

TEN LESSONS

WHAT PEOPLE WITH AUTISM HAVE TO TEACH THE REST OF US ABOUT SEXUALITY AND GENDER

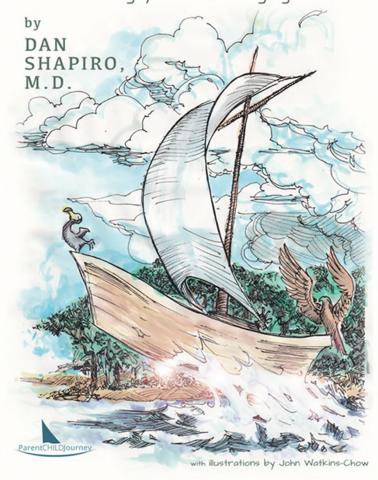
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DEVELOPMENTAL-BEHAVIORAL PEDIATRICS

PARENTCHILDJOURNEY.COM

Parent Child Journey

An Individualized Approach to Raising your Challenging Child



Parent Child Excursions

ADHD, Anxiety, and Autism

Dan Shapiro, M.D.

and a section on

Autism, Sexuality, and Gender Identity with Aaron Shapiro, M.D., M.P.H.



Illustrations by John Watkins-Chow

TEN LESSONS: WHAT PEOPLE WITH AUTISM HAVE TO TEACH THE REST OF US ABOUT SEXUALITY AND GENDER

- 1. Sexuality and gender exist along a spectrum; not simple, binary or fixed
- 2. Developmental difference does not equal disorder, but ...
- 3. Sexuality, hidden or not, is a central aspect of being human
- 4. One should not make assumptions about who can or can't have a fulfilling sex life
- 5. Autism magnifies how human variation affects sexuality (whether autistic or not)
- 6. Special sex education should be universal
- 7. Autistic culture (neurodiversity pride!) can support sexual diversity and liberation
- 8. If you don't look, you don't find (coexisting conditions)
- 9. Causation is complicated—and mostly speculative
- 10. Support and intervention matter

REED'S STORY YOUR REACTIONS?

- 7 year-old with autism, assigned male sex at birth
- Clips of brown construction paper as a pony-tail every day
- Teacher: "Do you want her to wear the ponytail in the class photo?"
- Parents confused and shocked: "Do you want to be a girl?" Reed: "No."
- Pediatrician: "He's probably not trans—just gay."
- Dad: "How about a soccer team?"
- Mom: "Back off. Can't you see you're just making things worse?"

LESSON 1: SEXUALITY AND GENDER—LIKE AUTISM— EXIST ALONG A SPECTRUM NOT SIMPLE, BINARY OR FIXED

<u>Terminology</u>

- Biological (natal) sex: assigned sex at birth
 - What's between your legs?
- Gender identity: who you are cognitively, spiritually, socially, and politically
 - What's between your ears?
- Gender expression: how you present your self
 - What's in the mirror?
- Sexuality: who you're attracted to, want to have sex with, engage intimately with
 - Who's between the sheets?
- LGBTQI: lesbian, gay, bisexual, transgender, questioning or queer, and intersex

OUR BODY PARTS DO NOT DEFINE OUR GENDER OR SEXUALITY

- Assigned biological sex is not always clear
- Even when assigned biological sex is clear, it may be inconsistent with traditional notions of gender identity, gender expression and sexuality
- Gender and sexuality are traditional, conditioned, cultural constructs
 - blue vs. pink
 - STEM career vs. home-maker
 - Heteronormative

Old boxes – male or female/ gay or straight (autistic or neurotypical) – do not contain all of humanity

PROBLEMS WITH THE GENDER-REVEAL PARTY IT'S A ...?





