PEPSA

Partnership for Effective Programs for Students with Autism

FOLLOW-UP ACTIVITIES

Peter F. Gerhardt, Ed.D.

February 15, 2008

Please contact your ESE District Staff or Staff Development Contact to determine the process for receiving in-service.

Employment Development and Supports for Learners with ASD 9:00 am - 12:00 pm

1. Visit three (3) or more possibly employment sites and assess potential job demands across the relevant parameters.
2. Schedule a meeting with a potential employer to discuss his or her concerns regarding hiring an individual with ASD.
3. Write a teaching program designed to increase both community independence and safety for an adolescent with ASD.
4. Write an employment plan for a specific individual focusing on "job carving."
5. For a particular student, develop a short co-worker training program intended to support great social inclusion on the job.

Sexuality and Sexuality Education for Learners with ASD 1:00 pm - 3:30 pm

1. Write a teaching program designed to increase personal safety for an adolescent with ASD.
2. For a particular student, assess their skill needs in terms of independent public restroom use and write a teaching program designed to address these particular skill deficts.
3. Develop the teaching materials, specific to your students and their classroom, to teach who can/who can't help you with personal care needs.

Employment Development and Supports for Learners with ASD

Peter F. Gerhardt, Ed.D.

February 15, 2008 **9:00 am - 12:00 pm**

ABOUT THE PRESENTER

Dr. Peter Gerhardt is President of the Organization for Autism Research, a nonprofit organization, the mission of which is to fund applied research and disseminate the relevant findings in support of learners with Autism Spectrum Disorders and their families. Dr. Gerhardt has over 25 years experience utilizing the principles of Applied Behavior Analysis in support of adolescents and adults with Autism Spectrum Disorders in educational, employment, and community based settings. He is the author or co-author of articles and book chapters on the needs of adults with autism spectrum disorder, the school-to-work-transition process, assessment of social competence, and analysis and intervention of problematic behavior. He has presented nationally and internationally on these topics. Dr. Gerhardt received his doctorate from the Rutgers University Graduate School of Education. Dr. Gerhardt was recently awarded the John W. Jacobson Award for Significant Contributions to Effective Behavior Intervention by New York State ABA.

Dr. Gerhardt has been an active member of Maryland ABA since relocating to Maryland (from New Jersey) 6 years ago and he is currently the President-Elect. Previously, he had served on the Board of Directors on New York State ABA and was a founding director of Connecticut ABA.

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TRAINING DESCRIPTION

Today, professionals, families and learners with ASD are beginning to redefine the outcomes of the transition process beyond simple job placement to focus on career development and measures of personal competence and life satisfaction. To this end, this presentation will provide an overview and practical suggestions for transition planning in support of desirable and individualized employment outcomes with attention to assessment, community based training, employment development, job-related social skills and quality of life concerns.

TRAINING OBJECTIVES

After having attended this workshop, participants will be able to:

- Identify the components of a comprehensive transition plan relevant to community employment
- Define the multiple constituent groups whose needs are to be met in the employment development process
- Discuss the importance of co-worker training in employment maintenance
- Describe the individually determined components of an assessment of quality of life

Bridges to Adulthood for Learners With Autism Spectrum Disorders: Employment Development and Support

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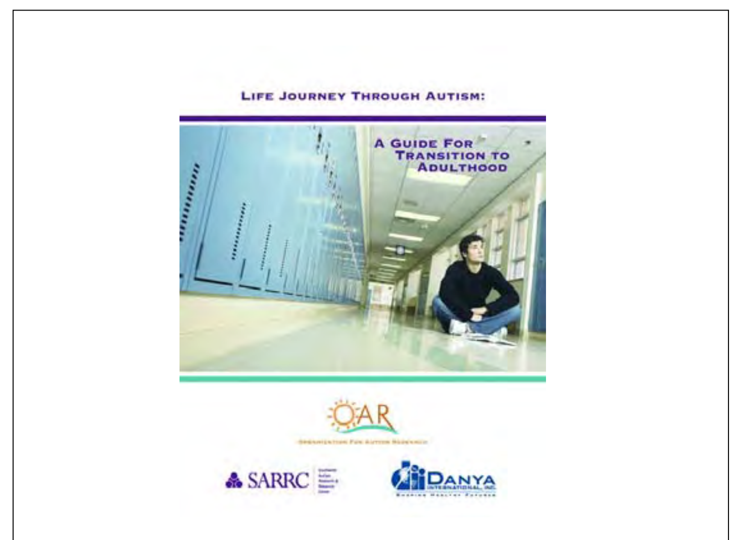
The Organization for Autism Research

