

Differences of Sex Development

Historical Perspectives and Current Approaches

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Objectives

- ❖ Recognize the importance of Native American gender “diversity” and the impact of historical trauma
- ❖ Recognize variations in human sex development
- ❖ Recognize historical and cultural perspectives on sex variations and approaches
- ❖ Examine current evidence of outcomes from “interventions”
- ❖ Recognize ethical considerations with differences in sex development

LGBTQ2 Well-being education series

January 10, 2014

LGBTQ Intimate Partner Violence

Presented by TBA

January 24, 2014

LGBTQ Coming Out Process and Identity Formation

Presented by Beverly Gorman, and Avron Kriechman, MD

February 14, 2014

Tribal Two-Spirit Identity

Presented by Harlan Pruden, Beverly Gorman

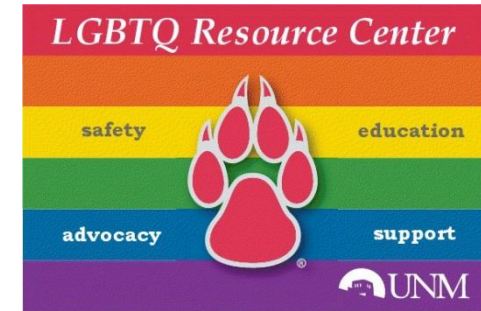
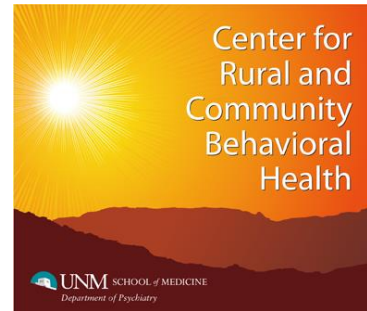
February 28, 2014

LGBTQ Community Advocacy, Native OUT

Presented by Louva Hartwell & Terra Matthews-Hartwell

LGBTQ2 Well-being Series Educators

- ❑ **Adrien Lawyer**, Director, Transgender Resource Center of New Mexico
- ❑ **Alaina George** (Diné), Tele-Health Coordinator, Albuquerque IHS
- ❑ **Alma Rose Silva-Bañuelos**, Director, UNM LGBTQ Resource Center
- ❑ **Avron Kriechman**, MD, Assistant Professor, Child, Adolescent & Family Psychiatrist, UNM CRCBH
- ❑ **Beverly Gorman** (Diné), MCSW/MBA, Researcher & Program Manager, UNM CRCBH
- ❑ **Chris Fore** (Choctaw), PhD, Albuquerque HIS
- ❑ **Harlan Pruden** (First Nations Cree), Co-Founder North East Two Spirit Society (NE2SS)
- ❑ **Jason Jones** (Mestizo), LISW, Five Sandoval Indian Pueblos Inc. Behavioral Health
- ❑ **Louva Hartwell** (Diné), Director NativeOUT
- ❑ **Nathaniel Sharon**, MD, Child & Adolescent Psychiatry Fellow, UNM Department of Psychiatry
- ❑ **Terra Matthews-Hartwell** (Tsimshian/Carrier), NativeOUT



Native American Gender “Diversity”

“There is no one ‘right’ or authentic way to be Two Spirit. It is whatever it means to you..... It is important that you find your own way of expressing your identity and know that you are not alone and that there is a history. “

“Becoming who we are meant to be....Gender and body do not have to necessarily match; gender represents expected role and status within tribal community.”

Karina L. Walters (2012), MSW, PhD, University of Washington; Webinar for SAMHSA’S Native American Center for Excellence Two Spirit Learning Community, December 18, 2012

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Genetic Diversity

- Diversity exists to increase likelihood of survival for a species
- Variations from what?
 - What is “typical”
- “Disorder”
 - Disruption in normal functioning

Language

✘ Sex

- +Chromosomal
- +Genetic
- +Molecular

✘ Gender

- +Identity
- +Role
- +Complex influences: hormones, genetic expression, social, personal, cultural influences
- +Typically develops in concordance with natal assigned sex

DSD Basics

✘ Differences in sex development

- +Variations in the presentation of genitalia
- +Variations in sex chromosomes
- +Variations in concordance between sex chromosomes and external genitalia
- +Differences can range from no perceived dysfunction or appearance differences to syndromes with functional impairment
- +Can manifest in infancy, puberty, adulthood or never

DSD Basics

- Many different causes (over 30)
 - Cause found 20% of the time
 - Congenital adrenal hyperplasia: most common for XX DSD
 - Etiology for XY DSD found only 50% of the time
- Rates
 - 1/1500 infants are born with some form of variation
 - 1/4500 infants are born with “ambiguous genitalia”

Medical Model of DSD

✘ Disorders of sex development

- +XX DSD, XY DSD, Sex chromosome DSD

- +Ovotesticular DSD

✘ Prior terms

- +Intersex

 - ✘ Some use to indicate variations in sex development

 - ✘ Some use regarding personal identity rather than sex

- +Hermaphrodite

- +Pseudohermaphrodite

- +Sex reversal

Medical Decision Making

✘ Management

- +Surgical

- +Hormonal

- +Gender assignment

- +Psychosocial

- +Depends on the amount of functional impairments (i.e.: electrolyte imbalances)

