

A Speaker's Handbook

for Intersex Activists & Allies



Photo taken at an ISNA presentation at San Francisco Public Library in summer 2001. Speakers are Howard Devore, T. Julian Holder, Hida Viloria, and David C. Strachan.

Created by and for the **Speaker's Bureau**
of **Intersex Initiative Portland (ipdx)**

www.ipdx.org | info@ipdx.org

A Speaker's Handbook for Intersex Activists and Allies
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Written and edited by Emi Koyama and Tara Medve.
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Intersex Initiative Portland
PO Box 40664
Portland, OR 97240
www.ipdx.org

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Introduction

WELCOME FROM THE DIRECTOR

First of all, thank you for your interest in speaking about intersex activism. This handbook is designed as a reference for intersex activists—both people who are themselves intersex and their partners, family members, friends and allies—who are interested in giving basic public presentations about intersex issues.

The 1993 publication of Anne Fausto-Sterling’s “The Five Sexes: Why Male and Female Are Not Enough,” which was problematic in many ways as Fausto-Sterling later acknowledges, nonetheless served as a catalyst for the birth of the intersex movement, as well as the explosion of societal interest in intersexuality. However, much of the public discourse about intersexuality focused on gender theories (e.g. Is gender biologically determined, or is it socially constructed? How many “sexes” should there be?), leaving behind lived experiences of intersex individuals. Even the medical “debate” over intersex treatment today continues to assume matching of one’s genital to her or his gender identity to be the ultimate goal of “good” medicine, rather than seriously considering overall quality of life for people who go through invasive and often traumatizing medical treatments.

In March 2003, Intersex Initiative Portland (ipdx) launched the Speaker’s Bureau, the program specifically designed to train volunteers—both intersex people and allies—to give basic presentations about intersex activism. We believe that we can reduce medical abuse of intersex children and build an intersex-friendly communities through education. We believe that parents who have heard about intersex activism before having an intersex baby or have friends who are knowledgeable about intersex activism are likely to seek social and psychological support for themselves and their child rather than resorting to the untested and unproven quick-fix recommended by many medical professionals. In short, we believe that we can change the society a little bit at a time through raising the awareness of real-life experiences of intersex people. This handbook is an invitation for you to join our little revolution.

As a new public speaker-to-be, you may be feeling anxious about getting in front of an audience. Or perhaps you are an experienced presenter who has given many workshops and lectures on another topic. You may be a survivor of intersex “treatment,” and feeling nervous about what to expect, or a non-intersex ally worried about misrepresenting intersex people’s experiences. All of these fears are valid, reasonable, and often manageable. Later in this handbook, you will find practical tips and strategies, as well as wealth of information that you can draw upon.

We hope that this handbook will help you become more confident in speaking about intersex activism, whether it is in front of a large audience, a classroom, a religious congregation, or your friends and family members. Please feel free to send us your feedback at info@ipdx.org or PO Box 40664, Portland OR 97240.

Emi Koyama
Director, Intersex Initiative Portland

WHAT IS INTERSEX INITIATIVE PORTLAND?

Intersex Initiative Portland (ipdx) is a network of intersex activists and allies working to stop the medical abuse of intersex children and to challenge the medical and social erasure of intersex existence through raising the awareness of issues faced by intersex people. ipdx was founded in January 2003 by Emi Koyama, the former staffer for Intersex Society of North America (ISNA).

While we believe in local (Portland, Oregon and the Pacific Northwest) action, we work with activists and allies from across the nation. In addition, we provide online and print resources (such as this handbook) for others to use elsewhere.

Intersex Initiative Portland is affiliated with Survivor Project, a Portland-based organization dedicated to addressing the needs of intersex and trans survivors of domestic and sexual violence.

SPEAKING AS SURVIVAL / SURVIVAL AS SPEAKING by Emi Koyama

Last year, I was invited by a small private college to “debate” with the former president of the Lawson Wilkins Pediatric Endocrinology Society (LWPES) who has published papers endorsing the concealment-based medical treatment (i.e. early surgery) of intersex conditions. While I do not regret having accepted the invitation and I feel confident that I swayed the audience to agree with me, it affected me emotionally in more ways than I had anticipated.

Some of the things I had expect were ignorant comments and flawed logic. But what affected me the most was not what he said, but what he didn't. It was not who he was, but who he wasn't. It took me a few days to realize this, but somehow, I had expected him to give me answers to the questions I was never allowed to ask in my childhood. I had expected him to play out the role of the omnipotent and omniscient doctor that I remembered my childhood doctors as. I wanted him to be the wise old man who would explain everything to me, the whole grand plan. I wanted him to be a brilliant mad scientist, a Darth Vader. Instead, I realized what I had always known: that he was (and my childhood doctors were) just like everyone else, neither particularly wise nor evil. In a strange way that is hard to explain, I felt deeply betrayed by this.

This is an extreme example (most presenters will not directly speak with leading physicians “on the other side,” after all), but speaking about intersex issues can be painful or triggering if you have personally lived through experiences of violation, shame, secrecy and isolation. Here, I am not only talking about intersex people; those who survived other forms of childhood sexual trauma may find it difficult. While speaking from one's own experiences can be a powerful strategy to influence people's minds, we need to prioritize our personal self-care. We won't be affecting social changes in the long-term if we took on too much burden too soon to the point that we burn out.

On the other hand, many survivors of childhood sexual trauma find it healing and empowering to participate in activism confronting the child sexual abuse. I personally feel that this is a large portion of why I want to be involved in intersex activism. Public speaking is one of the ways we can take concrete actions to confront the abuse we have experienced in our lives, although it is not the only

one. Writing about our experiences, creating art, talking with our friends, making donations to ipdx and other intersex activist groups, or simply surviving and thriving—all of these are building blocks of our movement.

Thank you for your interest in speaking out with us. Please carefully consider whether or not public speaking is for you, and if so, how much self-disclosure you want to make, how to make it empowering rather than painful for you, and what resources you have for emotional support. If you choose not to do public speaking, that is perfectly fine: I hope you will join us anyway because there are many other things you can do that are just as important. And above all, please do take care of yourself, and feel free to email me (emi@ipdx.org) if you want to exchange ideas.

WHY I AM SPEAKING ABOUT INTERSEX ISSUES **by Tara Medve**

When Emi asked me to participate in the Speaker's Bureau, I felt very excited and honored. However, I also felt nervous about speaking publicly about intersex because I am not intersexed and I was afraid that I might mislead or give inaccurate information to the audience. We thought that others might have similar fears and apprehensions as myself, hence the reason for this essay.

I first became interested in intersex while in college. To receive my B.A. in Women's and Gender Studies, it was required that I write a Capstone paper on a topic of my own choosing. I had heard a little about intersex, and like many other non-intersex academics before me, I wanted to use the concept of intersex to make an argument for social constructivism and gender performativity—and against biological determinism. Once I began researching, I realized that I was into something far greater than I had originally anticipated. My mind was suddenly opened to avenues not yet explored in my understandings of sex, gender, sexuality, and identity. With this, however, came the realization that the paper I had envisioned writing would be virtually impossible. My topic was way too large and vague, and it was imperative for me to narrow it down.