BEYOND BOY/GIRL BINARY: UNCERTAINTY AND COMPLEXITY REVEALED OLD BOXES DON'T ALWAYS WORK

ASSIGNED BIO SEX

GENDER IDENTITY

GENDER EXPRESSION

- Hormones
 - Ambiguous genitalia
 - Blind vaginal pouch
 - Congenital adrenal hyperplasia
- Genes
 - Kleinfelter's XXY
 - Turner's XO

- Cis
- Trans
- Fluid
- Non-binary, queer

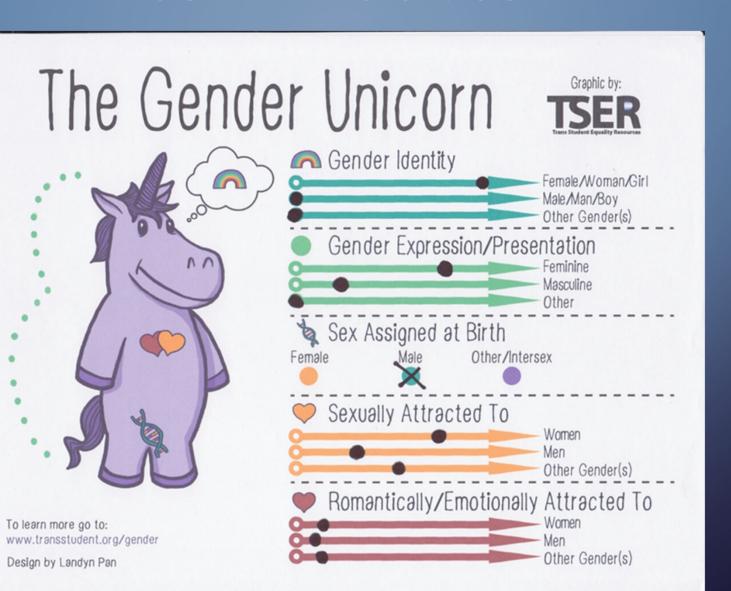
- Name
- Pronouns
- Hairstyle
- Clothing
- Speech
- Culturally normative behaviors
- Hormonal or surgical change

BEYOND BINARY: "GAY OR STRAIGHT" OLD BOXES DON'T ALWAYS WORK (CONTINUED)

SEXUALITY

- Sexuality and attraction (like gender) can be endlessly varied:
 - sexually attracted to one gender and have romantic feelings for another
 - sexually or romantically attracted to
 - Males or females
 - Neither or both
 - various non-binary identities
 - focused on gender identity, gender expression, or biological sex
- gay (homosexual), straight (heterosexual), bisexual, pansexual, and asexual

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LESSON 2: DEVELOPMENTAL DIFFERENCE DOES NOT EQUAL DISORDER BUT IT CAN BE ASSOCIATED WITH DISTRESS

- Difference Disorder
 - if recognized and supported, variation need not equal disorder
 - but dysphoria can occur
- Gender Dysphoria (intrapersonal/psychological)
 - females with penises and males with menstrual periods
- Minority Stress (interpersonal/social)
 - gender and sexuality closets
- LGBTQI individuals are "at-risk"
 - anxiety, depression, suicide
 - discrimination, violence
 - failure to graduate, unemployment, housing insecurity

Many LGBTQI people need psychotherapeutic, hormonal, surgical, or other interventions

LESSON 3: SEXUALITY, HIDDEN OR NOT, IS A CENTRAL ASPECT OF BEING HUMAN

- Most parents tend to deny or underestimate the sexual experience of their children – especially those with developmental differences like autism
- True, people with autism may have less partner experience and may experience puberty and sexuality differently
- But children with autism do not have delayed puberty
- And they need not be sexually active or in a relationship to think about sex
- People with autism have sexual identities and intimate relationships too

FACING OUR OWN DISCOMFORTS AND DOUBLE-STANDARDS COMMON EXPERIENCES IN SEXUAL DEVELOPMENT

- Self-exploration, masturbation
- Orgasm
- Early mutual exploration (genital play)
- Outercourse (touching, hugging, kissing, French-kissing, petting, giving a hand job, receiving a hand job, fingering, mutual masturbation)
- Romantic feelings, crushes, falling in love
- Dating in groups, dating in pairs
- Intercourse (giving or receiving penetration; oral, anal, or vaginal)
- Other forms of sexual expression (sexting)
- Dating, sexual and romantic relationships, falling in love
- Exploring sexual attraction/identity (gay, straight, bi-, pan-, a-sexual)