The mission of OAR is to apply research to the challenges of autism

The Organization for Autism Research Current Programs

- Annual research competition
- Annual graduate research competition
- The *OARacle*
- Life's Journey Through Autism series of Guidebooks
  - Parent's Guide to Research
  - Educator's Guide to Autism
  - Educator's Guide to Asperger Syndrome
  - A Guide to Transition to Adulthood
  - Best of the *OARacle* (2007)
  - Parent's Guide to Assessment (2008)
- Annual "Applied Autism Research and Intervention" Conference
- OAR Autism Research Convocation 2008
- Hispanic Outreach Program
- www.researchautism.org website



Why Research is Important

- Seeing is not believing
- Correlation does not mean causation
- With a population of 300,000,000 people, one in a million occurrences happen to 300 Americans each day just as a matter of chance and coincidence.
- As professionals, we have an ethical obligation to our clients to provide treatment and intervention that is evidence-based and, thereby, most likely to be effective.

What is applied Research?

- Applied research is direct, systematic research in support of individuals and families impacted by an autism spectrum disorder diagnosis and the systems charged with educating these learners across their lifetimes. Applied research addresses issues of practical importance, social significance, and results in outcomes with the potential to enhance the quality of life of individual learners. Applied research is not contradictory to and is, in fact, complimentary to research into the biomedical, neurological or genetic/cellular basis for autism spectrum disorders.

Understanding ABA as an Applied Science

ABA is a field of inquiry dedicated to to investigating and modifying behavior in a systematic way. ABA is:

- Data-based
- Analytical
- Able to be replicated
- Socially important
- Contextual
- Accountable (Sulzer-Azaroff & Mayer, 1991)

Applied Behavior Analysis and Real Life

- *A-----------------B---------------------C*
- *I cook --------- My Wife Says "MMM"--------I cook again*
- *A-----------------B---------------------C*
- *I drink tequila ------I get sick------------No more tequila*
- *A-----------------B---------------------C*
- *I go to work----------I don't get paid---------I quit*

Why Is ABA Effective For Older Learners with ASD?

- Applied Behavior Analysis is a vast scientific discipline based upon over 35 years of published research.
- Applied Behavior Analysts develop interventions that are based upon empirically validated research and best practices for *both* skill acquisition and behavior reduction.
- Applied Behavior Analysis interventions:
  - Highlight relevant stimuli while simultaneously minimizing extraneous stimuli
  - Recognize the power of positive reinforcement
    - Functionally determined, Contingent, Continual, Intermittent

Why Is ABA Effective For Older Learners with ASD?

- ABA utilizes systematic prompting and prompt fading
  - Promotes consistency across support staff
  - Provides for data based decision making
- In supporting adolescents and adults, there are times where previously accepted "prompt hierarchies" may have to be modified as a function of community standards
- Behavior Analysts respect the role of significant others in the individual's life as *central* to the implementation of an effective intervention.

Why Is ABA Effective For Older Learners with ASD?

- ABA…
  - through task analysis, breaks complex material into teachable units and identifies complementary repertoires (next)
  - represents a teaching method with tremendous versatility beyond discrete trial instruction
    - **Fluency/Rate-base instruction → Instructional Intensity**
    - **Shaping**
    - **Chaining**
    - Incidental strategies/NET
    - Environmental/curricular modifications
    - Peer instruction and support
  - provides *numerous* structured opportunities for learner to acquire and practice a new skill or response in isolation prior to expecting the learner to show discrimination

Why Is ABA Effective For Older Learners with ASD?

- Applied Behavior Analysis is a *PERSON CENTERED/POSITIVE* approach to behavior change.
  - Functional assessments enable identification of the underlying communicative intent of challenging behaviors
  - Functional assessments enable interventionists to respect goals, while helping the individual develop other ways to meet those goals
  - Behavior plans provide individuals with more acceptable tools for negotiating their environment

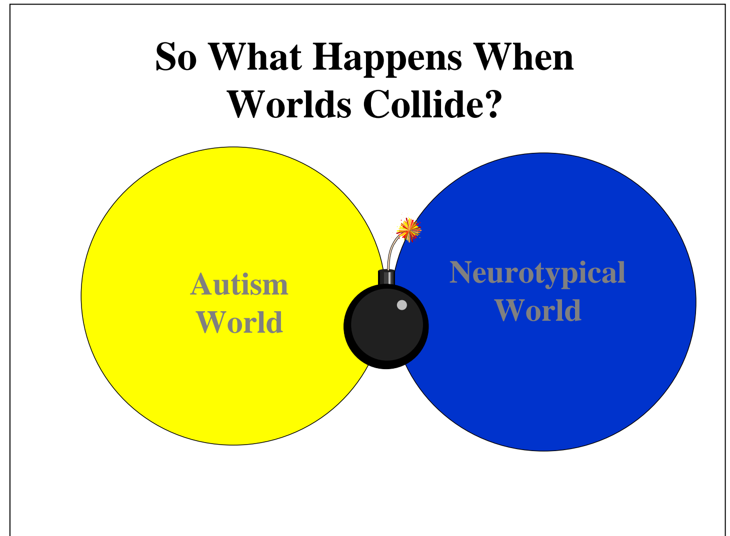
However, despite how evidence-based your instructional interventions may be...