After a few false starts and lots of brainstorming, I decided to analyze narratives written by intersex people about their experiences, and to transform my project into a sort of ethnography. Looking back, I wonder why I chose to focus on narratives, when originally I was interested in theory. The most obvious reason that comes to mind is that after reading several narratives, I realized that many of the common issues faced by intersex people would be neglected in a paper on gender theory because intersex is not about gender identity. I found that theories on intersex were not grounded in the lived experiences of intersex people; therefore, they could not, in good conscience, be the starting off point for my paper.

I was so incredibly moved by the stories that I had read- and so shocked and appalled at the treatment of intersex people in U.S. society—that it made sense for me to focus my paper on intersex people and their experiences. Also, I remember feeling angry and frustrated with the absence of intersex voices in the academic discourse on intersexuality, and I did not want to produce another text written by a non-intersex person theorizing about the societal and cultural implications of the treatment of intersex. I wanted my Capstone to be a place where the voices of intersex people could be heard, not ignored.

Since then, I have remained interested in the topic of intersex, and I have become an active ally in the movement. I am a firm believer in the idea of reciprocity in research, and for a while I felt that it was my duty to give something back. After all, these individuals had published their stories that I could use; the least I could do is try to help them with their mission. Plus, I have always believed that theory without action is impractical and useless, and there is so much opportunity for activism in the intersex movement. I am still learning, through speaking and other means, about intersex. I am in no way an expert on intersex, but I do know a lot more than most people. It is my responsibility to use my education and knowledge in a way that is beneficial to others, and participating in the Speaker's Bureau is a wonderful and rewarding way for me to do so.



Illustration by Jane Torpedo

Chapter One: Speaking for Social Change

Note: Portions of this section are heavily based on “Opening Hearts and Minds” speaker’s training program of Love Makes a Family, a Portland-based LGBT family organization. Please contact Love Makes a Family at PO Box 5163, Portland OR 97208 or 503-228-3892 for more information about the program. We would like thank Love Makes a Family and Bradley-Angle House for sharing their speaker training materials with us.

SPEECH AS NON-VIOLENCE

Intersex Initiative Portland uses the model that views speech as a type of action. And like other forms of action, it can be done violently or non-violently, abusively or lovingly. “Violent speech seeks to force compliance, to vanquish opponents with flashes of verbal brilliance, to obliterate opposing arguments with flawless logic. Non-violent speech works to discover and build upon common ground that nurtures both parties” (from “Opening Hearts and Minds”).

Non-violent speaking acknowledges general agreements on principles (for example, that we do not wish to harm anyone without justification and resistance) we share with those who might disagree with us in more specific ways, and build on them. By assuming that they are decent human beings who want to do the right thing once they realize what is, we give them the room to join us without feeling defeated.

Not only is this a good approach to dealing with societal disagreements in general, it is an essential one within the intersex movement. The goal of intersex movement is not to overthrow its “oppressor” (e.g. doctors and parents who endorse mutilation of children’s genitals) but to win over their minds by providing them more information. We will not achieve this goal by demonizing them. In fact, many of the most enthusiastic supporters of the intersex movement are medical professionals and parents who feel that they have unintentionally harmed children as the result of honest mistakes they made in the past because they simply lacked information. Most people are genuinely eager to do what’s best for our children, if they knew what that is.

LARA METHOD OF NON-VIOLENT RESPONSE

LARA method is a non-violent model for responding to hostile or ignorant arguments. It was developed Love Makes a Family and has been adopted by many organizations and activists.

LARA method consists of Listen, Affirm, Respond, and Add Information. When someone makes a hostile or ignorant comment or question, our first impulse is to directly respond by pointing out why that opinion is invalid. This is a natural tendency in a society where speech is made out to be instruments of competition and aggression; LARA model teaches us to unlearn this tendency, at least for the duration of the presentation, and proposes an alternative.

Under LARA method, the presenter will first listen closely to what valid motives, however misguided, one must hold in order to make a hostile or ignorant comment or question. There are usually a reasonable concern for justice and equality beneath hostile or ignorant comments. For example, those who are in favor of surgical treatment of intersex children are not in favor of harming or traumatizing children; they genuinely feel that it would help them grow up healthier. Here, the concern for children’s well-being is a common ground that we need to build our conversation from.

Second, the presenter will verbally affirm the common ground we have with our audience, and affirm the basic good intention of the person who made a hostile or uninformed comment. In the example above, the presenter would state how much we all care about the well-being of our children, and that we all want to help them.

Third, the presenter will respond to the issues raised. In the same example, we would discuss why surgery will not address the problem it claims to solve (e.g. it won’t actually make children feel “normal”), and how it will create additional problems, such as scars, loss of sexual sensation, and psychological trauma.

Lastly, the presenter will add relevant information or opinion that would “help the audience to see the issue in a new light, or that will redirect the discussion in a more positive direction.” Here, we could introduce the alternative we are proposing (i.e. psychological and social support), or discuss how surgical concealment goes against other widely held values such as self-determination and informed consent. We could also offer additional resources or add personal anecdotes.

In political debates, we often listen to our opponent until we hear the opponent’s weakest argument and then attack that point. LARA method suggests us to do the opposite: that we listen to our opponent until we hear the most reasonable or agreeable point, and use it to build a connection to them. By acknowledging the basic good human character in the opponent, we will make it more likely that they will hear and consider our facts than if we had started out by criticizing their ignorance or negating their point.

SPEAKING TECHNIQUES

Structure of a Speech

Below is a basic structure of speech that you can use as a starting point to build your presentation from.

Introduction

- a. Hook (Grab the audience’s attention)
- b. Connect (Establish common ground / what’s in it for them?)
- c. Preview

Body

- a. Define need/problem (facts, stats, examples)
- b. Solution

Conclusion

- a. Summarize (Tell them again in fewer words)
- b. Connect (Again)
- c. Close with high-impact technique

An outline of a typical presentation about intersex activism can be found in the Chapter Three of this handbook.

Attention Getters

These are effective ways to start and end your talk.

- a. Ask a question
- b. State an unusual fact
- c. Tell a story / Give an illustration
- d. Refer to the occasion
- e. Humor: Poke fun at yourself
- f. Refer to the purpose or theme of the meeting
- g. Use a quotation
- h. Emphasize the importance of the subject
- i. Compliment the audience with sincerity

High-Impact Techniques

- a. Self-disclosure
- b. Common ground
- c. Stories / Examples
- d. Humor
- e. Audience involvement (discussion, break-out, brainstorming, etc.)
- f. Demonstration
- g. Quotation

Speaker DON'Ts

Do not...

- a. Read from paper
- b. Speak in monotone
- c. Fidget with nervous habits
- d. Say "you know" or "and-uh"
- e. Ramble / Lose focus
- f. Appear uninvolved/bored
- g. Speak over time allotted
- h. Apologize unnecessarily
- i. Be defensive

Non-Verbal Checklist

- a. Appearance (make the audience feel comfortable with you)
- b. Posture
- c. Eye contact
- d. Hands and arms (let message flow through the body)
- e. Body movement (avoid rocking and pacing)
- f. Avoid distracting repetitive mannerisms

If you can, video-tape yourself and check for these.