LESSON 4: ONE SHOULD NOT MAKE ASSUMPTIONS ABOUT WHO CAN OR CAN'T HAVE A FULFILLING SEX LIFE

- Just because there might be some unique difficulties does not mean intimate relationships can not or should not happen
- News flash: Neurotypical people have relationship problems too!
- Stories of successful intimacy
 - Biographies:
 - Daniel Tammet, Born on a Blue Day
 - John Elder Robison, Look Me in the Eye
 - Helen Hoang, The Kiss Quotient
 - Graeme Simsion, The Rosie Project
 - TV shows, movies and documentaries
 - Autism in Love (2015)
 - Big Bang Theory (Sheldon)
 - Atypical (Netflix)
 - Keep the Change (2018)

LESSON 5: AUTISM MAGNIFIES HOW HUMAN VARIATION AFFECTS SEXUALITY (WHETHER AUTISTIC OR NOT)

- Differences in Navigation of Psychosocial Stages (page 345)
 - Erickson Stages 5 (identity vs. role confusion) and 6 (intimacy vs. isolation)
- Temperament Differences
 - inflexibility, high intensity of reaction, impulsivity
- Sensory Differences
 - hypo- and / or hypersensitivities
- Motor Differences
 - gross and fine motor coordination, stamina
- Attention Regulation/Executive Function Differences
 - distractibility, perseveration

LESSON 5: AUTISM MAGNIFIES HOW HUMAN VARIATION AFFECTS SEXUALITY (WHETHER AUTISTIC OR NOT)

- Social (verbal and nonverbal) Language Difference
 - communication, reading and sending cues, inferencing, context-blindness
- Psychiatric/Medical Issues
 - mood disorder, med sexual side-effects, GI problems
- Adaptive Behavior and Life-Skill Deficits
 - hygiene, other self-care
- Poor Sex Education
 - inadequate curricula, relationship deprivation
- Health-Care Deficiencies
 - STD and pregnancy prevention

UNDERSTANDING, ACCEPTING AND ENJOYING INDIVIDUAL DIFFERENCES

Autism magnifies the extraordinary range of human diversity and variation. Compared to typically developing individuals, the sociosexual challenges of people with autism spectrum disorders may be different in degree but not so different in kind. All people—not just people with autism—can misread social cues, think in all-or-none terms, and objectify others. All people can have idiosyncrasies and quirks, peculiarities and eccentricities, sensory preferences and sensitivities. Autism simply shines a light on these individual differences and compels us to take note. Autism teaches all of us the importance of understanding, accepting, and enjoying each and every person as they are, not how we wish them to be.

DEVELOPMENTAL VARIATION EXPLAINS ISSUES WITH SEX FOR PEOPLE WITH AUTISM – AND THE REST OF US

- Lack of sexual fulfillment
- Avoidance
- Relationship problems
- Inappropriate masturbation
- Sexual obsessions
- Victimization

Accurate explanation leads to effective management

LESSON 6: SPECIAL SEX EDUCATION SHOULD BE UNIVERSAL

General principles

- More individualized
- More proactive
- More explicit
- More visual
- More scripted

SPECIFIC SEX EDUCATION TECHNIQUES

- Use proper names for body parts, accurate description of sex acts
- Model comfort and open-ness in communication
- Use pictures, cartoons, video; social stories, cartoon conversations
- Correct unhealthy and distorted misconceptions (e.g. from internet porn)
- Relationship supervision/ coaching
- Teach, role play, and practice (e.g. "No means no, yes means yes")
- Anticipate and preview, not "in the heat of the moment"
- Cognitive-behavioral therapy (reciprocity and flexibility training) applied to sexuality
 - Unstuck and on-target (plan A/ plan B)
 - Social thinking (expected vs. Unexpected behavior)
- Professional sex therapy/ surrogate sexual partners

