



Transition Planning for Individuals with ASD: Part 3 of 4: The Central Importance of Sexual Education in ASD

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Educational Partnership
for Instructing Children

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A note on terminology

As a general rule I try to avoid using the terms “high functioning” or “low functioning” to describe where someone falls on the autism spectrum. The reason is that these terms often just describe someone’s degree of vocal verbal behavior than any actual level of functioning. So instead I try to use “high verbal” or “low verbal” which I think is more accurate. That , however is a personal choice maintained solely by self reinforcement. You are, of course, free to ignore.

Sometimes I think I am an autism professional who works in the field of applied behavior analysis. At other times I think I am a behavior analyst who works in the field of autism. The truth is that I am both.

This is important because

If you work with young kids you get to be a specialist. Whether you're a special educator, speech pathologist, occupational therapist, or board certified behavior analyst, you get to be a specialist. When working with adolescents and young adults you don't get to be a specialist and, instead, need to be something of generalist. In other words, you need a good working knowledge of ABA, IDEA, NCLB, Department of Labor regulations, Social Security and Social Security Work Incentive Programs, Mental Health concerns, medication side effects, sexuality, menstrual care, job development, job coaching, community-based instruction, generalized systems of communication, staff training, community training, and that's just to start.

Thankfully...

Applied behavior analysis has myriad applications far beyond ASD so my knowledge, expertise, and experience in the ABA/ASD field is generalizable to these other areas of need. The rest of what I know is just a bunch of facts equally useful (and necessary) in my work or as a contestant on Jeopardy.

However

It is relatively easy to be successful in our classrooms as we control most, if not all, of the relevant variables. But given that ABA is intended to deal with problems of social importance, produce strong & socially important effects, and operate in new environments & continue after formal treatment ends (Baer, Wolf, & Risley, 1968), success in our classrooms should only be our first step in behavioral intervention in ASD.

Sexuality and sexual
behavior are complex,
context-based and
societally mediated
topography of adaptive
behavior

Adaptive Behavior

“Adaptive Behavior is defined as those skills or abilities that enable the individual to meet standards of personal independence and that would be expected of his or her age and social group. Adaptive behavior also refers to the typical performance of individuals without disabilities in meeting environmental expectations. Adaptive behavior changes according to a person’s age, cultural expectations, and environmental demands.” (Heward, 2005).



This presentation contains language and imagery of a sexual nature and may be considered inappropriate for younger viewers and listeners.

Your Welcome.

For BCBAs
(along with everyone else)

Remember, you need to know the limits of your expertise and the breadth of your behavior analytic competence before venturing deeply into this aspect of our field. When in doubt, get assistance from someone more expert in this area.

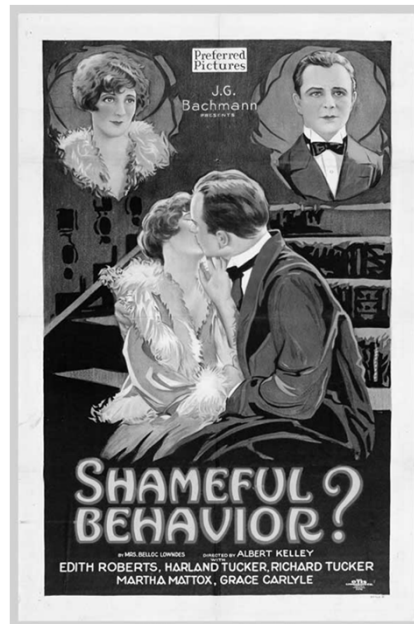


Prudish Promiscuity?

Sex and sexuality, as serious topics for discussion, are ones that many of us would rather avoid than address. In fact, according to the CDC fewer than half of all high schools and only 20% of middle schools offer a comprehensive Sex Ed curriculum. **Further, only 23 states mandate Sex Ed at all and, of those, only 13 require it to be medically accurate. (Orenstein, 2016)**

Orenstein, P. (March 20, 2016). *When did porn become sex ed?* **New York Times Sunday Review**. pp1, 6.

Now add to that the personal and societal constraints that move sexual behavior out of the realm of simple behavior and we have a cohort of skills in which there is high interest but limited knowledge.



But let's not forget there is, historically, more than a touch of misogyny in all this...

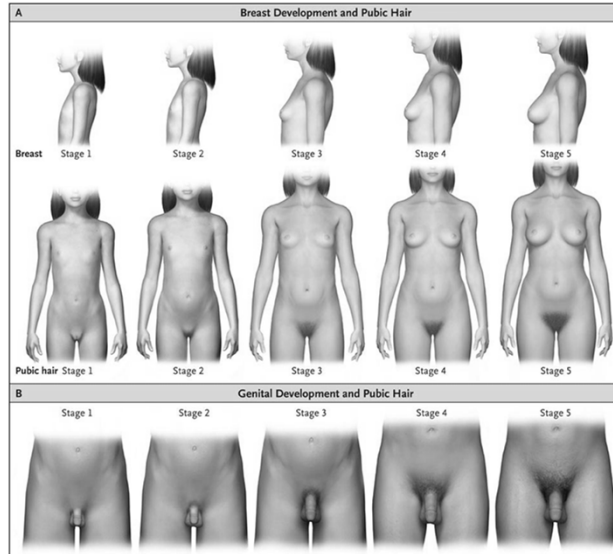


And when it came to individuals with DD

Richards, et al (2006) noted that, historically, individuals with DD been viewed ***as sexually deviant, prone to criminality, asexual, and problematic to society.*** Despite significant progress over the last 5 decades in many areas, the sexuality of individuals with DD is still grossly misunderstood by society. ***And although today the sexuality of individuals with DD is not entirely ignored, nor is sexual behavior universally punished, the perception that people with developmental disabilities as perpetual children, irrespective of their age, still lingers with significant, negative consequences.***

Richards, D., Miodrag, N., & Watson, S. L. (2006). Sexuality and developmental disability: Obstacles to healthy sexuality throughout the lifespan. *Developmental Disabilities Bulletin*, 34(1-2), 137-155.

Puberty



Puberty

According to Medilexicon's on-line medical dictionary puberty is a sequence of events by which a child becomes an adult, characterized by the beginning of gonadotropin secretion, gametogenesis, secretion of gonadal hormones, development of secondary sexual characteristics, and reproductive functions. In girls the first signs of puberty may be evident after age 8 with the biological process largely completed by age 16. In boys, puberty normally begins at age 9 and is largely completed by age 18. Ethnic and geographic factors may influence the time at which typical milestones may occur.

Puberty and Girls

- ❑ **Sexual organs** - the girl's clitoris and the uterus (womb) will grow.
- ❑ **Menstruation begins** - one of the first things that happens during a girl's puberty is the start of her monthly menstrual cycle.
- ❑ **Breast changes** - the girl's breast will start to grow.
- ❑ **Vaginal discharge** - vaginal discharge may start or change.
- ❑ **Body hair** - hair will begin to grow in her pubic area - firstly along the labia and then under her arms and on her legs.
- ❑ **Skin** - as the girl's oil and sweat glands grow her skin will become more oily and she will sweat more. Acne is common among girls during puberty.
- ❑ **Emotions** - a girl's emotions may change, especially around the time her period comes each month. These emotional roller-coaster type changes, which may include irritability, are mainly due to fluctuating hormone levels that occur during the menstrual cycle.

Puberty and Boys

- ❑ **Scrotum, testicles and penis** - the boy's scrotum will begin to thin and redden and his testicles will grow. Later, usually around the age of 13 his penis will grow and lengthen while the testicles will continue to grow.
- ❑ **Voice change** - the boy's voice will "break" or "crack" due to maturation of larynx.
- ❑ **Wet dreams** - boys may ejaculate during their sleep and wake up in the morning with damp sheets and pajamas. This does not mean the boy was having a sexual dream.
- ❑ **Involuntary erections** - These will occur without the penis being touched and without sexual thoughts triggering them.
- ❑ **Breast enlargement** - swelling of the breasts occurs with many boys during puberty.
- ❑ **Skin** - the boy's skin will become more oily during puberty. He will also sweat much more. It is not uncommon for boys to develop acne during puberty.
- ❑ **Body size** - growth spurts occur during a boy's puberty. This growth peaks at about two years after the onset of puberty.
- ❑ **Body hair** - hair will start to grow around the pubic area, under his arms, on his legs and arms, and on his face. Facial hair usually starts around the upper lip and chin.
- ❑ **Emotions** - boys may experience mood swings; one moment they are laughing and then they suddenly feel like crying. Boys may also experience intense feelings of anger. This is partly due to the increased levels of hormones in their body, as well as the psychological aspects of coming to terms with all the physical changes that are taking place. It helps if the boy can talk to a family member, or a good friend. **A recent study* indicates that mood swings may be explained by biological changes in the adolescent brain.**

*"Reversal of neurosteroid effects at alpha4beta2delta GABAA receptors triggers anxiety at puberty." Hui Shen, Qi Hua Gong, Chye Aoki, Maoli Yuan, Yevgeniy Ruderman, Michael Dattilo, Keith Williams and Sheryl S Smith. Nature Neuroscience Published online: 11 March 2007; doi:10.1038/nn1868.