Chapter Two: Intersex Activism Basics

CHILD SEXUAL ABUSE AND THE MEDICAL ABUSE OF INTERSEX CHILDREN by Emi Koyama

The notion “genital mutilation” evokes an image of the traditional, ritualistic cutting of young women’s bodies in Africa, but its equally ritualistic high-tech version is widely practiced in the U.S. and other Western countries in relative secrecy. Since 1950s, children born with intersex conditions, or physiological anomalies of the reproductive and sexual organs, have been “treated” with “normalizing” surgeries that many survivors say are damaging to their sexual and emotional well-being.

Contrary to the popular mythology, intersex people do not have “both sets of genitals”; they simply have body parts that are different from what is considered “normal”—large clitoris, penis with a urethra on its underside, missing vagina, mixed gonads, etc. Even though it has been practiced for many decades, there is no long-term study that shows that “corrective” surgery is safe, effective, nor necessary.

One of the biggest problems with this “treatment” is that it sets in motion a lifelong pattern of secrecy, isolation, shame, and confusion. Adult intersex people’s stories often resemble that of those who survived childhood sexual abuse: trust violation, lack of honest communication, punishment for asking questions or telling the truth, etc. In some cases, intersex people’s experiences are exactly like those of child sexual abuse survivors: when they surgically “create” a vagina on a child, the parent—usually the mother—is required to “dilate” the vagina with hard instruments every day for months in order to ensure that the vagina won’t close off again.

Even so, many intersex adults report that it was not necessarily the surgery that was most devastating for their self-esteem: for many, it is the repeated exposure to what we call “medical display,” or the rampant practice where a child is stripped down to nude and placed on the bed while many doctors, nurses, medical students, and others come in and out of the room, touching and prodding and laughing to each other. Children who experience this get the distinct sense that there is something terribly wrong with who they are and are deeply traumatized.

In the past decade, the movement to challenge these medical abuses of intersex children grew from complete obscurity into an international network of intersex individuals, scholars, supporters, and some sympathetic medical professionals. Still, it is estimated that five children per day continue to undergo the medically unnecessary and irreversible surgeries in the United States. Progressive activists and feminists need to work closely with the intersex movement in order to end the ritualistic sexual abuse of children in our own society, not just in other continents.

FREQUENTLY ASKED QUESTIONS ABOUT INTERSEXUALITY AND INTERSEX ACTIVISM

What is intersex?

Technically, intersex is defined as “congenital anomaly of the reproductive and sexual system.” Intersex people are born with external genitalia, internal reproductive organs, and/or endocrine system that are different from most other people. There is no single “intersex body”; it encompasses a wide variety of conditions that may not have anything in common except that they are deemed “abnormal” by the society. What makes intersex people similar is their experiences of medicalization, not biology.

Intersex is not an identity. While some intersex people do reclaim it as part of their identity, it is not a freely chosen category of gender—it can only be reclaimed. Most intersex people identify as men or women.

What do intersex activists want?

We are working to replace the current model of intersex treatment based on concealment with a patient-centered alternative. We are not saying that intersex babies are better off left alone; we want there to be social and psychological support for both the parents and intersex children so that they can deal with social difficulties resulting from being different than others. In the long-term, we hope to remove those social barriers through education and raising awareness. See Alice Dreger’s chart contrasting the two paradigms in the appendix of this handbook.

How common are intersex conditions?

No one knows exactly how many children are born with intersex conditions because of the secrecy and deception surrounding it, and also because there is no concrete boundaries to the definition of “intersex.” It is nonetheless estimated that about one in 2,000 children, or five children per day in the United States, are born visibly intersex, prompting early intervention.

Can’t they just do a test to find out babies’ true sex?

Medicine cannot determine the baby’s “true sex.” For example, chromosomes do not necessarily dictate one’s gender identity, as it is obvious from the fact that most people born with androgen insensitivity syndrome live as women despite their XY chromosomes. In other words: science can measure how large a clitoris is, but cannot conclude how large or small it needs to be. That is a social determination.

How do we know the correct gender of a child with an intersex condition?

We won’t know the child’s gender until she or he is old enough to communicate to us. It is recommended that the child be assigned a gender based on our best prediction, and allow her or him to determine for herself or

himself once she or he is old enough to do so. Irreversible surgeries on infants should be avoided in order to give them the widest range of choices when they are older. Performing surgeries will not eliminate the possibility that our prediction is wrong.

What is the correct pronoun for intersex people?

Pronouns should not be based on the shape of one's genitalia, but on what the person prefers to be called. For children too young to communicate what her/his preference is, go with the gender assignment parents and doctor agreed on based on their best prediction. Do not call intersex children "it," because it is dehumanizing.

Are there five sexes?

The notion of "five sexes" was popularized by Anne Fausto-Sterling's article "The Five Sexes: Why Male and Female Are Not Enough" published in 1993. In this largely tongue-in-cheek piece, she wrote that three subcategories among "intersex" should be considered as three additional sexes aside from male and female. Unfortunately, the "five sexes" theory does not help people with intersex conditions. In addition to exoticizing and sensationalizing intersex people, the distinction between three additional "sexes"—merm, ferm and herm—are artificial and useless in improving the lives of intersex people. Fausto-Sterling later wrote in *Sexing the Body* (2000) that she was "no longer advocating" these categories, "even tongue in cheek."

Are intersex people "third gender"?

Many people with intersex conditions identify solidly as a man or as a woman, like many non-intersex people. There are some who identify as a member of an alternative gender, like some non-intersex people. While we support everyone's right to define her or his own identities, we do not believe that people with intersex conditions should be expected to be gender-transgressive just because of their condition.

Is intersex part of "transgender" community?

While some people with intersex conditions also identify as transgender, intersex people as a group have a unique set of needs and priorities beyond those shared with trans people. Too often, these unique needs are made invisible or secondary when "intersex" becomes a subcategory of "transgender." For example, people who discuss about intersex in the context of transgender often stress the risk of assigning a "wrong" gender as an argument against intersex genital mutilation, which overlooks the fact that intersex medical treatment is painful and traumatic whether or not one's gender identity happens to match her or his assigned gender. It is for this reason that we prefer to have "intersex" spelled out explicitly rather than have it "included" in "transgender" umbrella.

What is the difference between “hermaphrodite” and “intersex”?

In biology, “hermaphrodite” means an organism that has both “male” and “female” sets of reproductive organs (like snails and earthworms). In humans, there are no actual “hermaphrodites” in this sense, although doctors have called people with intersex conditions “hermaphrodites” because intersex bodies do not neatly conform to what doctors define as the “normal” male or female bodies. We find the word “hermaphrodite” misleading, mythologizing, and stigmatizing. Although some intersex activists do reclaim and use this term to describe themselves, it is not an appropriate term to refer to intersex people in general. In short, snails are the hermaphrodites; humans are not.

Also, please avoid using the word “intersexual” as a noun; we prefer “intersex people” or “people with intersex conditions/experiences.”

How can I help intersex movement?

