Sexuality Education And Individuals with ASD: What Parents and Professionals Need to Know.

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The handouts from todays talk will be available on the EPIC School website as downloadable PDF files:

www.epicschool.org

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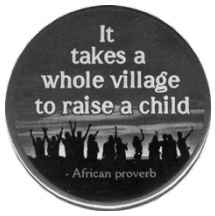
Sometimes I think I am an autism professional who works in field of applied behavior analysis. At other times I think I am a behavior analyst who works in autism. The truth is that I am both.

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.

But beyond that we all know



But to raise a child with ASD to be an employed, included, safe, and productive adult takes something like a village, 2 small towns, a mid-sized city, a chapter of the Hells Angels, half a dozen communes, a large trailer park, an on-call medical team, and a fleet of vehicles.

My point is that as individuals grow up, their needs become increasing complex IF, AND ONLY IF, we truly recognize them as being newly formed adults.

But this is complicated by our, well, ignorance of the issues.

- Shattuck, et al, (2012) conducted a comprehensive literature review regarding original research on services and interventions aimed at supporting success in work, education, independence, and social participation among adults aged 18 and older with an ASD published between 2000 and 2010.
- They concluded that the evidence base about services for adults with an **ASD *is underdeveloped and can be considered a field of inquiry that is relatively unformed.***

Shattuck, P., et al, (2012). Services for adults with autism spectrum disorders. *Canadian Journal of Psychiatry*, 57, 284-291.

All of which leads me to be both incredibly optimistic and terribly discouraged about the future of adults with ASD. I am discouraged about the level of in-fighting within the autism community that holds us back. I am discouraged by the fact that most people confuse isolation for safety when being included in your own community actually increases safety. I am discouraged that we are all afraid of mistakes yet, without mistakes, learning is nearly impossible. I am discouraged that ABA is still misunderstood as consisting of DTI implemented with 1:1 staffing when ABA is HUGE field. I am discouraged that all people want to talk about are the deficits associated with having ASD when the strengths are much more interesting and useful. And that's just to start…

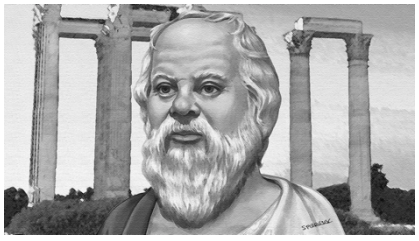
On the flip side

I am incredibly optimistic about the future of adults with ASD. I am optimistic as there is a generation of parents that refuse to accept second class citizenship for their son or daughter. I am optimistic as researchers are finally understanding the needs of adults with ASD as as important topics. I am optimistic as technology is increasing the possibilities for adults with ASD across the lifespan. I am optimistic as increasing numbers of professional are discovering just interesting and challenging working with older individuals can be. I am optimistic as the field of Behavior Analysis is starting to address larger issues such as quality of life, happiness, community inclusion, and complex decision making skills. I am optimistic as ASD is no longer a "mysterious" disorder but rather the someone down the street. And that's just to start…

Quality of Life

Quality of Life is Not a New Concept

Not life, but good life, is to be chiefly valued.
Socrates (469 BC - 399 BC)



The WHO has defined QOL as…

The individual's perception of his or her position in life ***in the context of the culture and value system, and in relation to one's goals, expectations, standards and concerns***. It incorporates the individual's physical health, psychological state, level of independence, social relationships, personal beliefs and his or her relationship to salient features of the environment in a complex way. (*The World Health Organization*, 1995)

World Health Organization (WHO) (1995) *World Health Organization Quality of Life Assessment (WHOQOL): position paper from the World Health Organization*. Social Science & Medicine 41: 1403–1409.

But a more useful definition is…

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.

Although 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 autism spectrum disorder 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: The International Journal of Research and Practice,* **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.FC., & 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.FC., & 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.

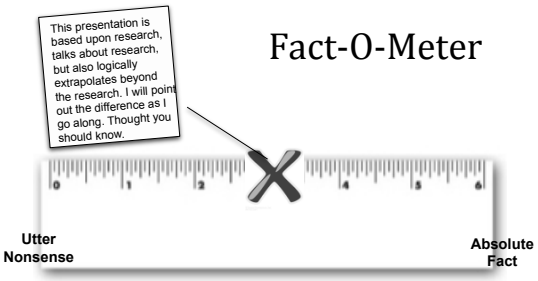
Parsons, S., (2015). *"Why Are We an Ignored Group?" Mainstream Educational Experiences and Current Life Satisfaction of Adults on the Autism Spectrum from an Online Survey.* International Journal of Inclusive Education. **19,** 397-421

Why is this so challenging?

- There may be many reasons including:
  - Conflicting definitions of QOL held by the individual with ASD, their family & the related professionals and the resulting disagreement as to whose voice should determining QOL?
  - QOL is temporal and highly individualized construct.
  - Limited fiscal and programmatic resources to implement necessary interventions or supports.
  - An over-emphasis on the deficits associated with ASD rather than the individual competencies displayed by those on the spectrum.
  - Fear of RISK and the potential for "bad" decisions on the part of individuals with ASD.
  - Low societal value placed on true quality services

Sexuality

Fact-O-Meter



A couple of quick points before we dive into this

1

Independent of how evidence-based your interventions are, teaching the wrong skills well is no better than teaching the right skills poorly

2

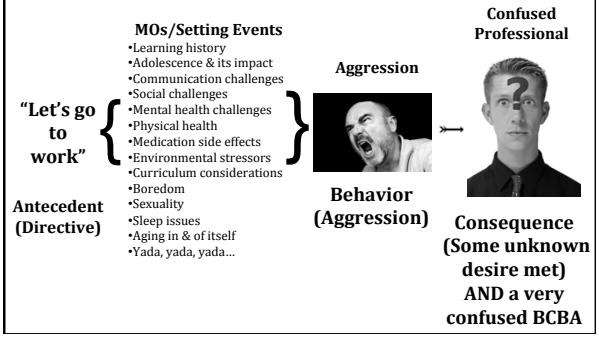
We really should be successful in our classrooms and clinics as we control almost every variable. The real test of our interventions is how successful we are outside of these environments.

3

Adults with ASD are not just little kids in big bodies. They are actual adults. Now, I know we all say that but very few of us behave in way that reflects that knowledge.

3-A

All adolescents and adults are complex



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You need to download and read this article.

JOURNAL OF APPLIED BEHAVIOR ANALYSIS 1990, 23, 79–89 NUMBER 1 (SPRING 1990)

BALANCING THE RIGHT TO HABILITATION WITH THE RIGHT TO PERSONAL LIBERTIES: THE RIGHTS OF PEOPLE WITH DEVELOPMENTAL DISABILITIES TO EAT TOO MANY DOUGHNUTS AND TAKE A NAP

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UNIVERSITY OF KANSAS

In the pursuit of efficient habilitation, many service providers exercise a great deal of control over the lives of clients with developmental disabilities. For example, service providers often choose the client's habilitative goals, determine the daily schedule, and regulate access to preferred activities. This paper examines the advantages and disadvantages of allowing clients to exercise personal liberties, such as the right to choose and refuse daily activities. On one hand, poor choices on the part of the client could hinder habilitation. On the other hand, moral and legal issues arise when clients are not allowed to exercise liberties. Recommendations are offered to protect both the right to habilitation and the freedom to choose.