Puberty and ASD

5 Things to remember about puberty and ASD:

1. The diversity of the emotional impact of adolescence on individuals with ASD.
2. Reflex, or spontaneous, erections are not the product of sexual arousal.
3. Genital stimulation is universal and should not be a source of panic.
4. Poor hygiene skills now become far more limiting socially
5. Personal (i.e., sexual) safety and the 5-year rule

ASD, Adolescence, and Mental Health

Beginning in adolescence, individuals with a DD are **two to four times more likely to have a psychiatric disorder than their Neurotypical peers.**

(Fletcher, et al., 2007)

Psychotropic Medication Use in ASD

Spencer, et al., (2013) examined rates of psychotropic use among insured children with (ASD). Using medical and pharmacy claims linked with health plan enrollment [] from 2001 to 2009, the results indicated that among children with ASD

- ❑ **64% had a filled prescription for at least 1 psychotropic medication,**
- ❑ **35% had evidence of poly-pharmacy (≥2 classes), and**
- ❑ **15% used medications from ≥3 classes concurrently. Median length of poly-pharmacy was 346 days.**

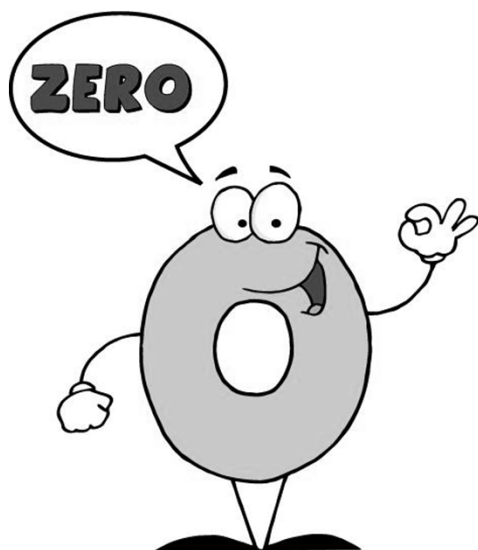
The authors concluded that despite minimal evidence of the effectiveness [] of multidrug treatment of ASD, psychotropic medications are commonly used, singly and in combination, for ASD and its co-occurring conditions.

Spencer, D., Marshall, J., Post, B., Kulakodlu, M., Newschaffer, C. Dennen, T., Azocar, F., & Jain, A. (2013). Psychotropic medication use and polypharmacy in children with autism spectrum disorders. *Pediatrics*. Nov;132(5):833-40.

Sex and sexuality are extensively under-researched areas of behavior in adolescents & adults w ASD



But really, how much research is there on
sexuality education & intervention in ASD?



Well, almost "0" actually

There is research on the prevalence of sexual behaviors, self reports of sexuality, parent reports, and parent training on sex education and ASD but basically nothing in the area intervention. For example....

Knowledge base

(McCabe & Cummins, 1996; Szollo & McCabe, 1995) concluded that individuals who have an intellectual disability have lower levels of sexual knowledge and experience in all areas except menstruation and body part identification when compared to a typical student population.

Watson, Griffiths, Richards, & Dysktra, (2002). *Sex Education*, In Griffiths, Richards, Federoff, & Watson (Eds.). *Ethical Dilemmas: Sexuality and Developmental Disability*. (pp 175-225). Kingston, NY: NADD Press

Sexuality in Adults with ASD in Residential Programs

VanBourgondien, Reichle, & Palmer (1997) surveyed the degree to which group home residents with autism engaged in sexual behavior. The behavior of 89 adults (72 males, 17 females) was observed indicating **that the majority of individuals were engaging in some form of sexual behavior with masturbation being most common sexual behavior (68% including 54 males and 4 females)**. Sexual behavior with signs of arousal directed toward another person was present in one-third of the sample.

Van Bourgondien, M. E., Reichle, N. C., & Palmer, A. (1997). Sexual behavior in adults with autism. *Journal of Autism and Developmental Disorders*, 27(2), 113-125

Stalking may be a problem...

Stokes, Newton, & Kaur (2007) examined the nature of social and romantic functioning in adolescents and adults with ASD. What they found was that individuals with ASD were more likely than their NT peers to engage in inappropriate courting behaviors; to focus their attention on celebrities, strangers, colleagues, and exes; and to pursue their target for longer lengths of time (i.e. stalking).

Stokes, M. Newton, N. & Kaur, A., (2007). Stalking and social and romantic functioning among adolescents and adults with ASD. [Journal of Autism Developmental Disorders](#). 37,1969-86.

Self-reports of Sexuality in ASD

Gilmour, et al, (2012) via an on-line survey, compared the sexuality attitudes and behaviors of 82 (55 female and 17 male) adults with autism with 282 typical adults. The results indicated that **adults with ASD displayed a level interest in sex and engaged in a variety of sexual behaviors similar to that of control group. However, a higher rate of asexuality was found among individuals with ASD. In addition, females with ASD reported a lower degree of heterosexuality than did males with ASD along with slightly higher reports of homosexuality.**

Dewinter, J., Vermeiren, R., Vanwesenbeeck, I., Lobbestael, J., & Van Nieuwenhuizen, C. (2015). Sexuality in adolescent boys with autism spectrum disorder: Self-reported behaviours and attitudes. *Journal of Autism and Developmental Disorders*, 45(3), 731-741.

Inappropriate Sexual Behavior in ASD

Beddows & Brookes (2015) conducted a literature review to identify the typographies of inappropriate sexual behavior displayed by adolescents with ASD. A total of 5,241 articles were found of which 42 met inclusion criteria. The review indicated that adolescents with ASD may engage in ***hyper-masturbation, public masturbation, inappropriate romantic gestures, inappropriate arousal, and exhibitionism.*** *They attribute this to a combination of the absence of appropriate sex education and the degree of severity of ASD. The authors note that despite this being a common problem the literature is surprisingly sparse regarding why inappropriate behavior occurs and what education is effective.*

Beddows, N., & Brooks, R. (2015). Inappropriate sexual behaviour in adolescents with autism spectrum disorder: What education is recommended and why. *Early Intervention in Psychiatry*. Advance online publication 8/12/15

Additional research out of the Intellectual Disabilities community can be found but much of it is not directly generalizable to individuals with ASD. Besides, much of it was poorly done, focused on congregate populations, and is generally pretty dated.

A Few Reasons Why We Should Teach Human Sexuality Education To Individuals With Autism Spectrum Disorders

Number 5

They Have The Same Hormones & Urges & Need To Make The Same Choices As Their Peers



Number 4

All sexual behavior is social behavior and, as such, is particularly challenging for individuals with ASD



Number 3

The Internet and other readily accessible media



Just how accessible is pornography?

In a national survey of youth ages 10-17 years, Mitchell, et al (2003) reported **that 25% of youth had unwanted exposure to sexual pictures on the Internet in the past year.** The use of filtering and blocking software was associated with a modest reduction in unwanted exposure, suggesting that it may help but is far from fool proof. The authors urge that social scientific research be undertaken to inform this highly contentious public policy controversy.

Mitchell, K. J.; Finkelhor, D.; and Wolak, J. (2003). The exposure of youth to unwanted sexual material on the internet: A national survey of risk, impact, and prevention. *Youth Society*, 34, 330-358.

For example, a search for “woman in kitchen” in Bing images with the safe filter off finds:

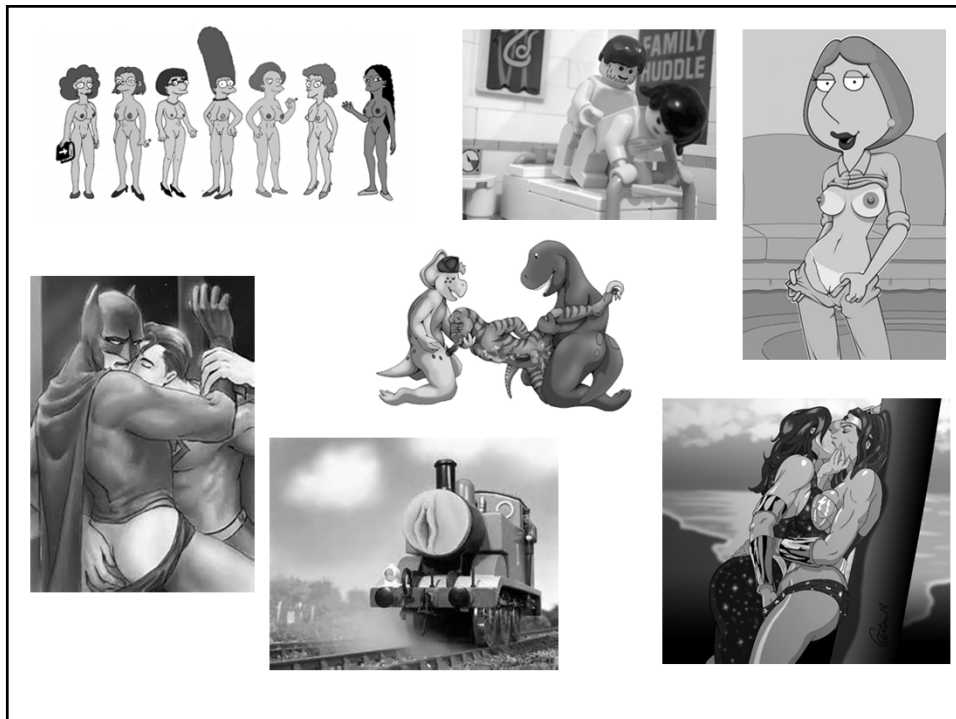


For typical kids...

According to Crabbe and Corlette (2010), porn has become a central mediator of young people’s sexual understanding and experience and a “go to” source for information of sex and sexuality in the absence of any formal sex education.

Crabbe, M. & Corlette, D. (2010) Eroticizing inequality: Technology, pornography, and young people. *DVRCV Quarterly*, 3, 1-6. Accessed on line on 3/36/16 at: <http://www.awe.asn.au/drupal/sites/default/files/Crabbe%20Corlett%20Eroticizing%20Inequality.pdf>

And then there is Rule 34: "If it exists, it exists as internet porn. No Exceptions."