SEX EDUCATION RESOURCES FOR PEOPLE WITH AUTISM—AND THE REST OF US

- Our Whole Lives, Unitarian Universalist Association, 2014
- Henault, Asperger's Syndrome and Sexuality: From Adolescence through Adulthood,
 2005
- Center for Parent Information and Resource, Sexuality Education for Students with Disabilities, 2018
- Planned Parenthood, Sexuality Education for Youth on the Autism Spectrum, 2017
- Newport & Newport, Asperger's & Sexuality: Puberty and Beyond, 2002
- Masturbation instruction manuals
 - "Finger Tips"/ "Sex for One: The Joy of Self-Loving" (Respectability, 2017)

SEX EDUCATION VIA THE INTERNET: FRIEND OR FOE?

- 1. safe and accurate source of information, exploration, and connection
- 2. dangerous source of distortion and predatory risk

LESSON 7: AUTISTIC CULTURE (NEURODIVERSITY PRIDE!) CAN SUPPORT SEXUAL DIVERSITY AND LIBERATION

- <u>Safe</u> sex as a helpful first step toward the development of mature relationships (3 to 1 or 1 to 3?)
- Rejection of taboos
- Acceptance of fixations, motifs, themes, fetishes
 - \bullet example: Domination and submission (D/s)
 - advantages of contracts/scripts regarding sexual behaviors, customs and rituals
- Sexual disinterest as normal human variation, not necessarily disorder

COEXISTING CONDITIONS LESSON 8: IF YOU DON'T LOOK, YOU DON'T FIND

- Increasing prevalence of gender dysphoria
 - DSM5 (2013): 0.002-0.014%
 - currently, closer to 1% overall
 - more trans females (natal males) than trans males (natal females)
- Increasing prevalence of autism spectrum disorder
 - CDC (2004): 1 in 166 (0.6%)
 - CDC (2018): 1 in 59 children (1.7%)
 - 4:1 male: female ratio; 1 in 37 boys (2.7%), 1 in 151 girls (0.7%)
- Coexistence of autism and gender variation: correlation or causation?

COEXISTENCE OF AUTISM AND GENDER VARIATION

- People with gender variation are more likely to have autism
 - 2010, DeVries (Denmark)
 - 115 boys and 89 girls referred to gender disorders clinic
 - 7.8% with autism
- People with autism are more likely to be gender variant.
 - 2014, Strang (DC Children's)
 - N=165 typically developing controls, 147 ASD, 126 ADHD, 62 epilepsy, and 54 neurofibromatosis
 - more children expressed cross-gender desire if they had autism (5.4 percent) versus TD, epilepsy or neurofibromatosis (1.7 percent)

CERTAINTIES AND UNCERTAINTIES ABOUT COEXISTING AUTISM AND GENDER VARIATION

- The finding of increased coexistence has been replicated in other studies
- I see more children with autism and gender variation in my own practice
- But some researchers doubt the association altogether
- Whether connected or coincidental, more autism + more gender variation = more children with both!

COEXISTING AUTISM AND GENDER VARIATION LESSON 9: CAUSATION IS COMPLICATED— AND MOSTLY SPECULATIVE

If there is a cause-effect connection, it is probably multifactorial

- Possible genetic factors
- Possible endocrine factors
- Possible psychological factors

POSSIBLE GENETIC FACTORS

- Increased incidence of autism in certain genetic and endocrine conditions that are also associated with differences in sex chromosomes and/or sexual development:
 - Kleinfelter's XXY (testicular feminization)
 - Turners, XO (ovarian dysgenesis)
 - Fragile X
- 4:1 male: female ratio in autism and other neurodevelopmental disorders

POSSIBLE ENDOCRINE FACTORS

Autism as "extreme male brain" (systematizing vs. empathizing)

- Male-female brain differences exist on functional MRI
- Higher incidence of autism in congenital adrenal hyperplasia and other in-utero exposures to excess male hormones
- Could explain:
 - greater incidence of trans males with autism and
 - 4:1 male: female (natal) ratio in autism
- But, does not explain why:
 - increased association of gender variation with autism occurs equally in trans females and trans males

POSSIBLE PSYCHOLOGICAL FACTORS DISTORTED THINKING

- Parts mistaken for wholes
 - perseveration on isolated cross-gender detail, blind to broader context; for example...
 - natal boy fascinated by mother's barrette or teacher's floralpatterned dress
 - natal girl strongly attached to a specific football team logo
- Normal developmental ambivalence carved into stone
 - "If I have a cross-gender thought, it must mean I'm the opposite sex."