Teaching wrong or inconsequential skills well is no better than teaching right or important skills poorly.

"These children often show a surprising sensitivity to the personality of the teacher [ ] They can be taught but only by those who give them true under-standing and affection, people who show kindness towards them and yes, humor [ ] The teacher's underlying attitude influences, involuntarily and unconsciously, the mood and behavior of the child.

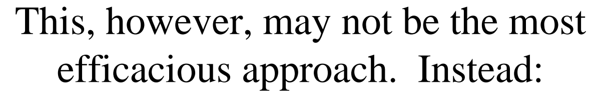
-Hans Asperger, 1944

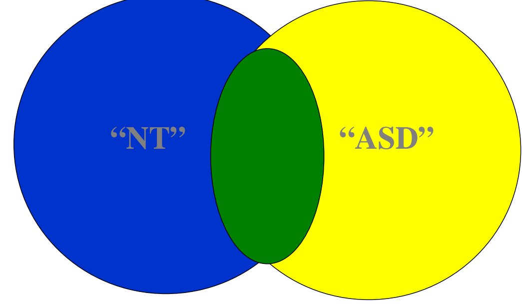
So What Happens When Worlds Collide?



There is a perception that the only acceptable outcome is for the person with ASD to be indistinguishable from the NT "Standard of Behavior"

NT





This area of potential overlap (of both skills & interests) may have the greatest potential for the development of mutually beneficial services and supports while recognizing the strengths and deficits of both worlds.

Neurotypical Syndrome

Definition:

A neurobiological disorder characterized by preoccupation with social concerns, delusions of superiority and obsession with conformity.

For more information visit: http://isnt.autistics.org/

DSN-IV (The Diagnostic and Statistical Manual of 'Normal' Disorders): Disorders Usually First Evident in Infancy, Childhood, or Adolescence
666.00 Neurotypic Disorder

The essential features of Neurotypic Disorder constitute a severe form of Invasive Developmental Disorder, with onset in infancy or childhood.

At least eight of the following sixteen items are present, these to include at least two items from A, one from B, and one from C. *Note: Consider a criterion to be met only if the behavior is abnormal for the person's developmental level.*

DSN-IV (The Diagnostic and Statistical Manual of 'Normal' Disorders): 666.00 Neurotypic Disorder

A. Qualitative impairment in independent social interaction as manifested by the following:

(The examples within parentheses are arranged so that those first mentioned are more likely to apply to younger or more handicapped, and the later ones, to older or less handicapped, persons with this disorder.)

(1) marked delusional sense of awareness of the existence or feelings of others (e.g., treats a person as if he or she were an extension of himself; behaves as if clairvoyant of another person's distress; apparently projects own concepts and needs onto others)

(2) extreme or abnormal seeking of comfort at times of distress (e.g., constantly comes for comfort even when ill, hurt, or tired; seeks comfort in a stereotyped way, e.g., cries, whines needs demands for attention whenever hurt)

(3) constant or mindless imitation (e.g., always wave bye-bye; copies mother's domestic activities; mechanical imitation of others' actions whenever perceived to be in context)

DSN-IV (The Diagnostic and Statistical Manual of 'Normal' Disorders): 666.00 Neurotypic Disorder

(4) constant or excessive social play (e.g., always actively participates in simple games; prefers group play activities; involves other children in play only as long as the other children are exactly like themselves with no differences "mirrored images")

(5) gross impairment in ability to make peer friendships (e.g., obsessive interest in making peer friendships with other Neurotypics; despite interest in making friends and afore mentioned delusion of clairvoyance, demonstrates lack of understanding for those who are different and an obsessive rigidity for social convention, for example, constantly seeks attention/positive reinforcement while staring mocking or laughing at others while they stim and rock and remain mute)

DSN-IV (The Diagnostic and Statistical Manual of 'Normal' Disorders): 666.00 Neurotypic Disorder

B. Qualitative impairment in verbal and nonverbal communication, and in imaginative activity, as manifested by the following:

(The numbered items are arranged so that those first listed are more likely to apply to younger or more handicapped, and the later ones, to older or less handicapped, persons with this disorder.)