DESCRIPTORS: developmentally disabled, ethics, client rights, choice behavior, manually recorded

Is the pursuit of efficient habilitation, many service providers exercise a great deal of control over the lives of clients with developmental disabilities (Gorte, Bennett, & Siegel-Causey, 1985; Kishi, Teshcknigh, Zollers, Park-Lee, & Meyer, 1988; Turnbull & Turnbull, 1985). Service providers often choose the client's habilitative goals, choose their work or day treatment setting, impose inflexible daily activity schedules, and regulate access to preferred activities. The choices made by the service provider may indeed promote habilitation, but these choices may not reflect the client's preferences. The purpose of this paper is to discuss the relation between the right to habilitation and the client's right to personal liberties. The following questions will be addressed: What does the "right to habilitation" mean for people with developmental disabilities? What are personal liberties? What are the advantages and disadvantages of allowing citizens with developmental disabilities to exercise their personal liberties? How might service providers better protect both the right to habilitation and the freedom to choose?

THE RIGHT TO HABILITATION

Habilitation involves teaching the skills needed to live as independently as possible (Favell, Favell, Riddle, & Risley, 1984). A long history of inadequate services for people with developmental disabilities has been the impetus for numerous class action suits and legislative reforms guaranteeing these citizens a general right to habilitation. In the most well known of the class action suits, *Wyatt v. Stickney* (1971, 1972, 1975), an Alabama court (and subsequently the Fifth Circuit Federal Court) determined that citizens with mental retardation have a "right to receive such individual habilitation as will give each of them a realistic opportunity to lead a more useful and meaningful life and to return to society" (*Wyatt v. Stickney*, 1975, p. 397). On the basis of this ruling, the court set minimum standards that included individualized habilitation plans, a humane physical environment, and assurance of enough qualified staff to administer adequate treatment (*Wyatt v. Stickney*, 1975, p. 395). Despite the Wyatt court's determined efforts to upgrade the standards for treatment, a constitutional right to habilitation has not yet been established. In fact, in a recent Supreme Court case, *Youngberg v. Romeo* (1982), the Court guaranteed only as much habilitation as needed to ensure freedom from undue restraint.

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As a general rule of thumb about 60% of sexuality education should be at home, about 37% can be done in the context of the school and, when necessary, about 3% by specialists. But I sort of just made that up

Basically, sex and sexuality are just socially constrained components 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).

Adaptive behavior is not considered one of the core symptoms of ASD and, as such, receives significantly less attention in terms of effective intervention and current research.

Adult outcomes can, at least in part, be seen be seen as a function of adaptive behavior competencies (Mazefsky, Williams, & Minshew, 2008). It is not an overstatement to say that adaptive behavior competencies will get you through times of no academic skills better that academic skills will get you through times of no adaptive behavior competencies

Matson, Rivet, Fodstad, Dempsey, & Boisjoli, (2009) evaluated 337 adults using the Vineland Adaptive Behavior Scale to assess the differential impact of having 1) an Intellectual Disability (ID), 2) an ID plus ASD, or 3) an ID, ASD, and an Axis I mental health diagnosis. **Adaptive skills were greatest for the ID group followed by the ID plus ASD, and ID and ASD plus psychopathology. Thus, the greater the complexity of diagnoses, the greater the skills deficits observed [ ]**.

Matson, Hattier, & Belva, (2012) noted that work, self-help, leisure, and hygiene skill deficits are often associated with a diagnosis on the autism spectrum. A number of interventions have been established to assist individuals with these impairments the most effective of which are interventions based upon applied behavior analysis (ABA)

Further…

- While all ADL skills are adaptive behavior not all adaptive behavior skills are ADLs.
- Adaptive behavior competencies are more complicated than inferential calculus.
- Adaptive behavior competencies involve both simple and complex decision making skills
- Adaptive behavior skills are not always highly preferred skills (e.g. tooth brushing) but, then again, some are (leisure skills).

Adaptive behavior is important because the world doesn't always play by the rules

And with some undesirable consequences at times

Many bowling alleys and restaurants have ice in the urinals to keep them fresh so it is important to let kids know never to eat ice they find in the bathroom.

Adaptive behavior intervention needs to start much earlier than is the current case.

Adaptive Skills (chores) that typical children can do.

AGE	CHORE
2-4 year olds	Help dust, Put napkins on table, Put laundry in hamper, Help feed pet
4-7 year olds	Set (or help set) the table, Put away toys, Help make bed, Help put dishes in dishwasher, Help clear table, Help put away groceries, Water the garden
8-10 year olds	Make bed, Set & clear table, Dust, Vacuum, Help wash car, Help wash dishes, Take out the trash
11 year olds and older	Above chores plus clean room, Mow lawn, Feed pets, Start doing own laundry, Make small meals, Shovel snow, Help with yard work, Empty and load dishwasher, etc.

Some of the work we are doing in understanding and teaching adaptive behavior

What defines a critical adaptive behavior target?

- Any skill that, when acquired, enables the individual to independently complete a variety of relevant tasks and engage in desired activities, AND
- Any skill that is used with sufficient frequency to remain in the individual's repertoire. The exception here are safety skills which, ideally, are low response frequency skills AND
- Any skill that can be acquired within a reasonable time frame*.

FREQUENCY OF USE

	Objective	≥ 1X/day	1X/day	2-3X/Wk	1X/Wk	1-2X/Mnt	Less Frequent	Importance* 0-2
1	*"When is your birthday?"*						X	0
2	*"Where do you live?"*						X	2
3	*Wiping after BM*	X						2
4	*Make a meal with recipe*				X			1
5	*Make meal with Microwave*			X				2

0 = Not Important; 1= Maybe important but not essential; 2 = Important

Adaptive Behavior Intervention

The parameters of effective intervention in adaptive behavior would appear to include:

1. ***Context*** – Where instruction takes place
2. ***Intensity*** – How often instruction takes place
3. ***Efficiency*** – What is the response effort/ equivalence associated with instruction
4. ***Transfer of control*** – Where does stimulus control lie
5. ***Value*** – Why might this skill be important to the student

Context

- The primary rule in the provision of effective adaptive behavior instruction is, "Teach where the behavior is most likely to be displayed." It has been long documented that most individuals with autism do not independently generalize skills to new environments or maintain skills that are of little use in their primary environments. This again highlights the importance of context as an instructional variable.
- Further, even the youngest individuals in transition will remain in a classroom environment for, at most, the next 7 years. Upon graduation, however, they will never again be in a similar environment and, instead, must be prepared with skills and competencies that work in the environments where they will spend the rest of their lives (i.e., their neighborhoods, communities of faith, home, etc.)

Intensity

- Intensity refers to the rate of instruction across a given time period; day, week, or month.
- There is an extremely large body of research supporting that fact that a certain level of intensity is required if skill mastery is to be demonstrated with all of us.

Intensity

- By way of example, consider the 5-year old with ASD who required 1,000 trials (50 sets of 20 trials) of color identification to consistently identify all 64 colors in the Crayola box across all teachers and all environments.
- Now take the same child at age 15 with the goal being that of buying lunch at Burger King. If he is provided 1(one) instructional opportunity (i.e., trial)/week, it will take more than 15 years to provide the 1,000 trials that were necessary to acquire a relatively simple discrimination skill (color ID).
- As such, a lack of skill acquisition is often not a function of learning ability but rather insufficient intensity within our instructional protocols.