POSSIBLE PSYCHOSOCIAL FACTORS POOR SELF-IMAGE, SOCIAL ISOLATION AND CROSS-GENDER ESCAPE FANTASY

- "I'm a boy with autism. If I become a girl, I won't have autism anymore."
- "It's better to be gender-nonconforming than socially disabled."
- "I'd rather be known as trans than autistic."
- "I was rejected by the opposite sex. I don't fit with the same sex. Maybe being the other sex will be better."

Warning: Fragmentary, situational or distorted autistic perseveration should not be confused with central, persistent and true trans-gender identity

POSSIBLE PSYCHOSOCIAL FACTORS LIBERATED THINKING

- For young children with autism, the nature, frequency, and depth of social interactions is usually different. Therefore:
 - more free of societal stereotypes and expectations?
 - less aware of gender-normative behavior?
 - less inhibited in expression of nonconformity?
- Might autistic youth (and adults) be more liberated from cultural conditioning to live their LGBTQI truths?

JOHN STRANG:

"Autistic people may be more bold and individualistic, less swayed by social expectations. Some of the front-line leaders of the trans rights movement have been trans and autistic—and there's a beautiful focus, for many of them, on being themselves and not bending to social expectations of what others expect them to be" (Slate interview, Urquhart, 2018)

FROM MY OWN PRACTICE

- "I didn't care what people said. It just made more sense to not have a gender."
- "You're fixated on boys acting like boys and girls acting like girls.

 I've just never had any interest in all of that boy-girl stuff."

INDIVIDUALLY AND SYSTEMICALLY LESSON 10: SUPPORT AND INTERVENTION MATTER

- Parents, autism, and gender variation
- Comprehensive treatment of gender dysphoria in autism
- Activism and cultural change

PARENTS, AUTISM, AND GENDER VARIATION

- "Not what I expected x 2!"/ coping with the "double-hit"
- Responding to non-conformity: first check your own pulse
- Gender and sexuality journeys are authentic and need to unfold over time
- What it's all about: unconditional love and acceptance
- Strong parent support is the key ingredient to life satisfaction, self-esteem, mental health, suicide prevention, secure housing for LGBTQI youth and adults
- Beware: Some treatments for autism may be gender-biased; such as,
 - Teaching gender-normative play skills (trucks and dolls)
 - Tolerating gender-normative types of clothing

COMPREHENSIVE TREATMENT OF GENDER DYSPHORIA IN AUTISM

- Need screening and expert intervention for both gender variation and autism
- Puberty blockers; Lupron and the gift of time
- Gender affirmation; feminizing and masculinizing interventions
 - speech therapy
 - cosmetics
 - hormones
 - surgery
 - psychotherapy (individual and group)
 - etc.

BEYOND INDIVIDUAL PARENT AND CHILD SUPPORTS ACTIVISM AND CULTURAL CHANGE

- Parent, child and adult group support (ASAN, PFLAG)
- School initiatives
 - gender-neutral restrooms
 - Gay-Straight Alliance clubs
 - guest speakers
 - sex ed curricula
 - Facilitation of peer interaction/ social engineering
 - education rights/anti-discrimination law

THE FUTURE OF DIVERSITY: NEURODEVELOPMENTAL, SEXUAL AND GENDER

- The normalization of difference
 - Inclusion movements
 - Exposure through TV, movies, literature
 - LGBTQI and Autism—Pride movements
 - New social standards
 - Legal protections
- Variation is becoming more mainstream
- "Them" is becoming "Us"

RESOURCES

- Welcoming Schools program developed by the Human Rights Campaign to support LGBTQ youth at school: https://www.welcomingschools.org
- Laurie Frankel, This is How it Always Is