✘ Not black and white

- +What is “medically necessary”

Problematic Approaches

- ✘ Based on need of physician and family to establish a gender of rearing
 - ✚ Focused on appearance of “binary sex” genitalia characteristics
- ✘ Concealment
 - ✚ Often involved non-disclosure to child and/or parents
- ✘ Medical stigmatization
 - ✚ Variations in genitalia are “traumatic”
 - ✚ Exams, photographs, multiple surgeries
 - ✚ “Disorder”, “medical and social emergency”
- ✘ Gender assigned based on sex anatomy, reproductive ability

Changing Approaches

- “Chicago Consensus”, 2006
 - Lawson Wilkins Pediatric Endocrine Society (LWPES) and the European Society for Paediatric Endocrinology (ESPE)
 - Changed medical terminology and management practices
 - “Disorder of Sex Development”
 - “congenital condition in which development of chromosomal, gonadal, or anatomical sex is atypical”

Changing Approaches

- ✘ Multidisciplinary approach

 - +endocrinology, urology/surgery, psychology/psychiatry, social work, nursing, bioethics, and child life

- ✘ Open disclosure and education

- ✘ Avoid gender assignment until team evaluation

 - +“All should have a gender assignment”

 - +Varying research and recs on when to assign gender and by who

- ✘ Shared decision making model

- ✘ Developmentally appropriate explanations to children

Changing Approaches

- Goals
 - Avoid unnecessary intervention
 - Keep gender options open for the future
 - Ensuring the best physical functionality (fertility)
 - Ensuring the best psychological outcomes
 - Supporting the child's gender and sexual development
 - Physical integrity for healthy sexual life

Changing Approaches

✘ Surgical interventions

- ✚ Still conducted for “severe virilization”
- ✚ Indicated to promote function or decrease risk of tumor development
- ✚ Evidence to support cosmetic interventions is lacking
- ✚ Call to stop all surgeries (apart from medically necessary)
- ✚ Multiple complications, no standardized techniques or consensus

✘ Hormones

- ✚ May be required for the medical well-being of the child
- ✚ May be given during adolescents to help develop puberty of sex/gender of choice of child

✘ Lack of agreement on needed age for interventions

Gender in DSD

- Preemptive approach
- Gender assignment” based on multiple factors
 - Gender outcome studies from different etiologies
- People with DSD are more likely to feel different from their natal assigned gender
- Continued assessment for gender dysphoria
 - Varied gendered behavior does not equal gender dysphoria

Gender in DSD

✘ Most gender outcomes studies in XX DSD with CAH

- ✚ Over 90% identify as female although display more “male typical” behaviors and preferences
- ✚ Gender dysphoria still more common in females with CAH than without
- ✚ No relationship between degree of prenatal androgenization and gender dysphoria

✘ PAIS

- ✚ Gender dysphoria occurs in 25% regardless of gender assignment

✘ Gender outcomes still widely unknown and variable making preemptive gender assignment and early medical management difficult

Influences on Approach

✘ Western medicine and science

- + Sex classification systems

- + Medical ethics

 - ✘ Beneficence (patient's welfare)

 - ✘ Nonmaleficence ("Do no harm.")

✘ Religious, family, and community beliefs/practices about sex/gender, autonomy of children

✘ Cultural acceptance of physical and gender diversity

- + Multiple cultures with 4-5 gender variations

- + Two-Spirit identity within Native cultures

- + <http://www.pbs.org/independentlens/two-spirits/map.html>

Evidence

- ✘ Few long-term studies regarding outcomes
 - ✚ Family and friend support, quality of medical/surgical care
- ✘ Little evidence to suggest impaired quality of life when raised with ambiguous genitalia
- ✘ In the absence of, physicians tend to go with their “gut” and personal feelings
- ✘ Medicalized versus non-medicalized education influences parental decision on surgery

Ethical and Legal Issues

✘ Principals of medical care for children

- + Best interest of the child

- + Assent and Consent

- + Pre-natal molecular gender screening

✘ “Disorder” continues to be controversial

✘ Parents cannot consent to elective sterilization of children

- + No laws specifically mandated for DSD in most countries

✘ Gender definitions by states may not match natal assigned gender

Resources

✘ Accord Alliance

- +Clinical Guidelines

- +Parent Handbook

- +Quality of Care indicators

✘ Intersex Society of North America

- +FAQS, Articles, Support Groups

✘ Androgen Insensitivity Support Group

✘ CARES Foundation

✘ Hypospadias and Epispadias Association

Resources

✘ Walters, K. I., et al. (2011). Bodies don't tell stories, they tell histories embodiment of historical trauma among american indians and alaska natives. *Du Bois Review Social Science Research on Race*, 8(1), 179-189.

Link to Video: Karina Walters, Choctaw, Speaks about the Embodiment of Historical Trauma and Micro-aggressions

<http://www.healingcollectivetrauma.com/karina-walters-embodiment-of-historical-trauma-and-micro-aggressions.html>

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