Join us! In addition to volunteering for or making donations to intersex activist groups such as Intersex Initiative Portland (ipdx), you can help by talking to your friends and family members about the intersex movement. The idea is that the more people are aware about us, the less likely they will accept surgery as the only option when they or someone they know have an intersex baby. Get your community, church or school group together and show documentary films about intersex (available from Intersex Society of North America) or invite us to present. If you have access to the internet, join the news announcement lists from ipdx, ISNA and Bodies Like Ours.

Where can I read more about intersex movement?

See appendix of this handbook for additional materials to read.

Chapter Three: Speaking About Intersex

TALKING POINTS FOR IPDX SPEAKERS

Below is a talking points for a typical basic presentation about intersex. You will probably want to add specific examples or additional information in addition to what's included here. Please note that your presentation will look very different if you are presenting from a particular personal perspective, such as a parent of an intersex child. Use below as a starting point, and build your own presentation that will work for you. We'd be happy to chat with you about the specifics.

BEGIN PRESENTATION with a brief introduction. In most cases, we recommend showing one of the two films at the beginning of the presentation: "XXXXY" (12 minutes) or "Total Patient Care" (20 minutes) immediately following the introduction.

- In the introduction, you might want to disclose what's in it for you, especially if you are an intersex ally. How did you end up getting involved in the issue? Non-intersex speaker might use this to connect with the audience, who are wondering what's in it for them as non-intersex people to care about the issue. If you are an intersex person yourself, do not feel pressured to disclose more than you want to: some people give fabulous presentations where they talk about their own experiences, while others prefer to give different kind of presentations.

DEFINING INTERSEX: Technically, intersex is defined as "congenital anomaly of the reproductive and sexual system." To paraphrase: medical conditions that is present at birth that involve internal reproductive organs, external genitalia, or endocrine system that are different from most males and females.

- **GIVE A COUPLE OF EXAMPLES:** Make the examples different enough (e.g. CAH and hypospadias) that the audience will understand that intersex is not just one thing, but covers a wide range of medical conditions.

- **AVOID** discussing intersex as between male and female. This is simply untrue, and it will lead the audience to confuse intersex vs. transgender.

- **EXPLICITLY STATE** that intersex is NOT about identity. Most intersex people are ordinary men and women, although some are (gender)queer. Define transgender/transsexual/genderqueer briefly in order to differentiate them from intersex.

"CONCEALMENT-BASED" MEDICAL PROTOCOL: Surgery is a major component of it, but the core ideology of this protocol is the view that intersex is something so shameful that it needs to be concealed at any cost. That is why

there is so much secrecy and dishonesty in this area.

- Suggested quote: “Since the overarching rule of this system is ‘avoid psychological confusion about the patient’s gender identity,’ doctors often do not tell intersexuals and their parents all that the doctors know, lest information about intersexuality confuse or complicate the family’s understanding of gender... In no other realm in medicine do doctors regularly argue for active, nearly wholesale deception.” (from *Intersex in the Age of Ethics*).

- There is no long-term study that show that surgeries are NECESSARY, SAFE NOR EVEN EFFECTIVE, although they have been going on since the 1950s.

- Most babies are assigned as girls because the standard for “functional” vagina (penetrable) is lower than the standard for “functional” penis (ability to pee standing, ability to penetrate). Depending on the audience, you might want to discuss the sexism and heterosexism inherent in this view. Quote: a prominent endocrinologist said “It’s easier to dig a hole than build a pole.”

DISCUSS CURRENT PROTOCOL’S IMPACT ON INTERSEX CHILDREN: Explain damages in all three areas: physical, emotional/psychological, and sexual.

- PHYSICAL: Scars, infections, pain, and possibility of repeated surgeries. Many intersex people suffer from poor health as adults because they avoid seeing doctors when they actually need them.

- EMOTIONAL: Secrecy, shame, and isolation. Surgeries are intended to remove shame and isolation, but they don’t; they only add another layer of secrecy behind it. More on this later.

- SEXUAL: Sexual sensation is often diminished. It’s also common for intersex people to feel sexually undesirable.

INTERSEX MEDICAL ABUSE AS CHILD SEXUAL ABUSE: Children experience medicalization as similar to child sexual abuse.

- STRONGLY STATE that this is not to condemn doctors. Most doctors are not rapists or child molesters—they are simply doing what they think is the best for the children. But from the CHILD’S POINT OF VIEW, it is indistinguishable from sexual abuse: performed by trusted adults, not given honest information, not allowed to ask questions (or being punished for asking questions), not allowed to tell anyone. Intersexuality is treated as a dirty family secret that child would have to keep to herself or himself.

- Let it be stated again: it is VERY IMPORTANT that you do NOT vilify doctors. They are generally trusted by most people. We won’t gain anything by being antagonistic toward doctors—it will only give those who disagree with us another reason to dismiss us.

- “MEDICAL DISPLAY”: It is extremely important to talk about “medical display,” or the rampant practice where a child is stripped down to nude and placed on the bed while many doctors, nurses, medical students, and others come in and out of the room, touching and prodding and laughing to each other. Children who experience this get the distinct sense that there is something terribly wrong with who they are and are deeply traumatized. Many adult intersex people say that this was the most horrible, humiliating experience they have ever had.

- ABOUT “DILATION”: After doctors perform vaginoplasty to create a vagina on a child, parents are told to “dilate” their daughter’s vagina every day in order to prevent the new vagina from closing up again. The “dilation” will last for many months. This basically means that parents are required to stick a dildo-like object into the child’s vagina every day, a practice many parents consider intolerable. Sometimes, parents are not told about the need for dilation until after the surgery. Parents who perform “dilation” out of desperation often feel guilty or ashamed about it, which further discourages them from speaking honestly about the condition to the child.

OUR ALTERNATIVE—PATIENT-CENTERED APPROACH: Raise the child either as a boy or as a girl, based on our best prediction for that particular condition, and prepare parents to adopt to changes if the prediction turned out to be wrong. No surgery is necessary until the child is old enough to have a say in the decision.

- Address social issues with social interventions, not medical technology. Replace surgery with social and psychological support. Accommodations can be made to make gym classes and other social situations comfortable for all involved (besides, surgery will not necessarily solve these social issues either).

- Why assign a gender at all? Because we live in a gendered society. Point out that we assign gender to all children, not just intersex ones—the difference is that intersex children are surgically mutilated, while other children aren’t.

SAMPLE PRESENTATION OUTLINE

Here is a sample outline for giving a basic presentation about intersex activism. Again, please use this as a starting point.

Sample Presentation

Venue: College Classroom

Audience: Students

Length: 1.5 hour

00:00 INTRODUCTION

- Who you are.
- About Intersex Initiative Portland (ipdx).
- Your personal connection to intersex; what it means to you.
- Ask what people know about intersex already—engage the audience.

00:10 FILM (XXX)

00:25 Definition

- Students will probably ask questions. Try to cut it short.

00:30 Concealment-based vs. Patient-Centered

- Use anecdotes from intersex people's stories.

00:50 Summary

- Talk about the work of ipdx again.

01:00 Questions & Answers

- Remember the LARA model—don't jump immediately into "R."