But most problematic, at least in my opinion, is Hentai which is pornographic Anime that is often very misogynistic and violent



From a new **facebook** friend

"Hey, I added you since you look familiar, but once I looked at your page I knew I was mistaken.. but hey, you seem like a good guy so i'll just introduce myself :) Im quirky, funny, and never afraid to have a good time.. I recently moved here about six months ago from a small town in Idaho for work and like it so far! Check out my profile.. if you want to I would love to meet sometime for lunch. Any way.. I wanted to attach more photos of me but its giving me some stupid error! If you give me your email addy I can send the pics to you that way. Hope to hear from you soon!"



From another new **facebook** friend

How are you doing today?? you are a really cool and enchanting dude that's why i did opt for a message to you ok winks....Just want to know more about you with due respect that's if you don't mind. do take care and have a wonderful day feel free to reply ok.....with regards Fiona



A recent (2/2016) facebook friend



Autism Specific Internet Dating

AutisticDating.net
Unique Screening Process for Safety Purposes

Home About Us Contact Us Services

Site Blog
Imagination and Real Caring - by Tim
Apr 11, 2016
70% are parents (by Phil)
Apr 11, 2016
Watch out for summer
Jan 26, 2016
Raising kids who
Jan 17, 2016
Learning to trust my gut
Jan 05, 2016
Sorry, an accident happened and I can't share my long story on "New Autism"
Dec 27, 2015
RESEARCH DEVELOPED A NEUROLOGICAL CLUE FOR AT LEAST SOME AMERICANS
Dec 18, 2015
"Don't blame Mental Illness for Gun Violence" (The New York Times)
Dec 18, 2015
This incident
Dec 15, 2015

Members near **Richmond, VA, United States** | **Any Gender**

| | | | | |
|-------------------------|-----------------------|-----------------------|-----------------------|-------------------------|
| 27 Women, United States | 29 Men, United States | 24 Men, United States | 24 Men, United States | 28 Women, United States |
|-------------------------|-----------------------|-----------------------|-----------------------|-------------------------|

AutisticPersonals
Have an account? [Sign In](#)

Welcome to the Best Autistic Personals Club!
Start Dating with Autistic Singles!

Meet Autistic Singles Who Understand Your Issues and Feel Different. Autistic Personals Club and Explore Our Base of Members Who Don't Let the Differences Prevent Them from Dating. Meeting Fun and Enjoying Romance and Love with Someone Special!

Step 1: What are you looking for

I am a:

Male

Looking for:

Female

[Next >](#)

Autistic Personals - Bringing Together Singles with ASD!

AUTISM Dating Service

MEET LOCAL AUTISTIC SINGLES AND START DATING

Step 1: What are you looking for

I am a:

Male

Looking for:

Female

[NEXT >](#)

Have an account? [Sign In >](#)

• Registration Is Fast and Easy! • Find Autistic Men and Women! • Chat, Send Flirts, IM, and More!

Number 2

Perhaps the most urgent issue in sexuality and ASD is the prevention of sexual abuse

Though research on sexual abuse and ASD is limited Sobsey, (1994), reported **that 25 percent of women with ID referred for family planning had a history of sexual abuse.** In a study of over 55,000 children with ID, Sullivan & Knutson (2000) found that **children with ID were 4 times more likely to be the targets of sexual abuse than their typical peers.** Most recently, Brown-Lavoie, Viccili, and Weiss (2014) examined the sexual knowledge and victimization risk in a group (N=95) of adults with high functioning autism. **78% of the respondents with ASD reported at least one incidence of sexual victimization (i.e., unwanted sexual contact, sexual coercion, or rape) compared to 47% of the comparison control group.**

Brown-Lavoie, S.M., Viccili, M.A., & Weiss, J.A. (2014). Sexual knowledge and victimization in adults with autism spectrum disorders. *Journal of Autism and Developmental Disabilities*, 44 , 2185-2196.

Sobsey, D. (1994). *Violence and abuse in the lives of people with disabilities: The end of silent acceptance?* Baltimore: Paul H. Brookes Publishing Co.

Sullivan, P.M. & Knutson, J.F. (2000). Maltreatment and disabilities: A population-based epidemiological study. *Child Abuse and Neglect*, 24 , 1257-1273.

Self-Protection

- ❑ Teach that refusing to be touched is a right
- ❑ Teach self-protection skills
 - ❑ Who can/can't touch the individual and where on his/her body
 - ❑ How and when to say "No"
 - ❑ How to ask for assistance
 - ❑ How to recall remote events and convey where an individual touched him/her

(American Academy of Pediatrics, 1996; Nehring, 2005; Roth & Morse, 1994; Volkmar & Wiesner, 2004)

Number 1

Because They Are People & Like All People
Individuals with Autism Have The Right To
Learn All They Can To Enable Them To
Become Sexually Healthy Persons



Why ABA-based
interventions to teach
sexuality?

First

Sex is just behavior. Whatever
body parts are involved it is all just
behavior.

Second

Despite a focus on self-determination in adulthood there continues to be an absence of any significant research into the effectiveness of sex education and training for persons with ASD which Behavior Analysis is able to provide.

and Third

- Many of the basic instructional goals in sexuality education boil down to complex discrimination skills. For example:
 - Boy or Girl
 - Men's room or Lady's room (or Blokes v. Shielas; Senors v. Senoritas; M v. W; and so on...)
 - Where or with who you can/cannot:
 - Be naked
 - Masturbate
 - Curse
 - Help with toileting or menstrual care
 - Touch certain parts of your body

But human sexuality is not an area where we in Behavior Analysis have done our best work, or even much work, at all.

Behavior and Social Issues, Volume 6, No. 2, Fall 1996

**A BEHAVIOR-ANALYTIC VIEW OF SEXUALITY,
TRANSSEXUALITY, HOMOSEXUALITY, AND
HETEROSEXUALITY**

Richard W. Malott
Western Michigan University

ABSTRACT: This article presents a behavior-analytic view suggesting that biological factors, whether genetic or otherwise, have little to do with our preference for same-gender or opposite-gender sexual stimulation. This view stresses the importance of behavioral history and current behavioral contingencies in understanding the causes of an individual's behavior and values. This view states that genetic and other biological factors are crucial in determining the behavioral processes that interact with our behavioral history and current behavioral contingencies; however biological factors have little direct effect on differences among human beings in their behavior and values. In addition, this behavior-analytic view suggests that the particular forms of behavior are arbitrary; whatever the human behavior with which we are concerned, the contingencies of reinforcement and punishment determine its particular forms.

In 1974

Bancroft (1974) noted that the two basic treatments for sexual deviancy are aversion treatment and desensitization. Aversion therapy consisted of the presentation of a potentially arousing (deviant stimulus) followed by the administration of noxious stimulus, often electric shock. The authors noted, however, the behavioral treatments engender the full ire of the deviant subculture.

Bancroft, J. (1974). *Deviant Sexual Behavior: Modification and Assessment*. Clarendon Press: Oxford, UK.

Things are starting to change however

Stein, (2013) notes that when working within sexuality and with people who engage in varying topographies of sexual behavior, the first thing to remember is that sex is behavior and it follows the same rules as all other topographies of behavior. The fields of sex therapy, sexuality education, sex research, and reproductive medicine all maintain a descriptive and evolving vernacular that is used by clinicians and academicians throughout. However, there are few who work to operationally define these terms in behavioral ways and then carry out research and intervention with a focus on behavior and its context instead of mental events. While it is difficult for many reasons we can identify discrete patterns of activity in which humans [] engage between sexual arousal and satiety. However, it can become particularly confusing when assessing sexual behavior within the context of behavior analysis because sexual stimuli can serve multiple functions.

Stein, S. (2013). Tackling terms and conditioning confusion: Sexual behavior and applied behavior analysis. Poster presentation October 9, 2013. South Bend, IN.

Remember

In ABA and ASD interactions between student and the Behavior Analyst may be more physical than most other professional relationships. For example:

- ❑ We may use tickles, hugs and kisses as social reinforcers for young learners but then neglect to discriminate as to whom, what, where, and when.
- ❑ We may provide help, in the form of prompting, in generally private situations such as toileting, showering, or menstrual care but neglect to discriminate as to whom, what, where, and when.
- ❑ Instruction in appropriate social distancing in early adolescence and beyond is often neglected under the guise of safety.

Working Definitions...

- ❑ **Sexuality** is an integral part of the personality of everyone: man, woman, and child. It is a basic need and an aspect of being human that cannot be separated from other aspects of human life. Sexuality is not synonymous with sexual intercourse [and it] influences thoughts feelings, actions, and interactions and thereby our mental and physical health” (WHO, 1975)
- ❑ **Sex** can simply mean gender, whether you’re male or female.
- ❑ **Sex** can also mean the physical act of sexual intercourse.

Further complicating things

- ❑ There are 4 levels of of sexual language including:
 - ❑ **Formal/polite** – *Vagina*
 - ❑ **Technical** – *Labia, Cervix, Clitoris, Vulva*
 - ❑ **Cute** – *Va-jay-jay, Muffin, Little man in the boat, Punani, Lady parts, etc.*
 - ❑ **Slang** – *Snatch, Beaver, Twat, Pussy, etc.*

Further

- ❑ Individuals with autism can be concrete thinkers who interpret things literally, so...
 - ❑ Be concrete and factual during instruction
 - ❑ Provide clear visual and verbal examples
 - ❑ Avoid euphemisms
- ❑ For example... (Rated R)

Some responses of adults with autism during an assessment* of sexual knowledge



http://www.camboday.com/UnderstandingSex/healthsex/img/sex_sofa.jpg

Q: Tell me about this picture.