Efficiency

- Directly related to both skill generalization and maintenance is response effort and equivalence. *This combination constitutes response efficiency which is the ease with which a task (desirable or not) can be accurately accomplished.*
- Incorporating the concept of response efficiency in instructional programming can be illustrated by the example below on cell phone use.
  - As a function of functioning level, different response efficient interventions may include:
    - *Teaching to initiate calling, dial numbers from memory, or look up in the relevant directory, or;*
    - *Teaching to dial by finding a familiar face or icon in the phone's contact directory, or;*
    - *Teaching to dial by pressing a single face or icon, out of a small number of such, on the phone's home screen, or;*
    - *Teaching simply to retain phone with him/her to allow for answering of the phone and, as appropriate, GPS monitoring.*

Transfer of Control

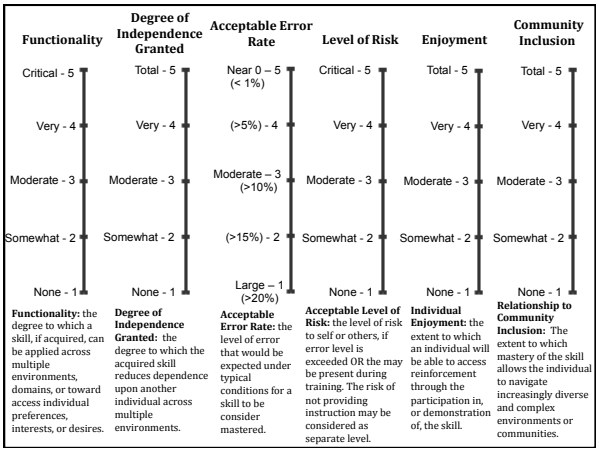
- A general goal of many ABA-based programs is for teachers to demonstrate stimulus control over their students and classroom.
- However, the ultimate goal of any transition program is to transfer such control from the teacher to both the environment (e.g., stop at the red light) and the individual themselves (e.g., via self management).
- Pragmatically, as individuals age and move from a ratio of 1:1 instructional support to, at best, a ratio of 4:1, the importance of transfer of control rapidly becomes clear.

Value

- Skills that are of great value (i.e., highly preferred, have significant functional utility or provide access to R+) to the individual tend to be skills that, once acquired, are maintained over time with little additional intervention.
- Conversely, skills that are of little value generally require significant instructional intensity both during skill acquisition and maintenance phases.
- Any effective and appropriate program of intervention needs to combine both high-value and low-value targets in such a way as to support engagement, competence, maintenance, enjoyment, and personal safety.

Using the following definitions

- **Functionality:** the degree to which a skill, if acquired, can be applied across multiple environments, domains, or toward access individual preferences, interests, or desires.
- **Degree of Independence Granted:** the degree to which the acquired skill reduces dependence upon another individual across multiple environments.
- **Acceptable Error Rate:** the level of error that would be expected under typical conditions for a skill to be consider mastered.
- **Acceptable Level of Risk:** the level of risk to self or others, if error level is exceeded OR the may be present during training.
- **Individual Enjoyment:** the extent to which an individual will be able to access reinforcement through the participation in, or demonstration of, the skill.
- **Relationship to Community Inclusion:** The extent to which mastery of the skill allows the individual to navigate increasingly diverse and complex environments or communities.



Method

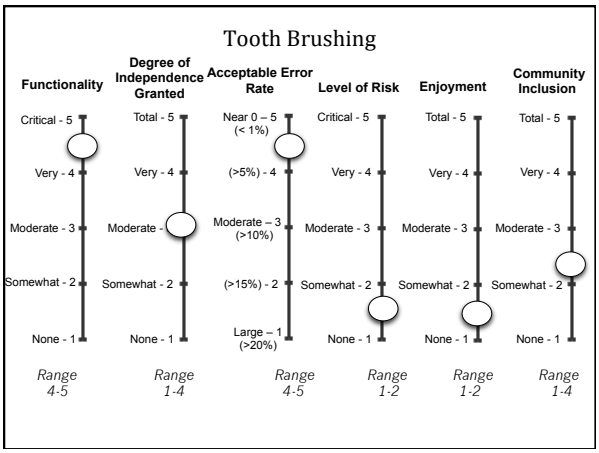
- An on-line survey was distributed via Survey Monkey to 60 educators and behavior analysts working at a behaviorally based school in NYC.
- Respondents were asked to use the Functionality Index (FI) to score 8 instructional goals randomly selected from an existing IEP developed for a 17 year old man with autism with an intellectual disability

Rated IEP Goals

- Tooth brushing
- Sight words
- Street Crossing
- Reading for information
- Math facts – Addition & Subtraction
- Using a Credit/Debit Card
- Playing a video game
- Sorting by categories

Results

- Of the 60 surveys, 33 were returned. Of these, four were considered unusable as they were incomplete leaving 29 usable responses.
- Rankings were totaled for each IEP goal and the averages were plotted on the FI. Results are presented in the following slides.


Tooth Brushing
Functionality
Degree of Independence Granted
Acceptable Error Rate
Level of Risk
Enjoyment
Community Inclusion
Critical - 5
Very - 4
Moderate - 3
Somewhat - 2
None - 1
Total - 5
Very - 4
Moderate -
Somewhat - 2
None - 1
Near 0 – 5 (< 1%)
(>5%) - 4
Moderate – 3 (>10%)
(>15%) - 2
Large – 1 (>20%)
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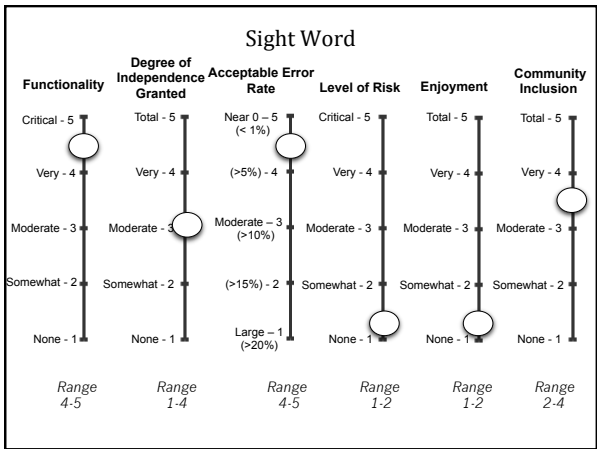
Range 1-4


Sight Word
Functionality
Degree of Independence Granted
Acceptable Error Rate
Level of Risk
Enjoyment
Community Inclusion
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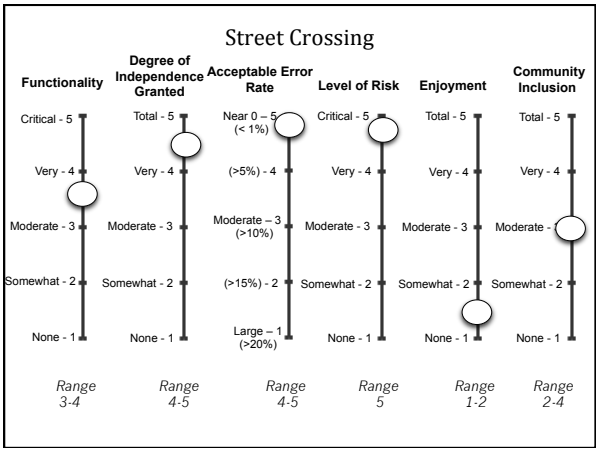
Street Crossing
Functionality
Degree of Independence Granted
Acceptable Error Rate
Level of Risk
Enjoyment
Community Inclusion
Critical - 5
Very - 4
Moderate - 3
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Range 3-4
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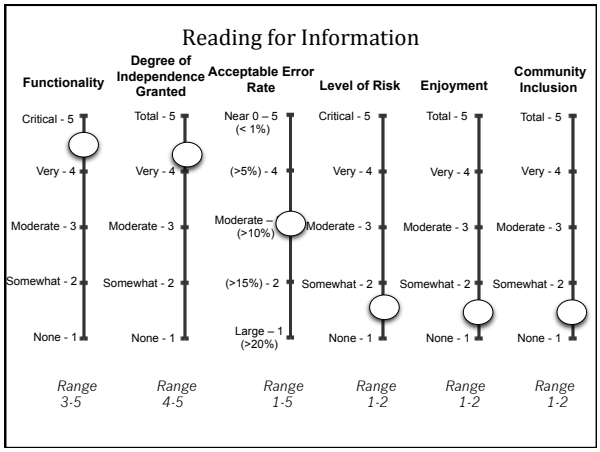
Range 5
Range 1-2
Range 2-4


