



Tomorrow's Doctors, Tomorrow's Cures

Learn

Serve

Lead

Reasons to Add and Reasons NOT to Add “I” (Intersex) to LGBT in Healthcare

A Webinar for the AAMC

May 4, 2015



Association of
American Medical Colleges

Order of presentation:

- Introduction of Alice Dreger from Tiffani St.Cloud of AAMC Diversity Policy and Programs
- Brief overview of what we're (usually) talking about when we talk about "intersex" from Alice Dreger; and intro of Pidgeon Pagonis
- Pidgeon Pagonis will provide a first-person story
- Alice will present "reasons to add/reasons not to add 'I' to 'LGBT' in healthcare"
- Pidgeon will respond
- We'll take questions and comments



Alice Dreger, PhD

Medical Humanities & Bioethics Program

Feinberg School of Medicine

Northwestern University

offers.aamc.org/lgbt-dsd-health

Basic overview:

- **SEX** → biology (genetics of sexual differentiation and development, gonads, genitals, hormones, etc.)
- **GENDER** → identity (how a person feels)
- **SEXUALITY** → erotic desires, behaviors, orientations, etc.

Basic overview:

- SEX → biology (genetics of sexual differentiation and development, gonads, genitals, hormones, etc.)

Basic overview:

- SEX → I
- GENDER → T
- SEXUALITY → LGB

Pidgeon Pagonis





Tomorrow's Doctors, Tomorrow's Cures

Learn

Serve

Lead

Reasons to Add and Reasons NOT to Add “I” (Intersex) to LGBTQ in Healthcare

Alice Dreger, PhD
Medical Humanities and Bioethics Program
Feinberg School of Medicine
Northwestern University



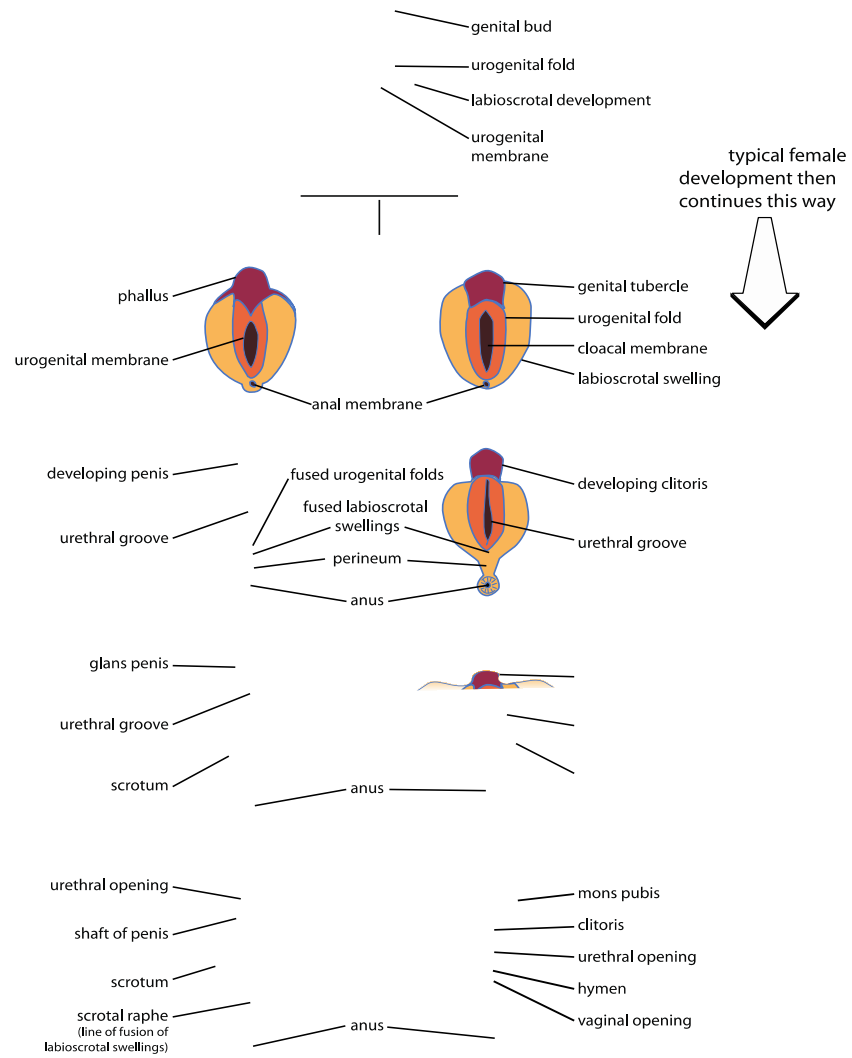
Association of
American Medical Colleges