A: “[T]he people were sitting on the couch ‘being friends’”

Konstantareas, M. & Lunsky, Y. (1997) , Sociosexual knowledge, experience, attitudes, and interests of individuals with autistic disorder and developmental delay. *Journal of Autism and Developmental Disorders*, 27, 397-413.

Some responses of adults with autism during an assessment* of sexual knowledge



<http://www.ural.ru/gallery/news/people/sex/bed.jpg>

Q: What does this picture show?

A: “two people lying on a towel.”

Myths about Sexuality & ASD



Myth 1:
Folks on the spectrum have little
or no interest in sexuality

**Myth 2:
People on the spectrum
are hypersexual**

**Myth 3:
People on the spectrum
are solely heterosexual**

But the Truth Is...

- ❑ Persons with ASD are sexual beings. However, individual interest in sex or in developing an intimate sexual relationship with another person varies widely across, and within, individuals at all ability levels. As such, there is a significant need for individualized, effective instruction for persons with ASD across the ability spectrum.

Sexuality education should be proactive

Most learners with a developmental disability receive sexuality education only after having engaged in sexual behavior that is considered inappropriate, offensive or potentially dangerous. This may be considered somewhat akin to closing the barn door after the horse has run. (Griffiths, 1999)

The three primary goals in
sexuality education

1. Provide accurate information
(Relatively easy)
2. Develop the necessary social
competence *(Relatively hard)*
3. Develop personal values
*(Somewhere between hard and
impossible)*

Goals of Comprehensive Sexuality Education:

INFORMATION

Basic guidelines for teaching

- Think ahead and be proactive
- Be concrete
- Serious, calm, supportive
- Task analyze everything that can be task analyzed
- Be consistent, be repetitive
- What are the practical/functional implications
- Teach all steps and in the correct order
- Consider using multiple instructional mediums
- Incorporate the social dimension of sexuality

Central Instructional Concepts

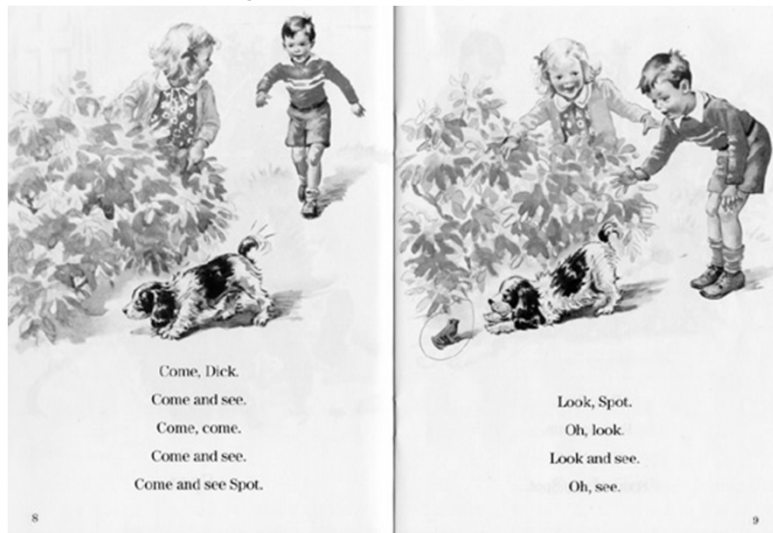
- Public versus private behavior
- Good touch versus bad touch
- Proper names of body parts
- “Improper” names of body parts
- Personal boundaries/personal spaces
- Masturbation
- Avoidance of danger/Abuse prevention
- Social skills and relationship building
- Dating skills
- Personal responsibility and values

What to teach and when: Some general guidelines.*

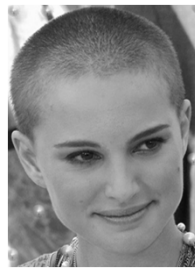
- ❑ Preschool through Elementary
 - ❑ Boys v. girls
 - ❑ Public v. private
 - ❑ Basic facts inc. body parts
 - ❑ Introduction to puberty (your changing body)
 - ❑ Introduction to menstrual care
 - ❑ Appropriate v. inappropriate touching

Source: Schwier, K.M., & Hingsburger, D. (2000)

Boys versus Girls



Boys versus Girls



- Middle School to High School and Beyond..
- Puberty & Menstruation (if not yet addressed)
- Ejaculation and wet dreams (if not yet addressed)
- How to say “no” (if not yet addressed)
- Masturbation (if not yet addressed)
- Public restroom use
- Attraction and sexual feelings
- Relationships and dating
- Personal responsibility and family values
- Love v. sex
- Sexual preference
- Laws regarding sexuality
- Pregnancy, safe sex, birth control
- Etc.

The 6 Rules of Presentation:

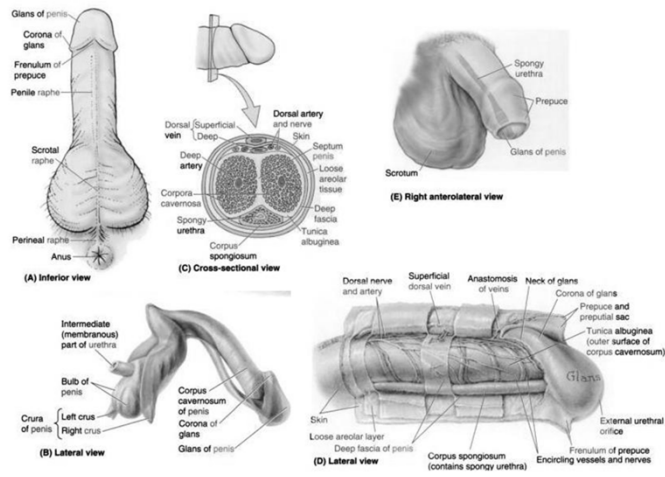
- Simple
- Visual
- Individualized
- Repetitive
- Fun
- Concrete



K.I.S.S.B.K.I.A.

(Keep It Simple Stupid But Keep It Accurate)

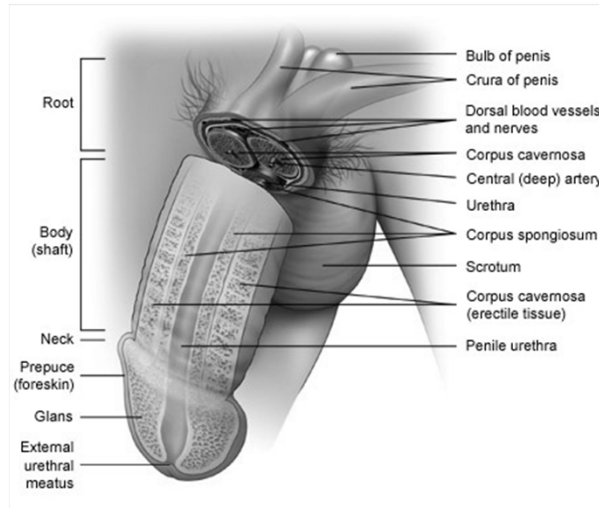
**BAD
VISUAL**



K.I.S.S.B.K.I.A.

(Keep It Simple Stupid But Keep It Accurate)

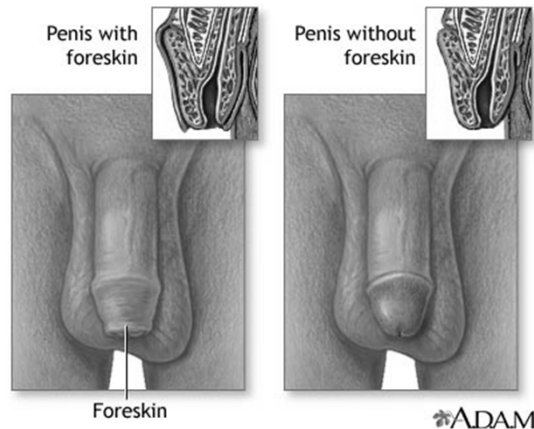
**PAINFUL
AND NOT
MUCH
BETTER**



K.I.S.S.B.K.I.A.