Reading for Information
Functionality
Degree of Independence Granted
Acceptable Error Rate
Level of Risk
Enjoyment
Community Inclusion
Critical - 5
Very - 4
Moderate - 3
Somewhat - 2
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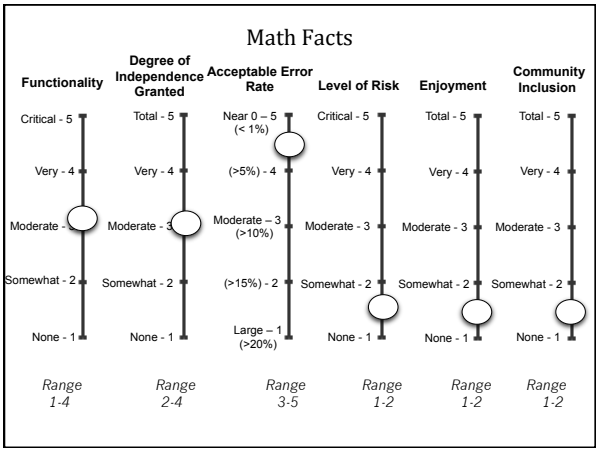
Math Facts
Functionality
Degree of Independence Granted
Acceptable Error Rate
Level of Risk
Enjoyment
Community Inclusion
Critical - 5
Very - 4
Moderate -
Somewhat - 2
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Range 3-5
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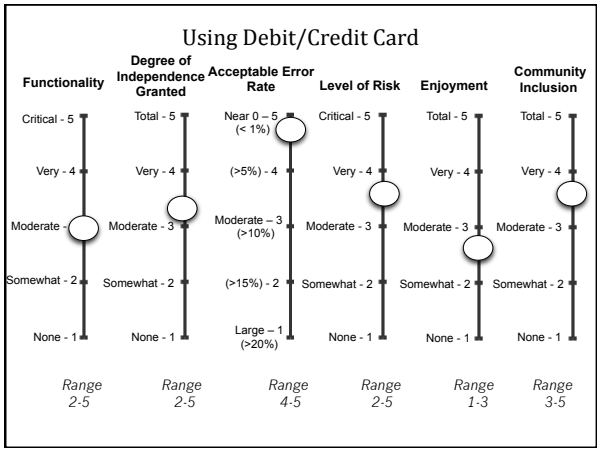
Range 1-2


Using Debit/Credit Card
Functionality
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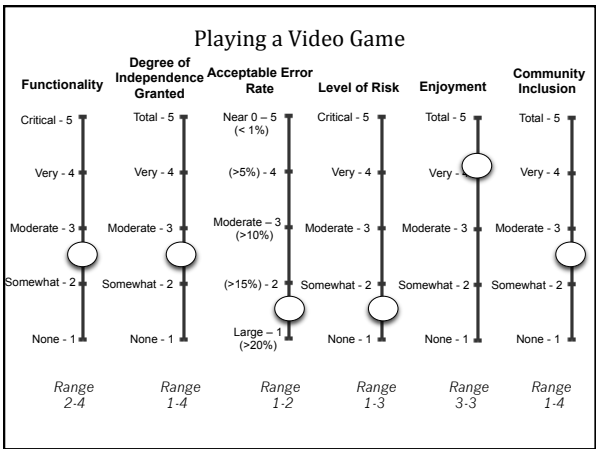
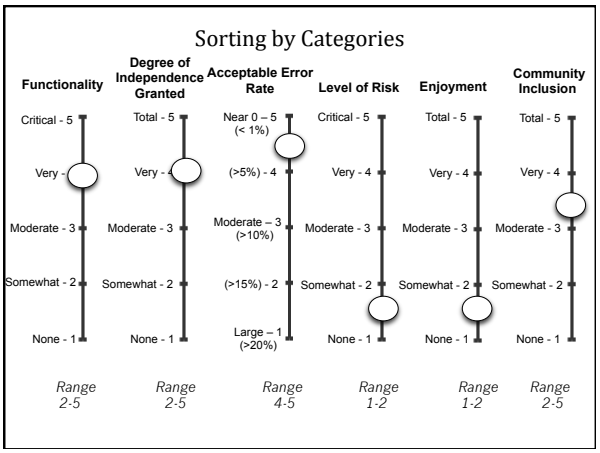
Enjoyment
Community Inclusion
Critical - 5
Very - 4
Moderate -
Somewhat - 2
None - 1
Total - 5
Very - 4
Moderate - 3
Somewhat - 2
None - 1
Near 0 – 5 (< 1%)
(>5%) - 4
Moderate – 3 (>10%)
(>15%) - 2
Large – 1 (>20%)
Critical - 5
Very - 4
Moderate - 3
Somewhat - 2
None - 1
Total - 5
Very - 4
Moderate - 3
Somewhat - 2
None - 1
Total - 5
Very - 4
Moderate - 3
Somewhat - 2
None - 1
Range 2-5
Range 2-5
Range 4-5
Range 2-5
Range 1-3
Range 3-5





Functionality Index Combined Scores

	Functionality Ranking	Risk
Street Crossing	12	Very High 4.9
Credit Card	14	Moderately High 3.6
Category Sort	17	Very Low 1.5
Tooth	18	Moderately Low 2.6
Sight Words	18	Very Low 1.6
Reading 4 Info	18	Very Low 1.2
Math Facts	25	Very Low 1.4
Video Game	25	Low 1.5

Discussion

- A new tool, the Functionality Index, was investigated as to its potential utility in assisting behavior analysts in goal selection.
- While very preliminary the results are promising and future research is warranted.
- On area of research would be to assess the extent to which the Functionality Index can act to support a predictive model of rate of skill acquisition, generalization, and maintenance.

Discussion

- Of particular interest was that the two skills rated highest overall in functionality (i.e., street crossing and using a credit card) were also rated highest in potential risk. This would indicate that skills or skill sets with the greatest potential to directly impact the lives of adolescents with autism may also be those where fewer of the associated variables are controllable or, for that matter, even known. These are, however, the conditions under which the field of ABA may have its greatest potential impact with reference to QOL. Unfortunately, this has not been an active focus of research or practice and, as such, our knowledge-base is lacking.