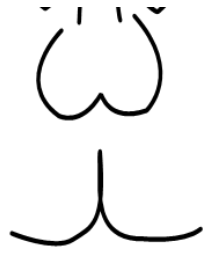
Take-home Lessons

1. Biology is not identity.
2. Normal and healthy are different.
3. Clinicians should focus on healthy outcomes.

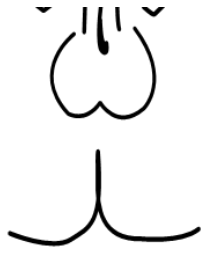
Intersex 101 (biology)

*SEX
DEVELOPMENT
IS
COMPLICATED!*

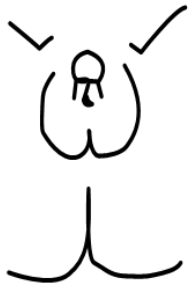




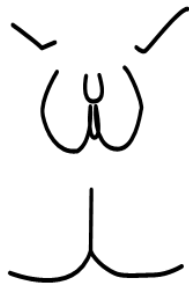
1



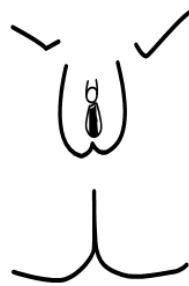
2



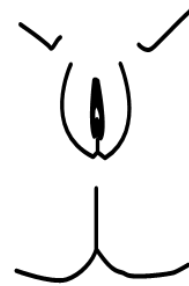
3



4



5



6

What forms do sex anomalies take?

In-between (“ambiguous”) genitalia (ex., CAH in 46,XX; hypospadias; pAIS)

Internal/external sex mismatches (ex., cAIS; some CAH in 46,XX)

“Sex chromosome” anomalies (ex., Klinefelter; Turner; mosaicism)

What forms do sex anomalies take?

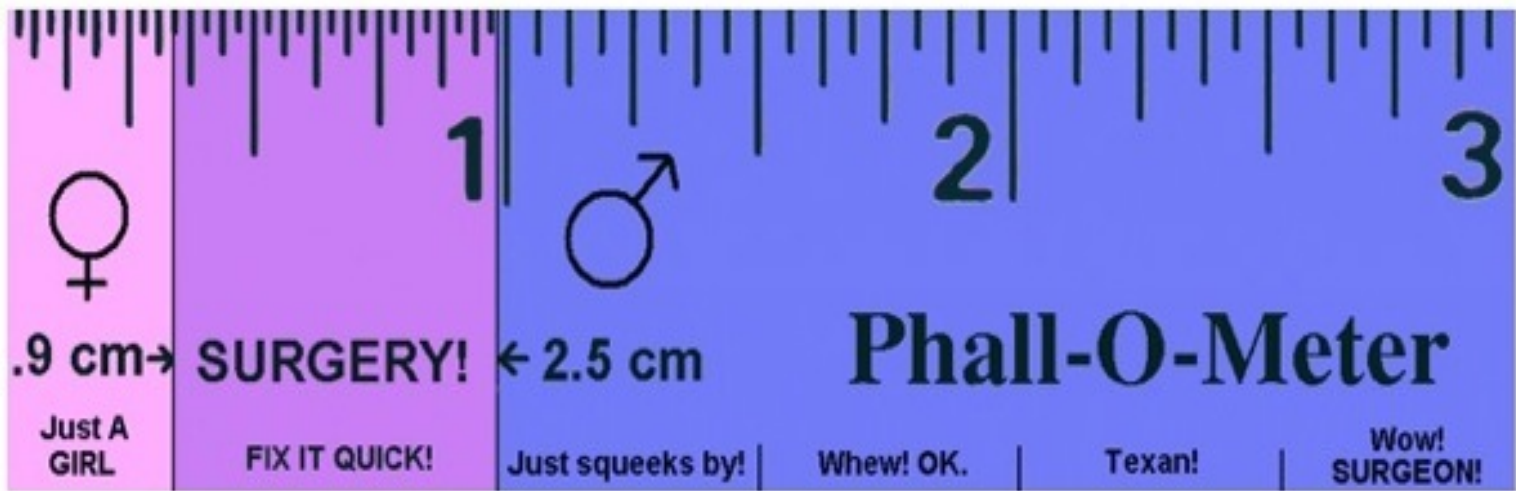
*All depends on what you count as
“normal”*