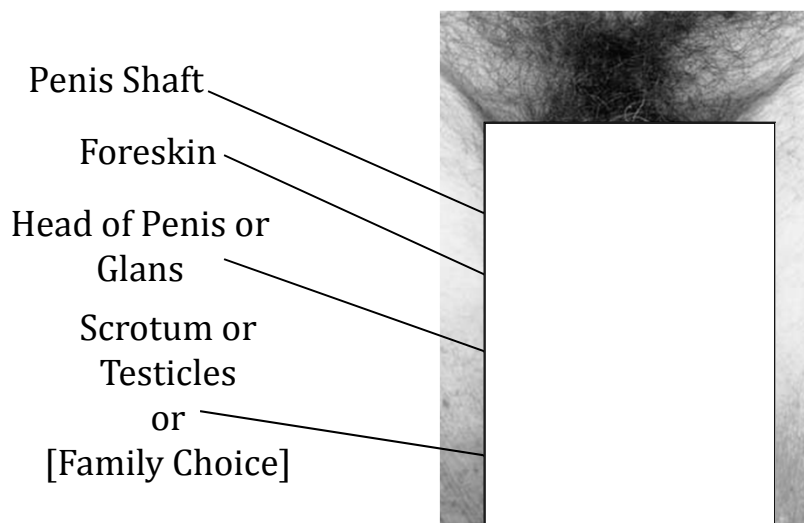
(Keep It Simple Stupid But Keep It Accurate)

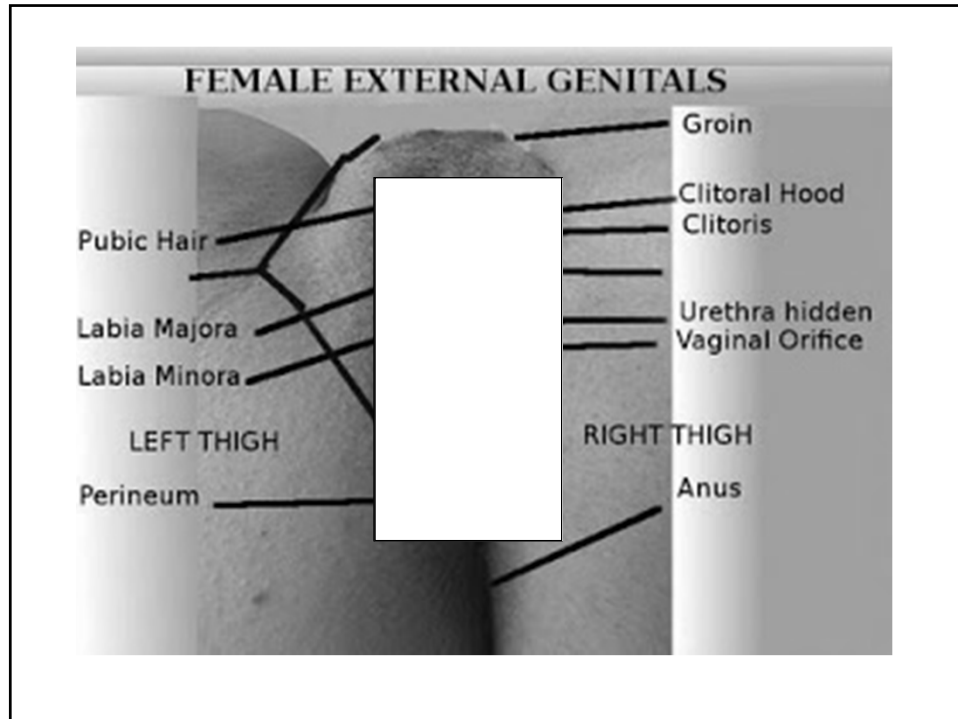
**PRETTY
DECENT**





What we would actually use





Teaching Materials

- Creating your own is easy and less costly
- Resources include:
 - Medical and nursing textbooks
 - Patient education materials
 - Sexuality education books at the library
 - Google Image search
 - Planned Parenthood
 - Homemade digital photos & videos (NOT of nudity or private activities)

Commercial products include:

- Anatomically-correct dolls
- Anatomical models of body parts
- Written materials and pictures
- Slide shows and videos

- Shop carefully-- most products were not created for people with ASD, and they are expensive



The scoop about masturbation



- Is normal and should not be condemned
- Exploration of genitals for self-pleasure begins in infancy
- Most people with autism learn to do it on their own, although some may have difficulty reaching orgasm
- Ineffective masturbation may contribute to ritualistic behaviors in some people with autism
- Masturbation may be the only realistic outlet for sexual release for some people with autism

(Ailey et al., 2003; Koller, 2000; Nehring, 2005; Volkmar & Wiesner, 2004)

Preventing problems with masturbation

- Teach where it is OK to masturbate
 - Individual's bedroom
 - Avoid teaching use of bathroom
- Teach rules for appropriate time/place
- Teach that sometimes it is not an option
- Provide opportunities for private time

(Baxley & Zendell, 2005; Koller, 2000; NICHCY, 1992; Volkmar & Wiesner, 2004)

Goals of Comprehensive Sexuality Education:

VALUES

The goal here would be to develop personal values reflective of family, religious, and cultural values in such areas as:

- Personal responsibility
- Justice
- Inclusivity
- Fairness
- Right v. wrong
- Self esteem
- Interpersonal respect
- Personal limits

“Values” intervention is somewhat external to our area of interest and expertise given that

- “Values” themselves fall into the realm of private behavior. Values themselves are difficult to define, target, and measure accurately.
- Behavior based upon values tends to require empathy which may be lacking in individuals with ASD.
- Values are generally a concern of the family and not the special educator, BCBA, etc.
- Once established, values are difficult to alter

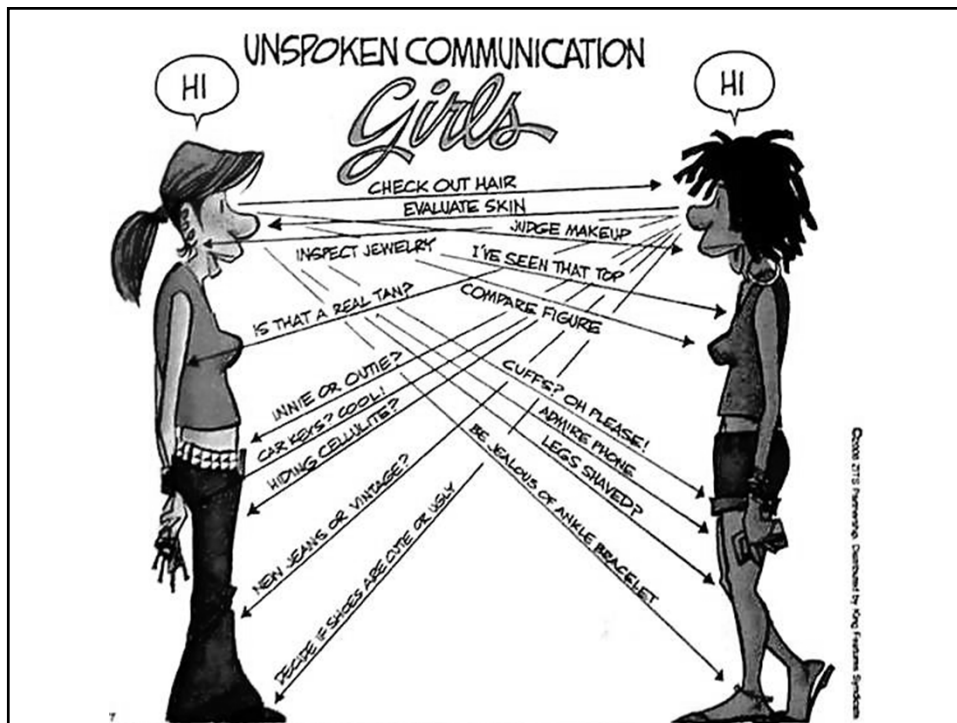
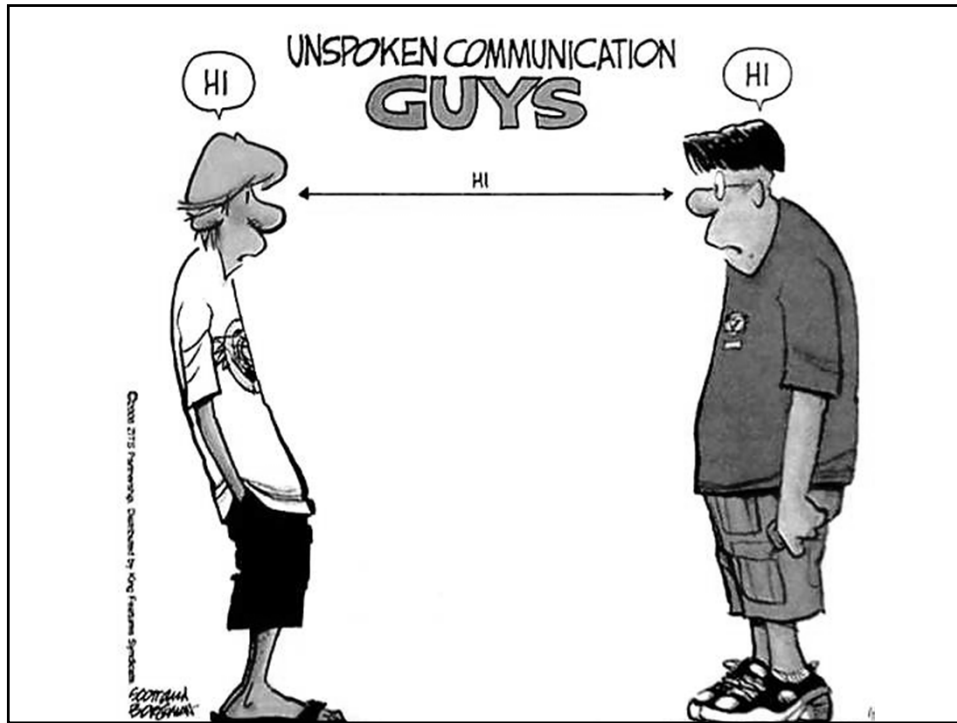
Goals of Comprehensive Sexuality Education:

SOCIAL

Promote the development of adequate and effective social repertoires inclusive of:

- Decision making skills
- Variable responding
- Advocacy skills
- Safety skills
- Dating & relationship skills
- And so much more