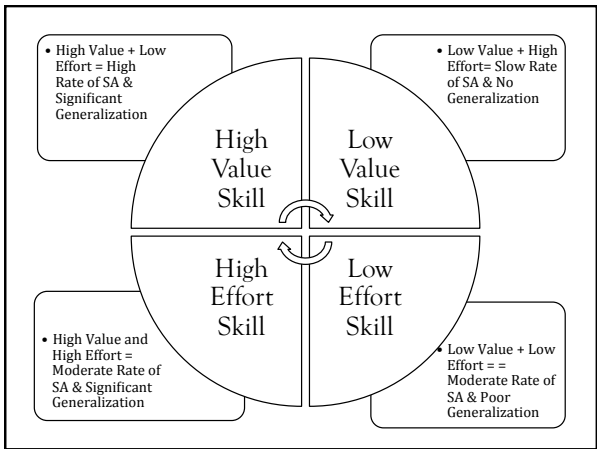
Risk

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

A future implication?

- It is generally accepted that individuals with ASD demonstrate challenges in the generalization of mastered skills from one environment to another (e.g., Handleman & Delmolino, 2005)
- Yet there are those children who generalize the operation of the DVD/ Blue Ray player from unit to unit, from house to house, and from home to school without any additional intervention.
- The question then becomes to what extent a failure to generalize a particular skill is due to:
  - A neurological challenge associated with a Dx of autism.
  - Our failure to attend to context as a critical variable?
  - Our failure to provide sufficient opportunities to respond that may be necessary for true mastery?
  - Our failure to consider the relationship between skill value the effort needed to complete the skill?
  - Our failure to transfer control from the classroom environs to the world outside?

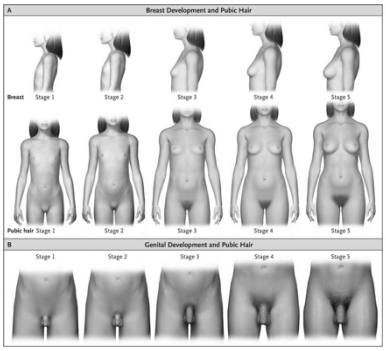


TV MA

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

Let's then start at the start

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.

Onset of Puberty

Over the past 2-3 decades the age of puberty onset has decreased. For girls, breast development, typical of 11-year-olds a generation ago, is now occurring in more seven-year-olds. Research indicates that childhood obesity may be the primary causative factor. However, family stress and chemical exposures in the environment may also play a role, but the data are unclear as to degree of contribution. For boys, the data are murkier, but one study did suggest that they, too, may be starting puberty earlier than before—perhaps by as much as six months to two years. (Maron, 2015)

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 & the testicles 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 though 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.
- ✓ **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 more.
- ✓ **Body size** - growth spurts occur during a boy's puberty.
- ✓ **Body hair** - hair will start to grow around the pubic area, under his 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 taking place. Research indicates that mood swings may be explained by biological changes in the adolescent brain.

Puberty and ASD

Not surprising, there is very little research on the impact/intersection of puberty and ASD. In fact, a quick search of the PsyScan database using "autism" and "puberty" as keyword search terms results in only 18 articles between 1979-2012. A similar search of the PubMed database results in 71 articles between 1963-2012. These results, while not unexpected, are still disheartening.

Puberty and ASD

- ✓ There is a tendency for parents and professionals to ignore or misinterpret:
  - ✓ The emotional impact of adolescence on growing individuals with ASD.
  - ✓ Reflex, or spontaneous, erections as being sexual in nature
  - ✓ Genital stimulation as something to punish
  - ✓ Sexuality in general and sexual interest of an individual in particular
  - ✓ The importance of anticipating this development and planning for such.
  - ✓ Personal (i.e., sexual) safety and the 5-year rule

Puberty and ASD

During puberty we can expect a certain percentage of individuals with ASD to develop a seizure disorder. Seizures are indeed more common in both children and adults on the autism spectrum. Epilepsy rates among those with autism spectrum disorders (ASD), range from 20 to 40 percent, with the highest rates among those most severely impaired by autism. Conversely, about 5 percent of children who develop epilepsy in childhood go on to develop autism.

ASD, Puberty, and Behavior

- ✓ There is an ongoing debate regarding the impact of puberty on the display of challenging behavior. None of these discussions, however, have resulted in any general agreement or actual data. What seems to be true, however, is:
  - ✓ For some individuals the onset of puberty may be associated with an increase in challenging behavior.
  - ✓ This increase, however, may then be reinforced as a result of their newly realized increase in size and strength (i.e., the behavior is now more effective).
  - ✓ We, not surprisingly, do tend to see behavior challenges associated with menstrual cycles.
  - ✓ A new class of behavior maintained by R+ in the form of sexual stimulation may develop.
  - ✓ But other factors such as curriculum, boredom, staffing, restrictiveness of the environment etc. may also be related.

Mental Health Concerns in Adolescence

Children & adults who have a DD and a co-existing psychiatric disorder are one of the most underserved cohorts in the US. Beginning in adolescence, individuals with a developmental disability are **two to four times more likely to have a psychiatric disorder than their Neurotypical peers**. (Fletcher, et al., 2007)

Anxiety Disorders

Vasa, et al (2013) examined age-related differences in the prevalence and anxiety in 1316 children and adolescents with autism spectrum disorder (ASD) who presented for initial evaluation at 14 outpatient autism centers around the country and in Canada. The prevalence of clinical and subclinical anxiety were examined in three age groups of children: preschool, school age and adolescents. **Findings showed that the prevalence of anxiety in each age group exceeded the prevalence of anxiety in the general population. Adolescents and school age children had the highest prevalence of clinical (40%) and subclinical anxiety (26%), respectively.** These data underscore the need for prevention and treatment of anxiety as well as research examining the characteristics of anxiety in children with ASD….

Vasa, R. A., et al, (2013). Age-related differences in the prevalence and correlates of anxiety in youth with autism spectrum disorders. *Research in Autism Spectrum Disorders, 7*(11), 1358-1369.

ASD, Cobmordid Psychiatric Conditions and Emergency Room Use

Kalb, et al (2012) examined the prevalence and characteristics of psychiatry-related emergency department (ED) visits among children with an autism spectrum disorder (ASD). The results indicated that 13% of visits among children with ASD were due to a psychiatric problem, as compared with 2% of all visits by youths without ASD. Results from the multivariate analyses revealed that the likelihood for a psychiatric ED visit was increased 9-fold compared with non-ASD visits. This study highlights the need for improving community-based psychiatric systems of care for youths with ASD.

Kalb, L.G., Stuart, E.A., Freedman, B., Zablotsky,, B., & Vasa, R. (2012) Psychiatric-related emergency department visits among children with an autism spectrum disorder. *Pediatric Emergency Care*, Dec;28(12):1269-76.

Psychotropic Medication Use in ASD

Spencer, et al., (2013) examined rates and predictors of psychotropic use and polypharmacy among insured children with (ASD). The authors used administrative medical and pharmacy claims data linked with health plan enrollment[ ] and 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 psychotropic polypharmacy (≥2 classes), and 15% used medications from ≥3 classes concurrently. Median length of polypharmacy 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.

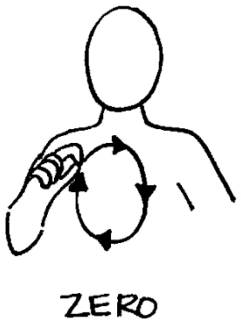
Sadly…

Sex and sexuality, as serious topics for discussion, are ones that many of us would rather avoid than address. This may be even more true when the issue is sexuality and learners with ASD.

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

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

But really, how much research is there on impact of sexuality education and related interventions in ASD?