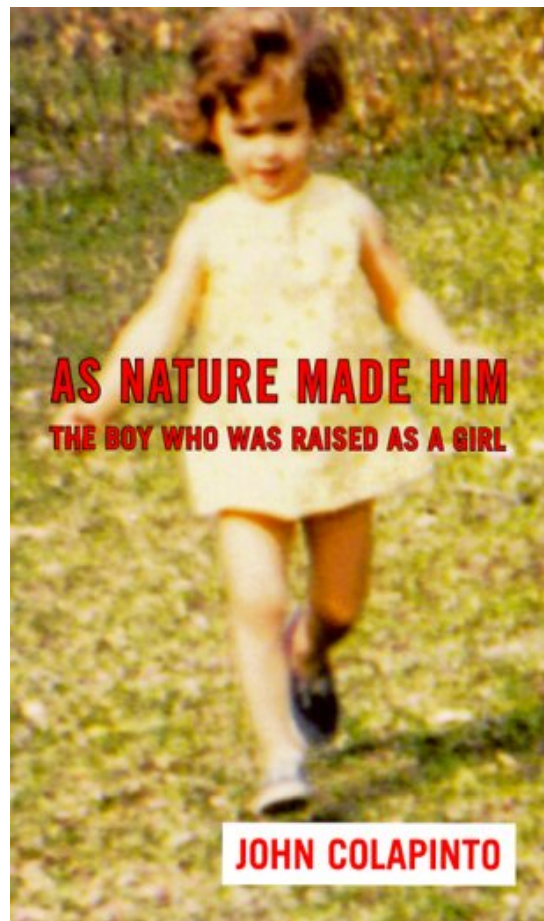
What do people born with differences of sex development (DSD) look like?



Intersex 101 (history)

- ❖ Out of Johns Hopkins
- ❖ Lawson Wilsons (ped endo) & John Money (psych)
- ❖ “Optimum Gender of Rearing”
- ❖ Focused on producing “normal” and apparently heterosexual adults





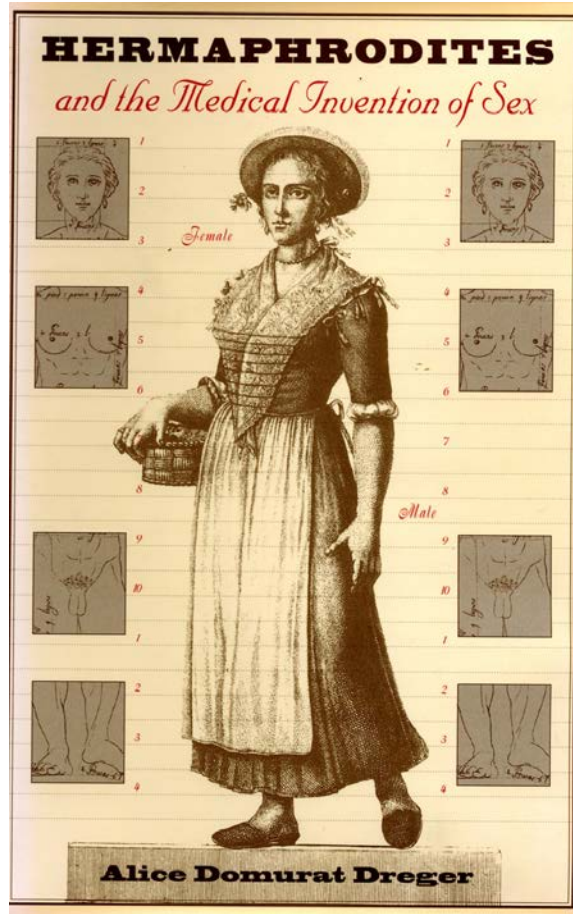
Why did an intersex patient rights movement happen?



Why did an intersex patient rights movement happen?

“Intersex is not primarily about gender. It is about shame, secrecy, and trauma.” – Bo Laurent, founder of ISNA

Terminology



“Hermaphroditism” and
“pseudohermaphroditism”
until about 2005

Terminology




“Hermaphroditism” and
“pseudohermaphroditism”
until about 2005

“Intersex” (political) 1993
forward:

“a body that someone
decided isn’t standard for
male or female” (c. 2002)

Terminology

	<p>Clinical Guidelines for the Management of Disorders of Sex Development in Childhood</p>	
		
	<p>CONSORTIUM ON THE MANAGEMENT OF DISORDERS OF SEX DEVELOPMENT Funded by the California Endowment and Arcus Foundation</p>	

Provided as a service of Accord Alliance, a project of the Tides Center

“Disorders of Sex Development (adopted in 2006 by “Chicago Consensus”)

Achieved:

- A unified vision of these conditions
- A hope of sorting out the social from the medical
- A recognition of the medical

“Disorders of Sex Development”

2006, defined as:

“congenital conditions in which development of chromosomal, gonadal, or anatomic sex is atypical”

Shift to DSD

Clinical Guidelines
for the Management of
Disorders of Sex Development
in Childhood



CONSORTIUM ON THE MANAGEMENT
OF DISORDERS OF SEX DEVELOPMENT
Funded by the California Endowment and Arcus Foundation