01:20 Closure

- Ask audience to sign up for the email newsletter.
- Discuss volunteer opportunity.
- Make sure that everyone has a copy of our brochure.
- Write our contact information (especially email and web addresses) on the board.
- Thank the audience.

01:30 End

WHAT IF... SITUATIONS

Here are some of the issues/questions that may come up during your presentation, and examples of how you might respond to these challenging situations. Be original and creative—but just remember LARA (listen, affirm, respond, and add information; see chapter one) method.

Question: Do doctors decide whether or not to do a surgery? Don't parents get to have the choice?

Listen: Most people trust that doctors would obtain full informed consent before doing anything as significant as genital surgery.

Affirm: Ultimately, parents do have the right to informed consent.

Respond: What exactly does this “informed” include? Parents are usually not told that there are adult intersex people organizing against the concealment-based treatment of intersex bodies, nor damages we feel it causes. Also, physicians often do not consider psychological and sexual traumas arising from surgeries and “medical display.” As the result of intersex activists’ and our allies’ work, there is a lot more information about intersex available today than ten years ago, which parents should be entitled to hear about (but often don’t).

Add Information: Quote Alice Dreger: “Since the overarching rule of this system is ‘avoid psychological confusion about the patient’s gender identity,’ doctors often do not tell intersexuals and their parents all that the doctors know, lest information about intersexuality confuse or complicate the family’s understanding of gender... In no other realm in medicine do doctors regularly argue for active, nearly wholesale deception.” (from *Intersex in the Age of Ethics*). Also, see Dreger’s article, “‘Ambiguous Sex’ or Ambivalent Medicine?” in *The Hastings Center Report*, May/June 1998.

Question: If there is no data to suggest that these surgeries are safe and effective, then why are they still being performed?

Listen: Many people trust medicine to be evidence-based, and as such have difficult time accepting that doctors would continue to promote something that seems so harmful when there is no evidence to support it in the first place.

Affirm: We want to believe that doctors base their practice on evidence.

Respond: The main goals of the existing treatment protocol are concealment and gender normalcy, which made it difficult to track individual cases for follow-up studies (intersex people were often not told about the treatment at all), and when studied, the only focus tend to be whether or not the gender assignment was correct. In the 1950s, when the surgical protocol began, there was little concern for psychological traumas or women’s (as most surgically altered babies were raised as girls) sexuality.

Add Information: Actually, there are studies from 1930s to 50s that showed no specific social problems arising from having intersex bodies even before the surgeries began. cf. Young, Hugh Hampton (1937). *Genital Abnormalities, Hermaphroditism, and Related Adrenal Diseases*. Baltimore: Williams and Wilkins.

Question: Should intersex babies be raised without a gender?

Listen: The audience is confused about *gender* assignment, which the society does for every child, versus *surgical* assignment.

Affirm: As long as all other children are raised as boys and girls, it would be difficult to raise a child without a gender.

Respond: We are not advocating for raising intersex babies without a gender. As long as all other children are raised as boys and girls, we can make an educated guess about the future gender identity of an intersex baby, based on how adults with the same intersex condition identify as. When our “guess” turns out to be wrong, we will help the child become who she or he really is.

Add Information: No amount of surgery will eliminate the possibility that our “guess” may be wrong.

Question: Can intersex people reproduce?

Listen: The audience is curious about intersex people’s lives.

Affirm: Having family is an important aspect of many people’s lives.

Respond: Point out that “intersex” covers a wide range of medical conditions, some of which affect fertility, while others don’t. For example, having a large clitoris will not cause someone to be infertile, but having gonadal dysgenesis obviously will.

Add Information: Despite the myths, nobody can produce both sperms and eggs.

Question: Do environmental factors affect the rate of intersex births?

Listen: Many people are concerned about the effect of endocrine disruptors released into the environment.

Affirm: This is a fair guess, as there are many news reports about alligators and fish that “change sex” due to endocrine disruptors.

Respond: Environmental factors do influence the rate of some intersex conditions, although not many others. Causes for most intersex conditions are known, and many have nothing to do with the endocrine disruptors.

Add Information: Intersex people have always existed throughout the history.

Question: How do you feel about male circumcision (or female genital mutilation in some African cultures)?

Listen: The audience is trying to make a connection with other issues they are familiar with.

Affirm: To the extent that everyone should be able to control what is done to their bodies, these issues are connected.

Respond: Not to minimize the violation of the child’s right to self-determination, the impact of intersex genital mutilation on the child’s physical, sexual, and emotional well-being is distinct because of its treatment as abnormal, shameful, and secret. Surgery is only a part of the long series of the child’s experiences of the systemic concealment and shaming of her or his bodies.

Add Information: We support everyone’s right to control what is done to their bodies, but our focus is ending the medical abuse of intersex children. Do not get into a long discussion about male circumcision versus intersex genital mutilation.

Question: How is intersex treated in non-Western cultures?

Listen: The audience feels that cultures less saturated with Western medicine might have better ways of dealing with intersex children.

Affirm: Concealment-based treatment of intersex is culturally and historically specific to Western societies since the 1950s.

Respond: There are indeed variety of ways in which intersex children are treated in other cultures, everything from being celebrated as spiritual leaders to being left to die. The important point is not to find the “perfect” approach, but to know that there can be different ways to treat intersex individuals in this society.

Add Information: Some intersex conditions (though not genitals) do require medical interventions for the person to stay healthy, and thus Western medicine is not all bad. Avoid idealizing non-Western cultures—be cautious of participating in orientalism (cf. Edward Said’s 1979 classic, *Orientalism*).

Question: Do you think there will be a “cure” for intersex in the future?

Listen: They hear how painful it is for people to grow up intersexed, and want to help stop it.

Affirm: It is natural for us to think that suffering would stop if intersexuality did.

Respond: For the most part, intersex people are not harmed by being intersex, but by how they are treated. Social problems can be resolved through social interventions, rather than medical or technical ones.

Add Information: Quote Esther Morris: “Not having a vagina was not my problem; having to get one was” (in “The Missing Vagina Monologue.”)

What should I do when asked technical (medical, biological) questions that I am unable to answer?

Listen: Your audience is curious about intersex, and wants to learn more.

Affirm: Learning about intersex is important in becoming an ally to intersex people.

Respond: Technical knowledge about intersex conditions is important, but is mostly irrelevant in the context of discussing intersex people’s civil rights (you do not need to know the biological basis of skin color in order to be anti-racist). We need to focus on the lived experiences of intersex people rather than the technical knowledge.

Add Information: If it seems necessary, refer your audience to contact ipdx.

What should I do when the discussion strays into transgender issues rather than intersex?

Listen: Many people confuse intersex and transgender/transsexual issues.

Affirm: Transgender/transsexual issues are important; we should all be free from gender-based oppressions.

Respond: Explain that you are not there to give a lesson on gender theory or transgender issues; clarify the difference between intersex and transgender, and how discussing intersex in the context of transgender skews the focus.

Add Information: Majority of intersex people are not transgender, just like the majority of non-intersex people. There are a small number of intersex people who are transgender, like a small number of non-intersex people. In other words, being intersex and transgender are two separate issues.

Question: What can I do to help?

Listen: They want to help! Woo hoo!

Affirm: YES! Thank you for asking that!