A few things we probably do know

(Kellaher, D., 2015)

- At least some of our gap in understand sexuality and sexual behavior in ASD stems from an general lack of understanding about sexuality and sexual behavior.
- High verbal individuals appear similar to typical peers in terms of sexual interest.
- While high verbal adults may know the language of sexuality, this does not seem to equate to qualitative or quantitative knowledge or behavior.
- There appears to be a greater diversity of sexual expression with high verbal individuals with higher reported rates of asexuality, bisexuality, and homosexuality, particularly among women.

A few things we probably do know
(Kellaher, D., 2015)

- Although data are limited there are published reports of paraphilic behavior among HV males but none involving HV females. The gender difference is due, most likely, to multiple confounding variables but it does appear that every permutation of sexual behavior we see in the typical community exists in the HV/ASD community.
- In ASD, however, some paraphilic behavior represent "counterfeit deviance" (Hingsburger, Griffiths, & Quinsey, 1991) in that it originates from an absence of knowledge, experience, or specific social competencies.

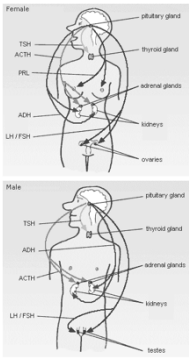
Kellaher, D.C. (2015). Sexual behavior and ASD: An update and discussion. Current Psychiatry Reports, 17, Published online March 2015

Hingsburger, D., Griffiths, D., & Quinsey, V. (1991). Detecting counterfeit deviance: differentiating sexual deviance from sexual inappropriatness. Habilitative Mental Healthcare Newsletter, 51-54.

A Couple of Good Reasons Why We Should Teach Human Sexuality Education To Individuals With Autism Spectrum Disorders

Number 4

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

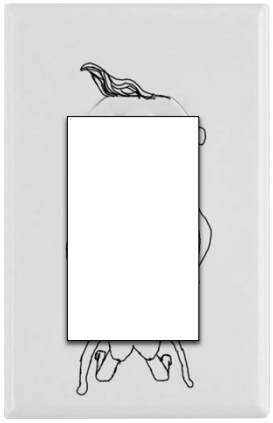


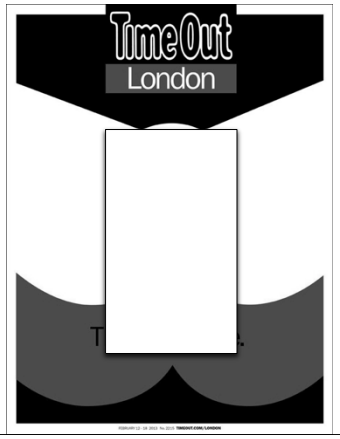
Number 3

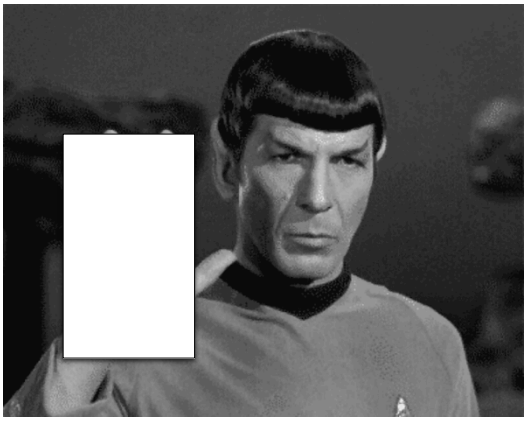
The Internet and other readily accessible media

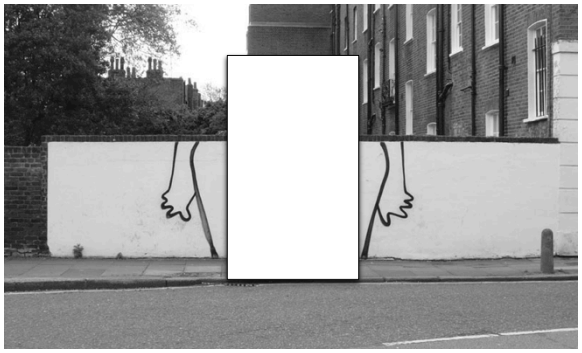
Internet Rule #34

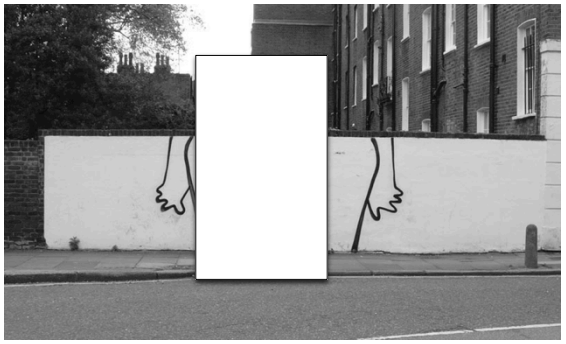
If you can imagine it, then it exists as internet porn.




Time Out
London







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

Number 2

Sexual Abuse

- In a recent study, Brown-Lavoie, Viecili, & Weiss (2014) noted that individuals with ASD reported higher levels of sexual victimization that did typical controls. In a 2005 study, Mandell et al reported that in a sample of 156 children with ASD 18.5 had been physically abused while 16.6% had been sexually abused. In their review of the literature, Sevlever, Roth, & Gillis (2013) note that more systematic research on the prevalence and risk factors of sexual abuse and offending is in great need if we are to adequately address this issue. The bottom line, however, is that independent of accurate numbers both the issue of abuse and offending require our attention and intervention before a problem develops.

Brown-Lavoie, S.M., Viecelli, M.A., & Weiss, J.A., (2014). Sexual knowledge and victimization in adults with ASD. Journal of Autism and Developmental Disorders, 44, 2185-2196
Sevlever, M., Roth, M.E. & Gillis, J.M. (2013). Sexual abuse and offending in ASD. Sexuality and Disability. 31, 189-200.
Mandell, D.S., et al (2005). The prevalence and correlates of abuse among children with autism served in comprehensive community-based mental health settings. Child Abuse and Neglect. 29, 1359-1372.

Self-Protection

- ✓ Teach that refusing to be touched is a right
- ✓ Teach that secrets about being touched are not OK
- ✓ 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 to teach this stuff?

First

Sex is just behavior. Whatever body part(s) is involved it is all just behavior.

-J. Bering, (2012)

Second

- ✓ Despite much discussion about decision making skills in the self-determination literature (e.g., Clark, et al., 2004), there continues to be "lack of evidence [supporting the] effectiveness of sex education and training for persons with developmental disabilities" (Duval, 2002, p. 453) 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
    - ✓ Leave school with
    - ✓ Touch certain parts of your body

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.
- ✓ *Sexuality education* is a life-long process that encompasses many things: the biological, socio-cultural, psychological and spiritual dimensions of sexuality.

Further complicating things…

- ✓ There are different types 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.*

In addition…

- ✓ Individuals with autism can be concrete thinkers who interpret things literally, so…
  - ✓ Be frank 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 & Lunsky, 1997, p. 411)

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

Q: What does this picture show?

A: "[t]wo people lying on a towel."

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

(Konstantareas & Lunsky, 1997, p. 410)

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

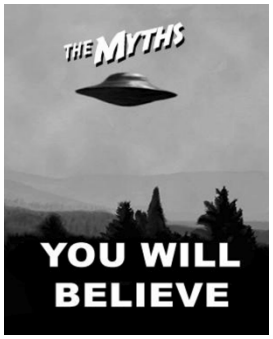
Q: What is this man doing?