Provided as a service of Accord Alliance, a project of the Tides Center

To get rid of “[pseudo]-hermaphroditism”

To get doctors to think of it LIKE other medical issues (necessity, safety, efficacy)

To lump ALL conditions together (to improve ped endo’s epistemology and save more kids)

Shift to DSD

Clinical Guidelines
for the Management of
Disorders of Sex Development
in Childhood



CONSORTIUM ON THE MANAGEMENT
OF DISORDERS OF SEX DEVELOPMENT
Funded by the California Endowment and Arcus Foundation

Provided as a service of Accord Alliance, a project of the Tides Center

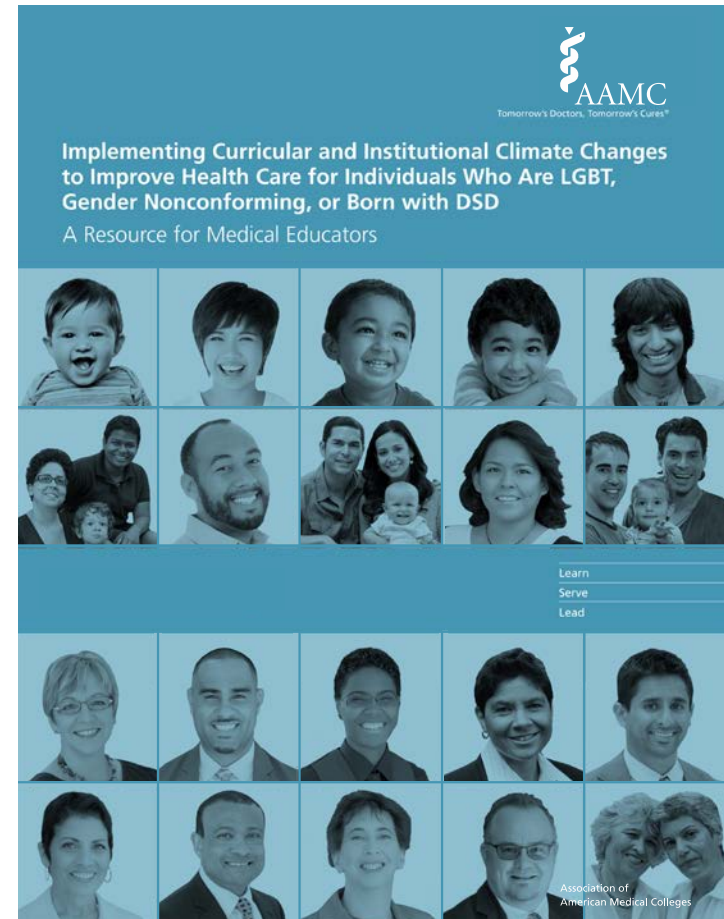
Today shifting from
“disorders” to “differences
of sex development”

Adults sometimes refer to
themselves as intersex

Why is there an LGBTQ patient rights movement?

1. Discrimination
2. Disparities (usually in the form of inadequate care, but also self-harming behaviors)

aamc.org/lgbtdsd




Why did an intersex patient rights movement happen?

- Attributed (then internalized) shame
- Iatrogenic harm (trauma)
- Need to change cultural attitudes and especially medical attitudes

So why add “I” to LGBTQ?

1. Increase visibility
2. Recognize homophobia and sexism as at the root of the problematic “treatment” of intersex
3. Create a safer place for people with intersex conditions


AAMC
Tomorrow's Doctors, Tomorrow's Cures[®]

Implementing Curricular and Institutional Climate Changes
to Improve Health Care for Individuals Who Are LGBT,
Gender Nonconforming, or Born with DSD
A Resource for Medical Educators

Learn
Serve
Lead

Association of
American Medical Colleges

So why *not* “+I”? (Why “+ born with DSD”?)

- “Intersex” functions as an identity term...and biology is not identity
- Intersex GOT wound up with LGBT, and that’s a problem for pediatricians
- “Intersex” started to be a term used by transgender people

So LGBTQ + I?

Advantages

Acknowledge homophobia, hetero/sexism, etc. as roots of problems

Makes intersex more visible

And maybe safer spaces

Disadvantages

Suggests biology is identity (which it isn't)

Could cause MORE problems (phobias → surgeries)

Confusion over who is "I"

Take-home Lessons

1. Biology is not identity.
2. Normal and healthy are different.
3. Clinicians should focus on healthy outcomes.
4. If you're going to talk LGBTQI, understand the potential harms

Some resources:

- aamc.org/lgbtdsd
- Accord Alliance (+ TRN)
- AIS-DSD Support Group
- Inter/Act Youth
- Advocates for Informed Choice



Tomorrow's Doctors, Tomorrow's Cures

Learn

Serve

Lead

Association of
American Medical Colleges