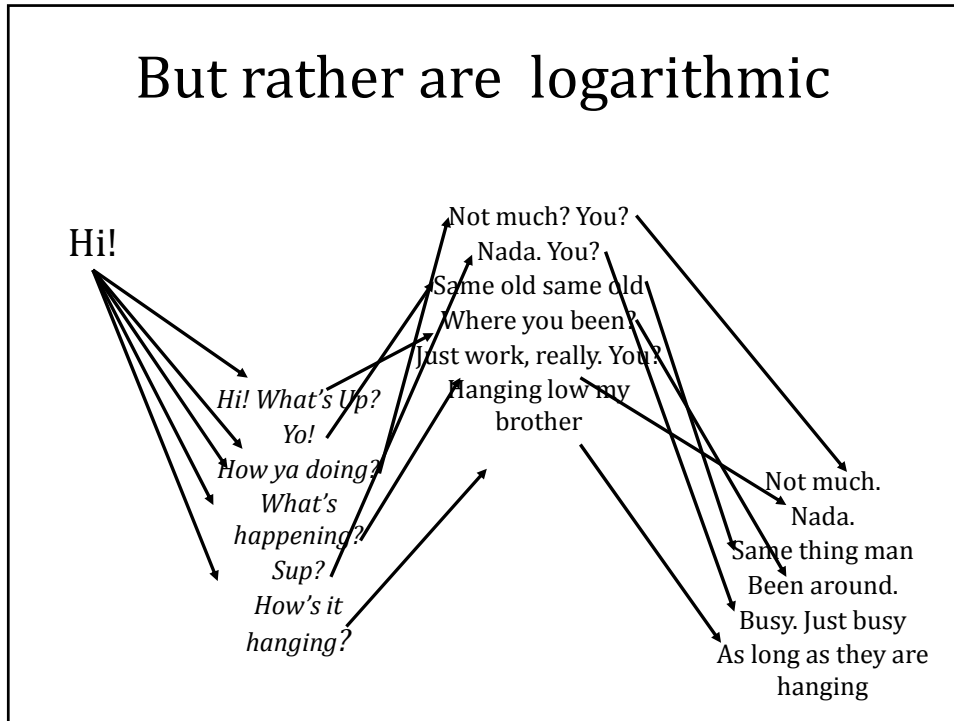
Source: NICHCY News Digest, Vol. 1(3), 1992. Available on-line at nichcy.org



One Thing Behavior Analysts Need to Understand about Social Skills

Hi! What's Not Not
 Up? Much. Much
 You?

Social Skills are NOT Linear



So remember

"A greeting is a social skill that is thought to be simple. However, further analysis shows this skill, which most take for granted, to be extremely complex. How a child greets a friend in the classroom differs from the type of greeting that would be used if the two met at the local mall. The greeting used the first time the child sees a friend differs from the greeting exchanged when they see each other 30 minutes later. Further, words and actions for greetings differ, depending on whether the child is greeting a teacher or a peer.... [G]reetings are complex, as are most social skills."

Myles & Simpson (2001)

Walton & Ingersoll (2013) note that most work on social skill interventions has been conducted with young children, and that a number of potentially effective interventions have been developed. While social skills intervention needs to begin soon after diagnosis, social skill intervention remains important across the lifespan. This is of particular importance given that the social deficits associated with ASD do not resolve with development and may, in fact, be more pronounced given the normative social repertoire of typical peers.

Watson, K.M. & Ingersoll, B.R., (2013) Improving social skills in adolescents and adults with autism and severe to profound intellectual disabilities: A review of the literature. *Journal of Autism and Developmental Disorders*. 43, 594-615

The Increasing Demands of the Social World

- Your social demands are often lowest within your home. Why? Because you set the rules of acceptable behavior.
- Your social demands at work are higher. However, work is a somewhat scripted social environment and one with a secondary measure of competence (i.e., production).



The Increasing Demands of the Social World

- ❑ Next comes the community at large. Why? Because in the community you have less control over events and actions that impact you.
- ❑ Lastly comes the world beyond your community. Whether a different social circle or different country, chances are your social skill repertoire may be less than adequate.












I LIKE TO GO OUT INTO THE
COMMUNITY AND MINGLE
WITH THE PEOPLE



The social context of urinals



The Urinal Game

| | | | | | |
|----------|---|---|---|----------|---|
| 1 | 2 | 3 | 4 | 5 | 6 |
| |  | |  | | |
| |  | |  | |  |
| |  |  |  | |  |

Self advocacy is a specialized subset of social competence



The cartoon shows a woman standing next to a signpost with three directional signs, each labeled "MY choice". She is holding a megaphone that says "INDEPENDENT ADVOCACY". A speech bubble from her says "me?". A large, jagged starburst behind her contains the text "ME!!!".

Self advocacy requires:

- 1) The ability to assess one's own skills and abilities as referenced to personal goals and the or demands of the environment
- 2) Awareness of the most efficient way to to meet these demands (e.g., accommodations)
- 3) Knowledge of their rights to these accommodations, and
- 4) The advocacy skills necessary to express their needs across multiple environments **WHILE ACKNOWLEDGING THAT SUCH SKILLS DO NOT ALWAYS WORK.**

Areas in Need of Advocacy Instruction

- Personal safety
- Leisure and recreation
- Service acquisition and choice
- Social relationships
- Sexual relationships
- Legal and civil rights
- Clothes choice, meals, bedtime, breakfast cereal, TV shows, etc.

Self advocacy instruction

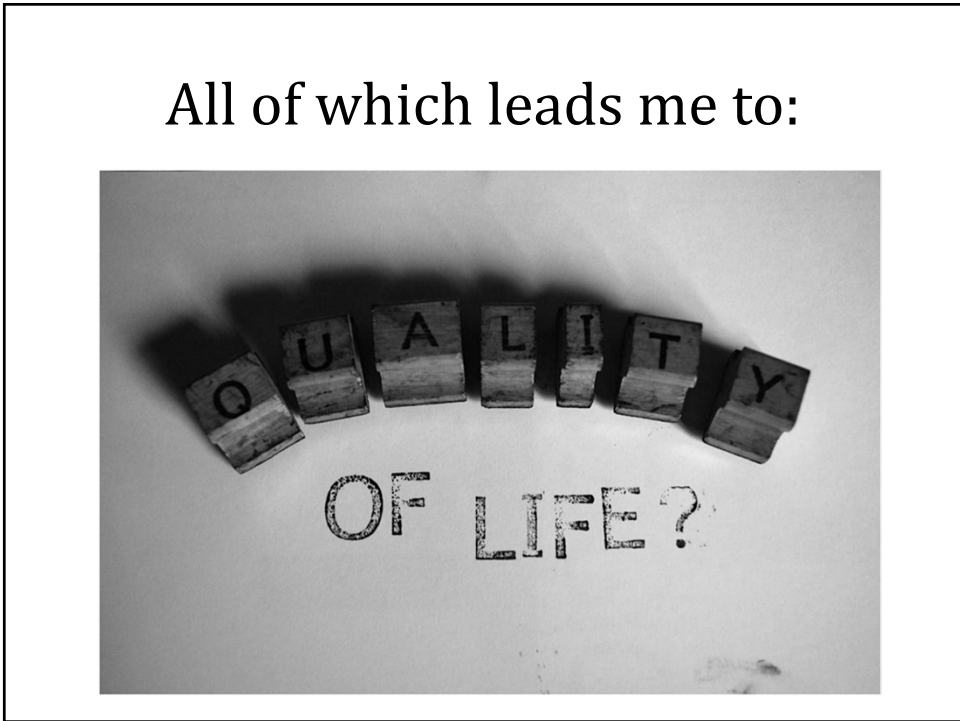
- Can be initially taught in the classroom.
- Can be taught using direct instruction, video modeling, role play, or CBT based interventions (e.g., Social Thinking).
- Is more effective if taught with a focus on individual student priorities.
- Needs to include the reality that sometimes even the best advocacy will not work.
- Needs to then be generalized to environments and events outside of the classroom

Some Poorly Understood Forms of Self Advocacy

- Aggression
- Self injury
- Disruption
- Stereotypy
- Elopement
- “Non-compliance”
- “Obsessing”
- Nagging or badgering

Functional Analysis of Social Responding

| | <i>Positive Reinforcement</i> | <i>Negative Reinforcement</i> | <i>Positive Punishment</i> | <i>Negative Punishment</i> |
|------------------------|---|---|---|-------------------------------|
| <i>Social Greeting</i> | Attention in the form of social greeting returned | Social isolation terminated? Prompting terminated? | Attention in the form of social greeting returned | Social isolation terminated |
| <i>Sharing Food</i> | Increased peer interactions (i.e, those reinforced by food. | Social isolation terminated? Prompting terminated? | Increased peer requests for food. | Removal of a quantity of food |



Top 10 Places to Live for QOL

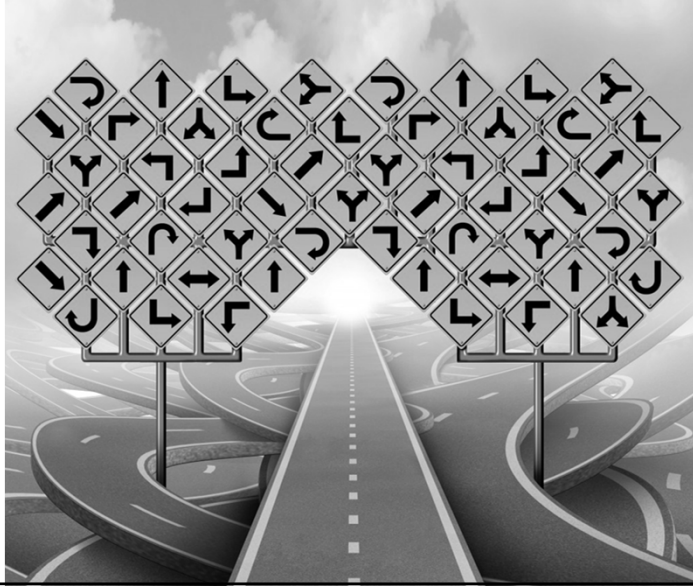
- ① Madison, Wisconsin.
- ② Lincoln, Nebraska
- ③ Minneapolis, Minnesota
- ④ St. Paul, Minnesota
- ⑤ Omaha, Nebraska
- ⑥ Buffalo, New York
- ⑦ Lexington, Kentucky
- ⑧ Lubbock, Texas
- ⑨ Fort Wayne, Indiana
- ⑩ Fremont, California

But I live here

(and wouldn't live anywhere else)



The point is, QOL is a Complex Construct



Quality of life (QOL) is a term used to describe a ***temporal condition of personal satisfaction*** with such core life conditions as physical well-being, emotional well-being, interpersonal relations, social inclusion, personal growth, material well being, self-determination, and individual rights. (Wehmeyer & Schalock, 2001)

Wehmeyer, M.L. & Schalock, R.L. (2001). Self determination and quality of life: Implications for special education services and supports. *Focus on Exceptional Children*, 33, 1-16.