A: "[T]he hand is somewhere; he chopped it off."

http://www.reuniting.info/images/0bedSM.jpg

(Konstantareas & Lunsky, 1997, p. 411)

Myths about Sexuality



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 individuals at all ability levels. As such, there is a significant need for individualized, effective instruction for persons with ASD across the ability spectrum.

What we don't know…

In two (somewhat) recent studies, (McCabe & Cummins, 1996; Szollo & McCabe, 1995) researchers 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

can sometimes hurt us.

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 autism spectrum disorder. *Journal of Autism and Developmental Disorders,* **37,** 1969-1986.

And for the Learner with ASD

Sexuality education is complicated by language and communication problems and social deficits. Unfortunately, while sexual feelings and interest may be high, a primary information source available to neurotypical teens, (i.e., other teens), is generally not available. (Volkmar & Wiesner, 2003)

Sexuality education should be proactive

Griffiths, (1999) notes that 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.

Guidelines for teaching

- ✓ Think ahead and be proactive
- ✓ Be concrete
- ✓ Serious, calm, supportive
- ✓ Break larger areas of information into smaller, more manageable blocks
- ✓ Be consistent, be repetitive
- ✓ What are the practical implications
- ✓ Teach all steps and in the correct order
- ✓ Consider using multiple instructional mediums
- ✓ Incorporate the social dimension of sexuality when and wherever appropriate

*Source: L. Mitchell, RCSW, The Cody Center

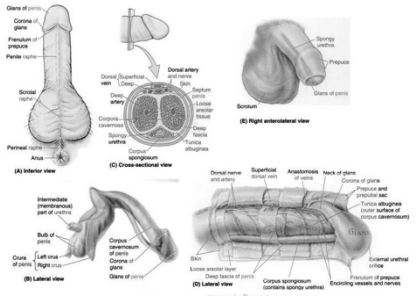
The 6 Rules of Presentation:

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

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

(Keep It Simple Stupid But Keep It Accurate)

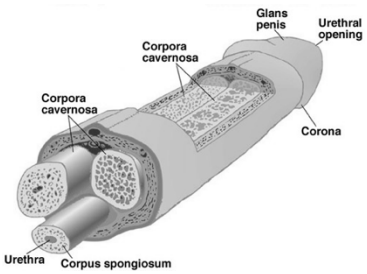
BAD VISUAL



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

(Keep It Simple Stupid But Keep It Accurate)

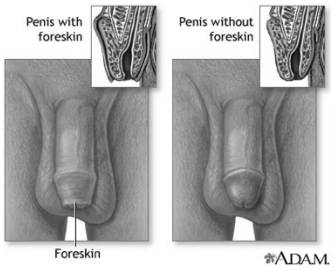
NOT MUCH BETTER



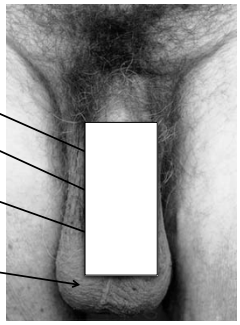
K.I.S.S.B.K.I.A.

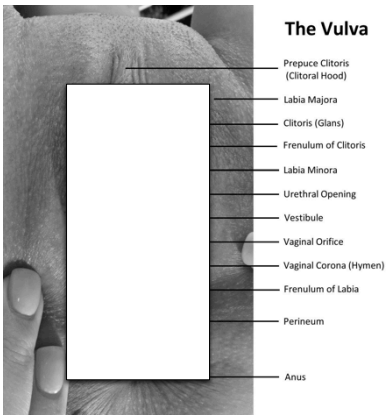
(Keep It Simple Stupid But Keep It Accurate)

PRETTY DECENT



What we would actually use





Teaching materials

- ✓ 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

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)

Guidelines for making materials

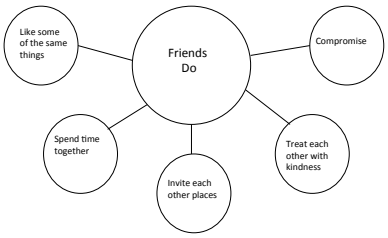
For example…

This is Nancy

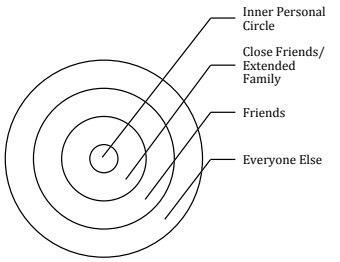
Which one is Nancy?

Which is Nancy?

Graphic Organizers: Social Issues



Circles of Comfort and Safety



Can help with my personal needs

Can help me but not in the bathroom or in private

Can help me but can only touch my hands/ arms/shoulders and with permission

Need to get others to help me and cannot touch me.

Goals of a comprehensive sexuality education

1. Provide accurate information
2. Develop personal values
3. Develop the necessary social competence

INFORMATION

- ✓ Provide information that is accurate, timely, and presented in such a way as to be understood. Potential areas of information include:
  - ✓ Human growth, development and puberty
  - ✓ Masturbation
  - ✓ Sexual abuse, personal safety and STDs
  - ✓ Pregnancy, childbirth and parenthood
  - ✓ Sexual orientation

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 & 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 same techniques we use to teach other behaviors can be used in this area too

- ✓ Some examples:
  - ✓ Picture schedules
  - ✓ Shaping
  - ✓ Cognitive rehearsal
  - ✓ Personalized stories
  - ✓ Video-modeling
  - ✓ Discrete Trial Instruction

Public/Private Discriminations

- ✓ Be clear about social and family rules about privacy and modesty
  - ✓ Restrict nudity in public parts of the house
  - ✓ Dress and undress in bedroom or bathroom
  - ✓ Close doors and shade windows for private activities
  - ✓ Teach use of robe
  - ✓ Caregivers should model knocking on closed doors before going in

(American Academy of Pediatrics, 1996; NICHCY, 1992; SIECUS, 2001)

Public/Private Discriminations

- ✓ Some concepts to teach:
  - ✓ Naked vs. wearing clothes
  - ✓ Places where it is OK to be naked (and where it is not)
  - ✓ Which parts of the body are private
  - ✓ What kinds of activities are private
  - ✓ Where it is OK to do private activities

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

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

- ✓ Designate 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 private time
- ✓ Schedule private time and help individual understand the schedule

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

Handling problems

- ✓ Interrupt the behavior but don't punish or overreact
- ✓ Remind the student of the rules for appropriate masturbation by referring to the visual cues he/she uses
- ✓ Redirect the student to:
  - ✓ An activity that requires use of hands
  - ✓ A physical activity
  - ✓ An activity that requires intense focus
  - ✓ To his/her bedroom, if available
- ✓ Reinforce student when he/she is engaging in appropriate behavior

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

VALUES

- ❑ To develop personal values reflective of family, religious and cultural values in such areas as:
  - ✓ Personal responsibility
  - ✓ Self esteem
  - ✓ Right v. Wrong
  - ✓ Reality v. Fantasy
  - ✓ Interpersonal respect
  - ✓ Personal limits

What Are Values?

Social Competence

What do we mean by SOCIAL SKILLS?

Social skills might best be understood as access and navigation skills… they are how we acquire desirables and avoid negatives by successfully navigating (and manipulating) the world around us. They are complex, multilayered skills that are bound by both content and context.