Respond: Appropriate suggestions for how to help depends on the venue. If the audience is mostly students, asking for donations will not get anywhere—but asking for volunteers or interns might. You might also suggest that they speak with five people about what they have learned: the more people are aware about intersex, the less they are likely to accept surgery as the only option when they or someone they know has an intersex baby. Always ask everyone to sign up for our mailing list, and have potential donors and volunteers fill out our Donor/Volunteer form.

Add Information: You might want to speak about your experience of being involved with intersex activism—why you do it, what you have learned, etc.

If you do not know the answer to any question, do not feel afraid to say so. You can always give out the contact information for Intersex Initiative Portland:

info@ipdx.org
PO Box 40664, Portland OR 97240
(503) 288-3191 [voicemail]

TIPS FOR NON-INTERSEX PEOPLE SPEAKING ABOUT INTERSEX by Tara Medve

Below is a list of tips and guidelines that we should keep in mind as allies when speaking about intersex issues. I felt that it would be useful to have these guidelines so that we can avoid some of the common mistakes people make when we try to speak about issues that do not directly impact us.

1. **Remember to center the voices and experiences of intersex people** in your discussions of intersex issues.
2. **You are not an expert on intersex experiences** and you should not pretend to be one. There is nothing wrong with saying that you do not know the answer to a question.
3. When speaking or writing about intersex, **it is important to portray intersex people as complete human beings**, and not to reduce them to their medical conditions.
4. **Be honest about who you are and why you are involved in intersex activism.** This includes thinking and talking about how intersex informs your own life and the society you live in.
5. **Speak responsibly and cautiously.** Your speech might be the first exposure to the topic of intersex that members of the audience have had.
6. **Stay on topic** as much as possible. So many people conflate the experiences of LGBT people that you will most likely have to field many questions regarding gender and sexuality. It is important to remind yourself that you are speaking on intersex, and to keep the discussion on topic. For example, even though I have a fairly solid grip on gender theory and thoroughly enjoy talking about it, a speech on intersex is neither the time nor the place to do so.
7. I am **continually learning how to become a better ally.** A large part of being a good ally is being open to criticism and guidance from intersex people.
8. Always **give your audience resources** for further learning.
9. **Do not use intersex to forward your own political agenda.** Being an ally requires you to focus on the issues most important to the people you are supporting, not the issues most interesting to you. Stopping the medical abuse of intersex people is the primary mission of intersex activism, and one should not lose sight of this while speaking about intersex.
10. **Do not assume that there are no intersex people in the room** just because nobody has come out as such. Do not ask hypothetical questions that take for granted that none of the people in the room is intersex or that none of them has a family member or friend who is.

Chapter Four: Speaking for ipdx

ABOUT INTERSEX INITIATIVE PORTLAND'S SPEAKER'S BUREAU

Speaker's Bureau is a program of Intersex Initiative Portland (ipdx) that trains our volunteers to give a basic presentation about intersex activism. We solicit for speaking engagements at universities, teachers, churches, professional organizations, and grassroots organizations, because everybody—not just medical professionals—needs to know (and will benefit from knowing) about intersex issues.

To join the Speaker's Bureau as a presenter, one needs to go through the following procedure:

- 1) Submit an application. Application is available for downloading from ipdx's web site, or you can use the one included in the appendix of this handbook. Completed applications can be sent via email or postal mail also. Our addresses are: info@ipdx.org, or PO Box 40664, Portland OR 97240.
- 2) We will review your application, and assuming that everything is okay, invite you to the next Speaker's Bureau training. We plan to hold the training several times a year in Portland.
- 3) Attend the Speaker's Bureau training. Please don't forget to submit your evaluation form!
- 4) We will set up a meeting with you to discuss your future involvement with ipdx. If we mutually agree that you will make a good fit with the Speaker's Bureau, we will officially enlist you as a presenter. If not, we will discuss in what other ways you can be involved in ipdx. Speaker's Bureau is just a small portion of the work being done at ipdx, and we have many other opportunities.
- 5) Even after you have signed onto the Speaker's Bureau, you are not expected to present by yourself until you have co-presented with another person a couple of times and feel comfortable going solo.

EXPECTATIONS FOR SPEAKERS ON INTERSEX INITIATIVE PORTLAND'S SPEAKER'S BUREAU

Speaker's Bureau of Intersex Initiative Portland (ipdx) has its own set of expectations for our presenters. Do not be intimidated by them—nobody is perfect, after all—but please do take them seriously.

- Tune into the audience. What is considered “appropriate” appearance or language varies depending on the specific venue. We will do our best to match the venue to the speaker, but in case you end up presenting for an audience that belongs to a different social cluster than your own, please use common sense. Err on the side of being nice and polite if there is any doubt.
- Use principles of non-violence and anti-oppression. Being non-violent does not mean that you would tolerate racist, sexist, homophobic, etc. comments you hear during the presentation—but it does mean that you show humility: LARA method applies here, too. Also, if you notice that you have made an oppressive comment, do not hesitate to correct yourself.
- Stay on topic. Discussions about intersex can quickly lead to a discussion about gender theories or transgender issues. Do not be afraid of redirecting the conversation. After internal discussions, we have decided that ipdx Speaker’s Bureau will not take part in any workshop that is about both intersex and trans because we cannot think of any way to do so without reducing intersex into a gender issue.
- Do not use the ipdx presentation to advance other causes, such as transgender or genderqueer issues, social constructivism, or anti-circumcision activism. These are interesting and important topics, but do not belong in an ipdx presentation. If questions about these off-topic issues come up, redirect. For example, when asked about our position on male circumcision, say: “We feel that everyone deserves the right to control her or his own body. But that said, our focus is to end medical abuse of intersex children.”
- Do not pretend to know more than you know. You are not expected to know about details about medical conditions, for example. If you are unsure, you can give out our contact information (info@ipdx.org, 503-288-3191).
- In each presentation, ask the audience to sign up for the email newsletter using the sign-up sheet. In addition, ask the audience to join us—which could mean volunteering, making donations, or both, depending on the venue. Always give out our organizational brochure for the audience members to keep so that they can look us up on the web or email us later.
- If you disagree with the views of ipdx on any of the issues and you need to state it, make sure to attribute it to yourself so that the audience know where ipdx as an organization stands. Please tell us about your disagreement too—we are learning too, and we love to hear new ideas.
- We obviously cannot restrict you from giving presentations about intersex outside of the ipdx Speaker’s Bureau, but if you do, please be careful not to mislead the audience into thinking that you are speaking on our behalf. Consult with us if you plan on using materials we provide. If you are planning to submit a workshop proposal about intersex for a conference, talk to us first to see if we can collaborate.

- Let us know when your contact information (email, phone, etc.) changes, so we can keep in contact with you. Or, if you are going to be out of contact for an extended period of time (say, six months), do let us know in advance.

- When you no longer want to take part in the Speaker's Bureau, please let us know. We would like to know if it is due to changes in your personal life, or because of something that happened while you are on the Speaker's Bureau. There are other opportunities for you to stay involved even if you decide that public speaking is not for you.

