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

A Webinar for the AAMC
May 4, 2015
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
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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
Reasons to Add and Reasons NOT to Add “I” (Intersex) to LGBTQ in Healthcare

Alice Dreger, PhD
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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!
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
Phall-O-Meter

.9 cm $\rightarrow$ 1 cm

Just a girl

FIX IT QUICK!

2.5 cm $\rightarrow$ 3 cm

Just squeaks by

Whew! OK.

Texan

Wow! Surgeon!
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
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“Intersex” (political) 1993 forward:

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

“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

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

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
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