A quick opinion here:

I currently think that no other set of adaptive competencies relies so heavily on extremely subtle environmental cues for their correct display than do social competencies. So in this special case, the "Applied" is as critical as are the "Behavior" and the "Analysis". Absent context, the vast majority of social competencies are meaningless. I would, therefore, point out that independent of how evidence-based your interventions may be, teaching social skills well but out of context is really no better than teaching these skills poorly, either in or out of context.

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 you social skill repertoire may be less than adequate.

Strategies that May Promote Social Competence

Demand Assessment	Peer Mediated Interventions	Social Stories or Scripts
Joint Attn. Intervention	Reciprocal Imitation Training	Self-monitoring
Video Modeling	Social Skill Groups	CBT Based Interventions
CBT/Social Thinking Strategies	Naturalistic Strategies and Support	Value Assessment

Joint Attention Intervention

Deficits in joint attention are generally considered to be an early predictor of an autism diagnosis and are considered central to deficits in language, play, and social development. Although there is now a small, but significant, body of research on interventions designed to teach the behaviors associated with joint attention, the impact of such intervention on social skills in adolescence or adulthood remains undocumented. In addition there is little, if any, research on teaching joint attention behaviors to older individuals.

Video Modeling

- Video modeling interventions involve having an individual with ASD watch a video of an adult, peer, or him/herself perform a behavior correctly, in hopes that the individual with ASD will begin to spontaneously perform the observed behavior after viewing it on video.
- Video modeling has been used to teach a variety of social, educational, adaptive, and vocational tasks to individuals with autism (Bellini and Akullian 2007) altough only one study (Nikopoulos and Keenan, 2003) has targeted social skills in older individuals

Bellini, S., & Akullian, J. (2007). A meta-analysis of video modeling and video self-modeling interventions for children and adoles- cents with autism spectrum disorders. Exceptional Children, 73, 264–287.

Nikopoulos, C., & Keenan, M. (2003). Promoting social imitation in children with autism using video modeling. Behavioral Inter- ventions, 18, 87–108.

CBT/Social Thinking

Social thinking, as developed by Michelle Garcia Winner, is an social skills intervention designed to teach high verbal individuals how to think about social interactions and how that thinking affects behavior, which in turn affects how others respond to us, which in turn affects our own emotions. Although there is limited research into the effectiveness of Social Thinking there does appear to some secondary CBT research that may support its effectiveness.

Peer Mediated Interventions

A small number of studies have found that peer-mediated interventions, can be effective at increasing social interactions of individuals with ASD (Chan et al, 2009). Peer mediated interventions are those in which typically developing peers are taught strategies for interacting with individuals with ASD. Peer-mediated strategies are meant to capitalize on the existing social skills of typical peers and to serve as models of appropriate social behavior. (Chan et al. 2009).

Chan, J., Lang, R., Rispoli, M., O'Reilly, M., Sigafoos, J., & Cole, H. (2009). Use of peer-mediated interventions in the treatment of autism spectrum disorders: A systematic review. Research in Autism Spectrum Disorders, 3, 876–889.

Social Skill Groups

- Social Skill Groups, while commonly used with high verbal individuals, lack an adequate research based. Among the myriad questions are what constitutes a social skills group, what curriculum is used, what social behaviors are targeted, how frequently should sessions be run and, how many sessions are needed to produce behavior change.
- There are, however, a few emerging, manualized group models (e.g., The PEERs Model) that have answer the above questions and have some intitial research to support their effectiveness.

Reciprocal Imitation Training

Reciprocal Imitation Training (RIT), is a naturalistic imitation intervention that emphasizes the social role of imitation (Ingersoll, 2008). In RIT typical development is used to guide selection of treatment targets and children are taught social communication through affect-laden interactions with responsive caregivers. While much of the research has been with young children, Ingersoll, et al, (2013) used RIT to improve social behaviors in four adolescents with autism and significant ID.

Social Stories or Scripts

Social Stories, popularized by Carol Gray, consist of brief stories or scripts describing a particular social, behavioral, or problem solving skill. Though popular, the research into the effectiveness of Social Stories is, at best, mixed. One possible explanation is that there may be two different groups of individuals (i.e., responders v. non-responders) but, beyond a certain level of language comprehension, the characteristics of each group are undefined.

Self Monitoring

Self-management strategies are intended to teach individuals with ASD to independently regulate their own behaviors and act appropriately in a variety of home, school, and community-based situations. Considered an evidence-based practice, the critical elements of self-management include goal setting, monitoring behavior, evaluating progress and self reinforcement.

Value Assessment

Directly tied to demand assessment and relevant to the generalization of acquired skills is value assessment. In some ways, value assessment might best be understood as a functional analysis of the contingencies that may support the display of the newly acquired skill.

Functional Analysis of Social Responding

	Positive Reinforcement	*Negative Reinforcement*	*Positive Punishment*	*Negative Punishment*
Social Greeting	Attention in the form of social greeting returned	Social isolation terminated? Prompting terminated?	Attention in the form of social greeting returned	Social isolation terminated
Sharing Food	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

Naturalistic Strategies

Given the connection between context and appropriate social behavior, strategies that target skill development in the natural environment would appear to have, minimally, face validity. Among the behavioral strategies that may be effective in the natural environment include, but are not limited to, shaping, differential reinforcement, video modeling, modeling, and permutations of interventions based on matching law.

Challenges to Sexuality Education for Learners with ASD.

- The social dimension of sexual behavior
- Differentiation between public and private behavior and reality v. fantasy
- Ensuring the maintenance of learned skills, particularly those associated with sexual safety
- Balancing individual safety with personal respect and individual rights
- Issues related to law enforcement

In summary

Challenges to Supporting Adults

- Limited body of research upon which to base comprehensive intervention
- Discontinuous services between school and the adult world
- Dearth of services/Limited interest
- Staffing concerns in the areas of recruitment, retention, and quality
- Access to adequate medical care
- Issues with the criminal justice system
- Substance abuse issues

Some closing thoughts…

But what is happiness except the simple harmony between a man and the life he leads.

Albert Camus (1913 - 1960)

That's the difference between me and the rest of the world! Happiness isn't good enough for me! I demand euphoria!

Calvin, speaking to Hobbs

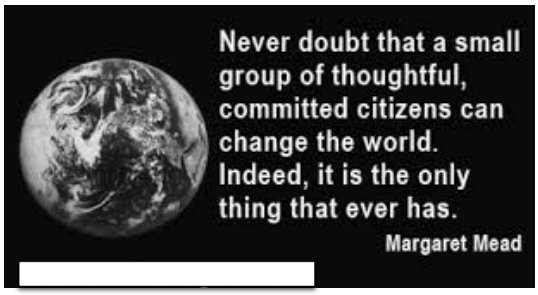
If I had to live my life again, I'd make the same mistakes, only sooner.

Tallulah Bankhead (1903 - 1968)

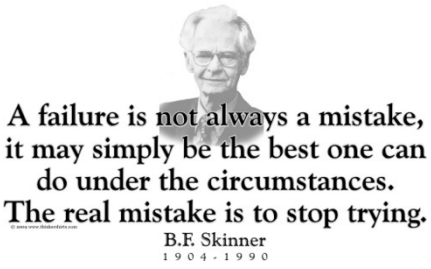
"Oscar, you know that's not good for you!"

"Felix, when I look back on the best times on my life, none of them were good for me!"

Felix Unger and Oscar Madison
The Odd Couple



Don't dream it. Be it!



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Stolen, without permission, from the University of Houston, Clear Lake ABA Program Website.

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