But in ASD, while the concept of quality of life has been used for over 30 years in the field of intellectual disabilities, the factors contributing to quality of life of persons with ASD have received relatively little attention (Renty & Roeyers, 2006) in the literature and in practice.

Renty, J.O., & Roeyers, H. (2006). Quality of life in high-functioning adults with autism spectrum disorder: The predictive value of disability and support characteristics. *Autism*, 10, 511-524.

Much of the research on QOL and ASD has focused on a limited number of aspects of adult life (e.g., employment) and primarily on quantitative aspects of these few domains (e.g., employed v. employment satisfaction). QOL, however, is much more complex state of being (Van Heijst & Geurts, 2015).

Van Heijst, B.F.C., & Geurts, H.M ((2015). *Quality of life in autism across the lifespan: A meta-analysis*. *Autism: The International Journal of Research and Practice*, 19, 158-167.

Van Heijst & Guerts, (2015) recently completed a meta-analysis on the topic of QOL and adults with ASD. An extensive literature review **identified a total of 10 peer reviewed studies published on 2004-2012**. The results indicated that the quality of life is significantly lower for people with autism when compared to their typical peers. Age, IQ and symptom severity did not predict quality of life in this sample. Across the lifespan, people with autism experience a much lower quality of life compared to people without autism.

Van Heijst, B.F.C., & Geurts, H.M ((2015). *Quality of life in autism across the lifespan: A meta-analysis*. *Autism: The International Journal of Research and Practice*, **19**, 158-167.

However...

Parsons (2015) conducted an online survey designed to solicit the views of adults with ASD about current life satisfaction. Fifty-five respondents, most of whom attended mainstream schools and were diagnosed later in life, completed the survey. Respondents were least satisfied with their current employment situation and most satisfied with personal relationships. There was substantial individual variation in responses demonstrating the importance of respecting personal views, circumstances and aspirations. This is significant as little is known about the actual views of adults with ASD on QOL and that, in general, "good outcomes" in adult life are often judged according to normative assumptions of quality.

Parsons, S., (2015). *"Why Are We an Ignored Group?" Mainstream Educational Experiences and Current Life Satisfaction of Adults on the Autism Spectrum from an Online Survey*. *International Journal of Inclusive Education*. **19**, 397-

421

This is sometimes referred to as the “Disability Paradox”

The disability paradox (Levine,1987), states: “*Why do many people with serious and persistent disabilities report that they experience a good or excellent quality of life when to most external observers these individuals seem to live an undesirable daily existence?*” To examine its parameters, Albrecht & Devlieger (1999) interviewed 153 persons with disabilities and 54% with significant disabilities reported having an excellent or good QOL (i.e, disability paradox). Analysis of the interviews indicates that quality of life was associated with finding a balance between body, mind and spirit and on establishing and maintaining a positive relationship with the person's social context and external environment.

Albrecht, G. & Devlieger, P., (1999). The disability paradox: High quality of life against all odd. *Social Science and Medicine*. 48, 977-988.

So in summary

We are just beginning to understand what it means to be an adult with autism within the context of quality of life, directed habilitation, personal freedom, and safety. This complex understanding of adulthood now needs to be the goal of all the behavior analytic intervention across an individual's life. With that we, as behavior analysts, need to get increasingly competent working the post-school environment where services are underfunded and understaffed, and needs are really complicated. Sexuality is one of the more complex aspects adulthood but, if we are serious about the ability of our science to produce socially significant outcomes, it simply becomes another challenge to overcome.

A few recommendations going forward

#1

Focus on Choice/Decision Making Skills



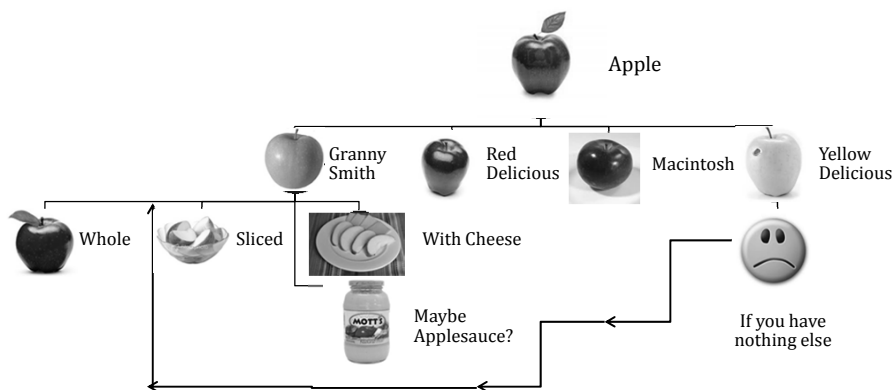
Effective choice making is central to many of the competencies of adulthood. However, most of us master simple either/or choices pretty early in life.



VS



But even most simple choices are less simple than you think. For example:
“Would you like an apple?”



#2

Teach Resilience as Part of Problem Solving*

(*or, as a behavior analyst, behavioral cusps that are resistance to extinction)

Resilience is an individual's ability to properly adapt to stress and adversity. Resilient behavior develops over time and is composed of a variety of factors which prescribe the manner in which we respond to challenges. Behavioral competencies associated with resilience include:

- Perseverance, or the ability to continue with the behavior in question in the absence of high rates of positive reinforcement.
- Flexibility, or the ability to generate new strategies to solve a particular problem.
- A learning history that has included error identification and correction as a specific instructional goal (i.e., problem solving)
- The ability to manage impulsive behavior and/or ignore environmental distractors

Problem Solving

In an attempt to identify factors that may contribute to improving outcomes for individuals with ASD in college programs Giaquinto, (2015) surveyed 40 young adults ages 18-26 across 4 college campuses in order to investigate correlations between mindfulness, social problem solving, social anxiety and Quality of Life. Predictive relationships among social anxiety and Quality of Life were also examined. **Results indicated Positive Problem Orientation to social problem solving was a predictor of [high] psychological Quality of Life scores. Students reported higher physical Quality of Life scores than did their parents.**

Giaquinto, M. B. (2015). Mindfulness, social problem solving, social anxiety and quality of life in college students with autism spectrum disorders. *Dissertation Abstracts International Section A: Humanities and Social Sciences*, 75(10-A(E)). (UMI No. AAI3622265)

#3

Train the Typical

“If you neurotypicals have all the skills, why don’t you adapt for a while dammit! Why is it always me fault?”

Donna Vickers

Knowledge can be Powerful!

“... under appropriate conditions interpersonal contact is one of the most effective ways to reduce prejudice between majority and minority group members.” (Alpert, 1954)

A corollary to #3

Consider Assessing Social Validity

Social Validity refers to the acceptability of, and satisfaction with, intervention procedures, usually assessed by soliciting opinions from the people who receive and implement them. Intervention procedures for child [and adult] behavior are socially valid when people judge them as being acceptable. (Luiselli & Reed, 2011)

Luiselli, J.K., Reed, D.D., (2011). Social Validity, in S. Goldstein & J. Naglieri (Eds). Encyclopedia of Child Behavior and Development. Pp. 1406. New York: Springer.

#4

Teach the right skills in the right context (i.e., where the behavior is most likely to be displayed.

What you do
EVERY DAY
matters more than
what you do
ONCE IN A WHILE.

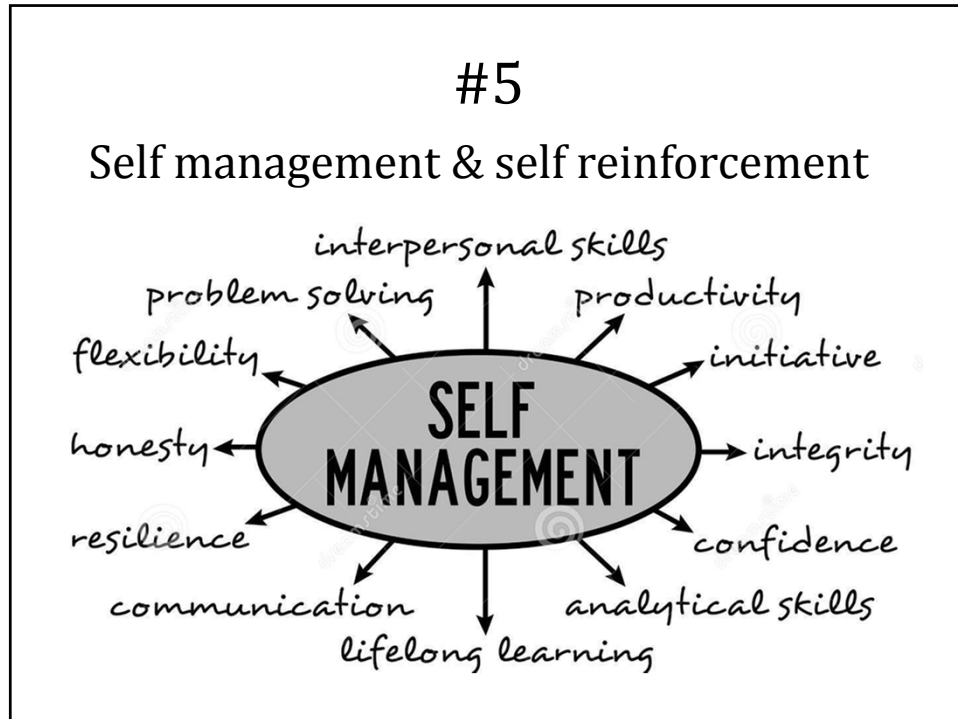
– Gretchen Rubin



Gretchen Rubin is the author of "*Better than Before*" and "*The Happiness Project*" among other best-selling publications.