SOLICITING FOR SPEAKING ENGAGEMENTS

Portland-based speakers do not need to do any of their own promotion because we will handle that part. However, speakers from other cities may be interested in finding out how to solicit speaking engagements in their own area. Below is how we promote Speaker's Bureau in Portland:

1) Send letters to organizations that might be interested in your presentation. Include: why this issue is important (stress urgency of the issue and offer solution); who we are; and how to contact us or to have us present.

2) Follow-up with a telephone call within two weeks.

3) Ask for honorarium without intimidation: "We are available to present for free, but my organization requires me to ask if there is any honorarium to cover the expenses."

Ask if it would be appropriate to ask audience for donations at the presentation.

Do not underestimate the power of word-of-mouth to open up opportunities. If you are giving good presentations, others will hear about it and contact you to ask for your presence. Cherish your—and our—reputation.

Appendices

APPENDIX A: RESOURCES FOR FURTHER LEARNING

As a presenter for Intersex Initiative Portland Speaker's Bureau, it is your responsibility to continue to educate yourself about intersex issues. Below is some of the materials we recommend.

BOOKS:

- "Intersex in the Age of Ethics" ed. by Alice Dreger
- "Hermaphrodites and the Medical Invention of Sex" by Alice Dreger
- "Lessons from the Intersexed" by Suzanne Kessler
- "Sexing the Body" by Anne Fausto-Sterling
- "As Nature Made Him" by John Colapinto

Comment: Of these, "Intersex in the Age of Ethics" is essential. Reading first-person stories in this collection will definitely help your presentation. "As Nature Made Him" is actually not a book about intersex, but it tells the story of a child who was treated similar to how intersex children are treated.

FILMS:

- "First, Do No Harm—Total Patient Care" available from ISNA
- "XXXY" not available for distribution; we have a copy in our library.
- "Redefining Sex" available from ISNA
- "Hermaphrodites Speak!" available from ISNA
- "Mani's Story" available from ISNA

Comment: "XXXY" and "Redefining Sex" are both wonderful documentaries, but each have some problem. "First, Do No Harm" is a new medical training video produced by ISNA, and as such make all the good points, although it may seem boring (it's a roundtable of several specialists talking with each other). "Mani's Story" is absolutely wonderful but it's a bit long for most presentations.

WEB SITES:

- Intersex Initiative Portland - <http://www.ipdx.org/>
- Bodies Like Ours - <http://www.bodieslikeours.org/>
- Intersex Society of North America - <http://www.isna.org/>
- AIS Support Group UK - <http://www.medhelp.org/www/ais/>
- MRKH.org - <http://www.mrkh.org/>
- CAH Our Voices and Our Stories - <http://www.cahourstories.net/>

Comment: To keep up with all the new developments in the intersex activist community, check out ISNA, ipdx and Bodies Like Ours. Other sites are selected because they offer many first-person stories that you can read.

APPENDIX B: SHIFTING THE PARADIGM OF INTERSEX TREATMENT by Alice Dreger

Shifting the Paradigm of Intersex Treatment
 Prepared by Alice Dreger, Ph. D (dreger@isna.org)
 for the Intersex Society of North America.
 Reprinted with permission.

Key points of comparison	Concealment Centered Model	Patient Centered Model
What is intersex?	Intersex is a rare anatomical abnormality which is highly likely to lead to great distress in the family and great distress for the person with an intersex condition. Intersex is pathological and requires immediate medical attention.	Intersex is a relatively common anatomical variation from the “standard” male and female types; just as skin and hair color vary along a wide spectrum, so does sexual and reproductive anatomy. Intersex is neither a medical nor asocial pathology.
Is gender determined by nature or nurture?	Nurture. Virtually any child can be made into a “boy” or a “girl” if you just make the genitals look convincing. It doesn’t matter what the genes, brain, hormones, and/or prenatal life are/were like.	Both, surely, but that isn’t the point. The point is that people with intersex conditions ought to be treated with the same basic ethical principles as everyone else—respect for their autonomy and self-determination, truth about their bodies and their lives, and freedom from discrimination. Physicians, researchers, and gender theorists should stop using people with intersex conditions in “nature/nurture” experiments or debates.
Are intersexed genitals a medical problem?	Yes. Untreated intersex is highly likely to result in depression, suicide, and possibly “homosexual” orientation. Intersexed genitals must be “normalized” to whatever extent possible if these problems are to be avoided.	No. Intersexed genitals are not a medical problem. They may signal an underlying metabolic concern, but they themselves are not diseased; they just look different. Metabolic concerns should be treated medically, but intersexed genitals are not in need of medical treatment. There is no evidence for the concealment paradigm, and there is evidence to the contrary.

<p>What should be the medical response?</p>	<p>The correct treatment for intersex is to “normalize” the abnormal genitals using surgical, hormonal, and other technologies. Doing so will eliminate the potential for parents’ psychological distress.</p>	<p>The whole family should receive psychosocial support (including referrals to peer support) and as much information as they can handle. True medical problems (like urinary infections and metabolic disorders) should be treated medically, but all non-essential treatments should wait until the person with an intersex condition can consent to them.</p>
<p>When should treatments designed to make a child’s genitals look “normal” be done?</p>	<p>As soon as possible because intersex is a psychosocial emergency. The longer you wait, the greater the trauma.</p>	<p>ONLY if and when the intersexed person requests them, and then only after she or he has been fully informed of the risks and likely outcomes. These surgeries carry substantial risks to life, fertility, continence, and sensation. People with intersex conditions should be able to talk to others who have had the treatments to get their views.</p>
<p>What is motivating this treatment protocol?</p>	<p>The belief that our society can’t handle genital ambiguity or non-standard sexual variation. If we don’t fix the genitals, the child with an intersex condition will be ostracized, ridiculed, and rejected, even by his or her own parents.</p>	<p>The belief that the person with an intersex condition has the right to self determination where her or his body is concerned. Doing “normalizing” surgeries early without the individual’s consent interferes with that right; many surgeries and hormone treatments are not reversible. The risks are substantial and should only be taken if the patient has consented.</p>
<p>Should the parents’ distress at their child’s condition be treated with surgery on the child?</p>	<p>Yes, absolutely. Parents can and should consent to “normalizing” surgery so that they can fully accept and bond with their child.</p>	<p>Psychological distress is a legitimate concern and should be addressed by properly trained professionals. However, parental distress is not a sufficient reason to risk a child’s life, fertility, continence, and sensation.</p>

