: The Dubious Diagnosis

[One in 2000](#)

26 minutes

[Orchids: My Intersex Adventure](#)

60 minutes