What you do every day might include

- | | |
|----------------------------------|--------------------------------|
| 1. Wake to alarm clock | 14. Get the mail |
| 2. Morning routine | 15. Unlock the door. |
| 1. Shower, dress, hygiene, etc. | 16. Change out of work clothes |
| 3. Coffee/Breakfast | 17. Get something to eat |
| 4. Remember keys & lock door | 18. ADLs |
| 5. Get to work somehow | 19. Prepare dinner and eat |
| 6. Follow verbal/written prompts | 20. Clean up. Use dishwasher |
| 7. Use restroom | 21. Go on-line |
| 8. Take a break | 22. Home/Office work |
| 9. Purchase and eat lunch | 23. Shower |
| 10. Fix mistakes | 24. Prep for bed inc. meds |
| 11. Ask for help | 25. Review next day schedule |
| 12. Use computer/smart phone | 26. Set alarm clock |
| 13. Get home somehow | 27. Sleep |



#6

Access Technology Supports

Technology, whether low tech or high tech, is part of the world as we know and is changing the lives of individuals with ASD. From assistive communication technology on an I-Pad, to GPS tracking, to Apple Pay, to self driving cars, and to instruction via virtual reality we really have only scratched the surface in terms of technology's potential.

Please do not limit you, or your student, to “special needs” apps. Many of the most useful apps are designed for the general population. This might include apps that allow you to purchase without using money, let you know what bus to take where and it’s schedule, identify appropriate clothing as a function of the weather report, or walk safely from Point A to Point B following a map and verbal directions. For many adolescents and adults with ASD, the question is not, “Do they need some form of tech support?” but rather “What form of tech support do they need?” (Gerhardt & Glickman, 2016).

Gerhardt, P.F., & Glickman, A., (2016). *Hi-tech visual supports for adolescents and adults with ASD*. In M. Cohen & P. Gerhardt (Eds). Visual Supports for People with Autism: A Guide to Parents and Professionals. (pp. 143-153). Bethesda, MD: Woodbine House.

#7

Risk is Part of Life

Risks threatens things that we value. What we do about them depends on the options we have, the outcomes we value, and our beliefs about the outcomes we value that might follow contingent on each option we may choose. The outcomes can be certain or uncertain and our choices simple or complex. (Fischhoff & Kadvany, 2011) Risk, it seems, is unavoidable. However ignoring risk, under the guise of safety, would only seem to invite greater risk for the individual in question.

(Fischhoff, B., & Kadvany, J. (2011). *Risk: A Very Short Introduction*. New York: Oxford University Press

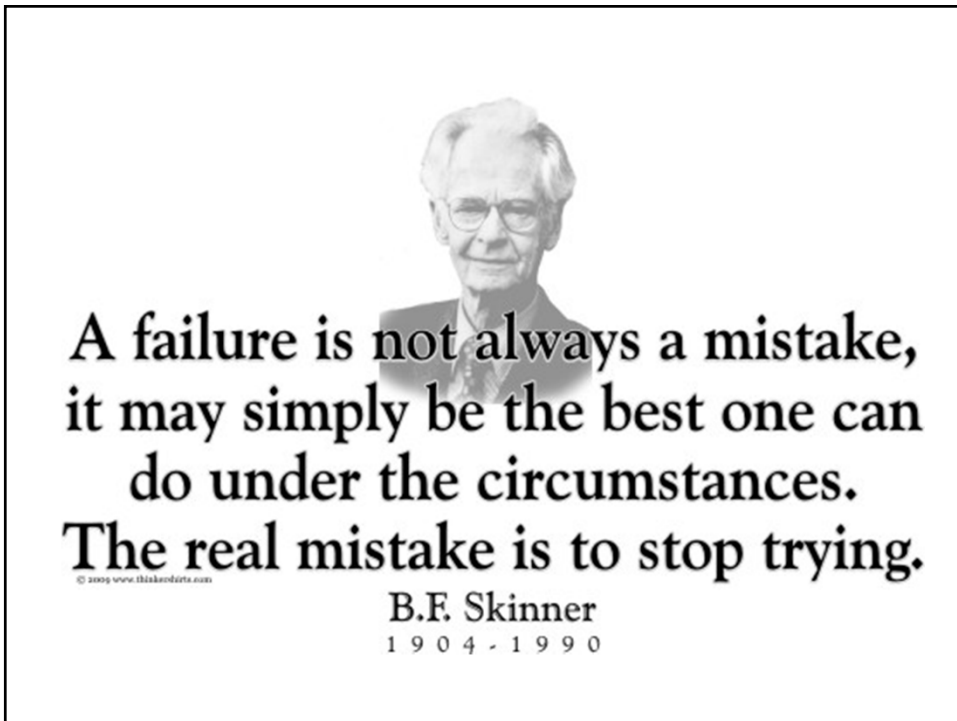
Most Studied Risk Factors for Cancer

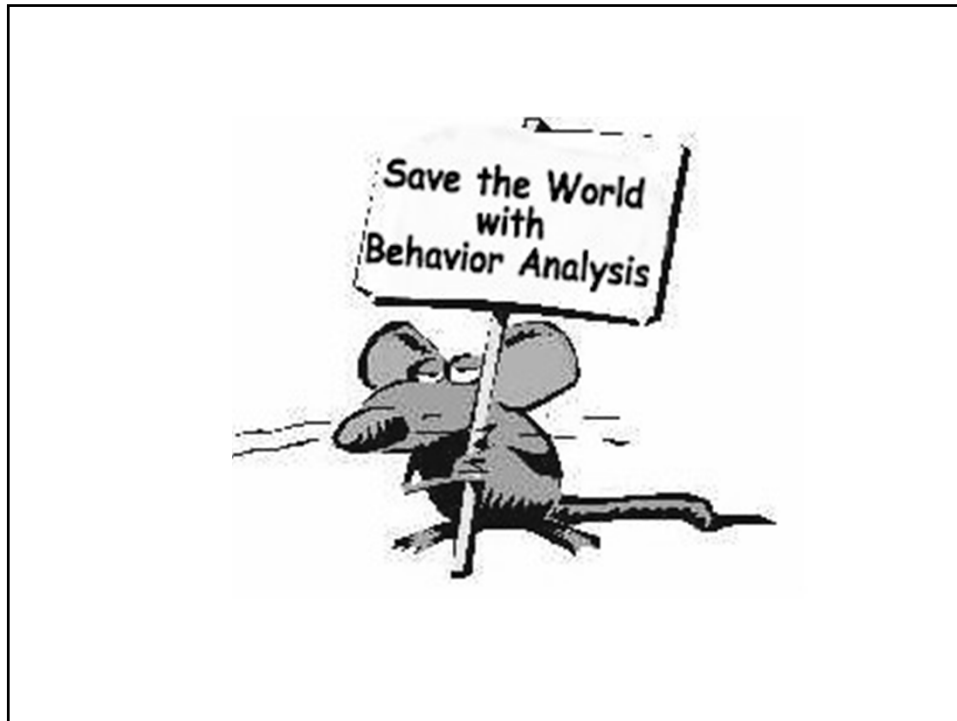
- Growing older
- Tobacco
- Sunlight
- Ionizing radiation
- Certain chemicals and other substances
- Some viruses and bacteria
- Certain hormones
- Family history of cancer
- Alcohol
- Poor diet, lack of physical activity, or being overweight

Source: National Cancer Institute. Accessed June, 2016 at:
<http://www.cancer.gov/about-cancer/causes-prevention/risk>

Risk means that life is not perfect

- A recent study found that 15% of men & 7% of women didn't wash their hands at a public restroom. When they did wash their hands, only 50% of men used soap, compared to 78% of women. Only 5% who washed their hands scrubbed long enough to kill germs that can cause infections.
- In a recent study on casual sex during spring break, researchers found that 15% of men and 13% of women had sex with someone they just met. Further 77% of college-age women and 83% of men reported having had casual sex at least once.
- National Research Council of the US and the Institute of Medicine:
 - 39% of all sexually active U.S. high school students did not use a condom at last intercourse.
 - 6% of all U.S. high school students had sexual intercourse before age 13.1
 - Almost 14% of all U.S. high school students have had sexual intercourse with 4 or more partners.
 - Although data are limited on sexual behaviors of middle school students it does appear that approximately 20% of have had sexual intercourse.
- Errors and mistakes happen all the time. The trick is minimize big mistakes while accepting a certain, "non-dangerous" error level. So is competence to be average? Better than average? What? Be aware of risk, make reasonable attempts to control risk, but accept some level of risk.





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