<p>How do you decide what gender to assign a newborn with an intersex condition?</p>	<p>The doctors decide based on medical tests. If the child has a Y chromosome and an adequate or “reconstructable” penis, the child will be assigned a male gender. (Newborns must have penises of 1 inch or larger if they are to be assigned the male gender.) If the child has a Y chromosome and an inadequate or “unreconstructable” penis according to doctors, the child will be assigned a female gender and surgically “reconstructed” as such. If the child has no Y chromosome, it will be assigned the female gender. The genitals will be surgically altered to look more like what doctors think female genitals should look like. This may include clitoral reduction surgeries and construction of a “vagina” (a hole).</p>	<p>The parents and extended family decide in consultation with the doctors. This approach does not advocate selecting a third or ambiguous gender. The child is assigned a female or male gender but only after tests (hormonal, genetic, diagnostic) have been done, parents have had a chance to talk with other parents and family members of children with intersex conditions, and the entire family has been offered peer support. We advocate assigning a male or female gender because intersex is not, and will never be, a discreet biological category any more than male or female is, and because assigning an “intersexed” gender would unnecessarily traumatize the child. The doctors and parents recognize, however, that gender assignment of infants with intersex conditions as male or female, as with assignment of any infant, is preliminary. Any child may decide later in life to change their gender assignment; but children with intersex conditions have significantly higher rates of gender transition than the general population, with or without treatment. That is a crucial reason why medically unnecessary surgeries should not be done without the patient’s consent; the child with an intersex condition may later want genitals (either the ones they were born with or surgically constructed anatomy) different than what the doctors would have chosen. Surgically constructed genitals are extremely difficult if not impossible to “undo,” and children altered at birth or in infancy are largely stuck with what doctors give them.</p>
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<p>What should the person with an intersex condition be told when she or he is old enough to understand?</p>	<p>Very little, because telling all we know will just lead to gender confusion that all these surgeries were meant to avoid. Withhold information and records if necessary. Use vague language, like “we removed your twisted ovaries” instead of “we removed your testes” when speaking to a woman with AIS.</p>	<p>Everything known. The person with an intersex condition and parents have the right and responsibility to know as much about intersex conditions as their doctors do. Secrecy and lack of information lead to shame, trauma, and medical procedures that may be dangerous to the patient’s health. Conversely, some people harmed by secrecy and shame may avoid future health care. For example, women with AIS may avoid medical care including needed hormone replacement therapy.</p>
<p>What’s wrong with the opposing paradigm?</p>	<p>Parents and peers might be uncomfortable with a child with ambiguous genitalia. Social institutions and settings like locker rooms, public restrooms, daycare centers, and schools will be brutal environments for an “abnormal” child. The person with an intersex condition might later wish that her or his parents had chosen to have her or his genitals “normalized.”</p>	<p>The autonomy and right to self determination of the person with an intersex condition is violated by the surgery centered model. In the concealment model, surgeries are done without truly obtaining consent; parents are often not told the failure rate of, lack of evidentiary support for, and alternatives to surgery. Social distress is a reason to change society, not the bodies of children.</p>
<p>What is the ideal future of intersex?</p>	<p>Elimination via improved scientific and medical technologies.</p>	<p>Social acceptance of human diversity and an end to the idea that difference equals disease.</p>
<p>Who are the proponents of each paradigm?</p>	<p>John Money and his followers, most pediatric urologists and pediatric endocrinologists, and many gynecologists and other health care practitioners.</p>	<p>Intersex activists and their supporters, ethicists, some legal scholars, medical historians, and a growing number of clinicians.</p>

For additional reading or to download a copy of this comparison chart, please visit the website of the Intersex Society of North America: <http://www.isna.org/>

APPENDIX C: MEDICAL FACTS PREMIER

Information here is provided to you not because you need to know each of these in order to give a good presentation, but so you can understand how “intersex” is made up of wide variety of conditions. In fact, **we strongly discourage you from distributing this list or discussing specifics** in your presentation: it will only feed into the audience’s voyeuristic curiosity without adding anything to the discussion. Also, remember that below is not a complete list of intersex conditions, nor are they complete description of any of them.

Androgen Insensitivity Syndrome (AIS)

Androgen insensitivity syndrome is a genetic condition in which XY individuals do not respond to androgens. In “complete” AIS (CAIS), testes remain in the abdomen while the external genitals appear female. At puberty, CAIS individuals grow breasts but do not menstruate. The testes are sometimes removed from the abdomen because they may develop cancer. Partial AIS (PAIS) is marked by a limited response to androgens. The external genitals are ambiguous. Depending on the selection of hormone treatment, PAIS individuals may exhibit partial male or partial female development at puberty.

Congenital Adrenal Hyperplasia (CAH)

Congenital adrenal hyperplasia is the most prevalent cause of intersexuality amongst XX people. It is caused when an anomaly of adrenal function causes the synthesis and excretion an androgen precursor, initiating virilization of a XX person in-utero. Because the virilization originates metabolically, masculinizing effects continue after birth. Sex phenotype varies along the full continuum, with the possible added complication of metabolic problems which upset serum sodium balance. The metabolic effects of CAH can be counteracted with cortisone. The long term use of cortisone itself produces significant dependence and other side effects.

Gonadal Dysgenesis

Gonadal dysgenesis is a condition where gonads do not develop or function fully because of a genetic mutation. Complete gonadal dysgenesis in XY individuals is known as Swyer’s syndrome and result in female-appearing genitals due to lack of androgens. In the case of partial gonadal dysgenesis in XY individuals, some androgen is produced and thus the genitals appear ambiguous. Individuals with Turner’s syndrome (XO), who have female genitals, also have gonadal dysgenesis.

Hypospadias

Hypospadias refers to the condition in which the urethra is located along the underside, rather than at the tip of the penis. In some hypospadias, the urethra may be located in the glans. In more pronounced hypospadias, the urethra may be open from mid-shaft out to the glans, or the urethra may even be entirely absent, with the urine exiting the bladder behind the penis.

Klinefelter's Syndrome

Individuals with Klinefelter's syndrome are phenotypical males with XXY chromosomes. Some people with Klinefelter's syndrome may have small penis and testes or experience breast development at puberty.

Mayer-Rokitansky-Kuster-Hauser Syndrome (MRKH)

MRKH is a condition where vagina and/or other internal reproductive organs are partially or wholly missing for an unknown cause in otherwise "normal" XX females. Women with MRKH have functional ovaries and can produce egg. While non-surgical alternative is available to deepen vagina, sometimes surgery is necessary to discharge the menstruation.

Micropenis

Micropenis is a perfectly normal in shape and function, except it is much smaller in size than the "normal" penis. Under the belief that one cannot grow up to be an emotionally adjusted healthy male without a "normal" size penis, surgeries have been performed on micropenis to make the child into girls. When micropenis is left intact and the patient is raised as a boy, he typically receives androgen to achieve masculinizing puberty.

Turner's Syndrome

Individuals with Turner's syndrome has the karyotype of XO, which means they are missing a chromosome. People with Turner's syndrome have female genitals, but do not have fully developed ovaries.

5-Alpha Reductase Deficiency Syndrome (5ARD)

5-alpha reductase deficiency syndrome affects XY individuals. While individuals with 5ARD have "normal" testes, they lack the enzyme necessary to convert testosterone to dihydrotestosterone (DHT), and develop penis and scrotum that resemble female genitals. People with 5ARD experience a typical male puberty, as DHT is no longer essential for masculinizing the body at that stage.

Information in this list has been taken from web sites of Intersex Society of North America, MRKH.org, and Johns Hopkins University Medical School.

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This handbook is not intended as an introductory reading for the general audience. If you need materials to share with the general public, please request other materials from us.

If your organization is interested in starting a speaker's bureau for intersex issues or incorporating intersex in your existing speaker's bureau, please contact us. Our staff may be able to provide additional materials such as the training curriculum and possibly do a speaker's training for your organization.

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