(1) blatant overuse of all modes of communication, such as communicative babbling, facial expression, gesture, mime, or spoken language

(2) markedly abnormal nonverbal communication, as in the use of eye-to- eye gaze, facial expression, body posture, or gestures to initiate or modulate social interaction (e.g., anticipates and enjoys being held, does not stiffens when held, constantly looks at the other person or smiles when making a social approach, compulsively greets parents or visitors, insists on invasively stares into the eyes of others in social situations)

DSN-IV (The Diagnostic and Statistical Manual of 'Normal' Disorders): 666.00 Neurotypic Disorder

(3) excessive imaginative irrelevant activity, such as playacting of adult roles, fantasy characters, or animals, lack of interest in computers or other logical fulfilling pastimes

(4) marked abnormalities in the production of speech, including volume, pitch, stress, rate, rhythm, and intonation (e.g., gregarious grandiose tone, overly emotional or syrupy melody, or over controlled pitch)

(5) marked abnormalities in the form or content of speech, including stereotyped and repetitive use of speech (e.g., immediate mindless or mechanical repetition of NT peers' latest 'in' or catch phrases such as "whatever" to mean "I am saying I disagree with you but I want you to be upset by my saying so in this way"); idiosyncratic use of words of phrases (e.g., "are you dissing me?" to mean "don't disrespect me"); or frequent irrelevant remarks (e.g., starts talking about the behavior of autistics at a table nearby during a meal at a restaurant)

DSN-IV (The Diagnostic and Statistical Manual of 'Normal' Disorders): Disorders Usually First Evident in Infancy, Childhood, or Adolescence
666.00 Neurotypic Disorder

(6) marked impairment in the ability to refrain from initiating a conversation or once initiated to sustain a full thought during conversation with others, despite adequate speech (e.g., unable to stay on topic/on thought due to the interjections from other Neurotypics)

C. Markedly restricted repertoire of activities and interests, as manifested by the following:

(1) inability or lack of understanding for or interest in stereotyped body movements, e.g., hand-flicking or -twisting, spinning, head-banging (except for during certain types of rock concerts), complex whole-body movements

DSN-IV (The Diagnostic and Statistical Manual of 'Normal' Disorders): 666.00 Neurotypic Disorder

(2) persistent lack of awareness or inability to perceive parts of objects (e.g., seeing 'a windmill' but failing to see the existence of the many beautiful finite parts which comprise the whole object, oblivion to feelings of texture of materials, spinning wheels of toy cars) or has an attachment to unusual objects (e.g., insists on driving around in a BMW, wearing Rolex watches, carrying a cellular phone or briefcase)

(3) marked oblivion to changes in aspects of environment, e.g., when a vase is moved from usual position

(4) unreasonable insistence in sameness in others in precise detail, e.g., insisting that exactly the same social behaviors always be followed when shopping

DSN-IV (The Diagnostic and Statistical Manual of 'Normal' Disorders): 666.00 Neurotypic Disorder

(5) markedly restricted range of interest and a preoccupation with one narrow interest, e.g., interested only in status quo climbing, impressing friends, or in pretending to be smarter or better than they are.

D. Onset during infancy or childhood. Specify if childhood onset (after 36 months of age).

Author: Shelley from Kalamazoo
http://isnt.autistics.org/

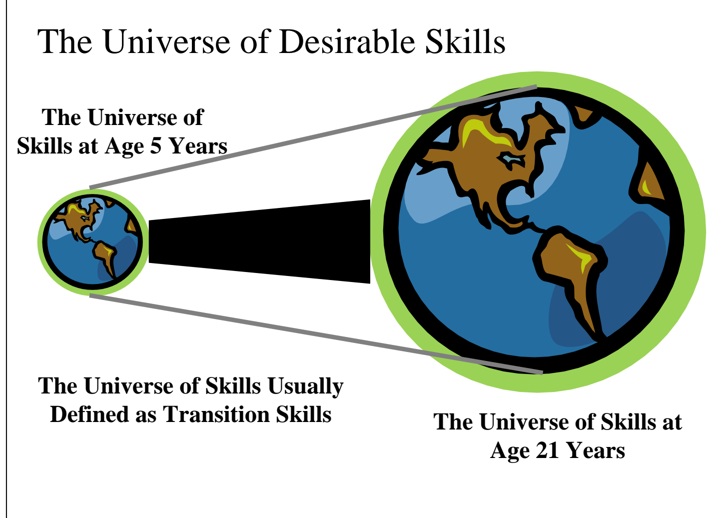
Defining Characteristics in Adulthood

- Career choices
- Where and how we live… Lifestyle issues
- Leisure, recreation, and hobbies
- Our public social circle
- Our private social circle
- Quality of life concerns

Which Means …

Failure to attend to any one of these defining components may lead to significant challenges to the development of services that support a positive quality of life.

The Universe of Desirable Skills



First, It Might Be Appropriate for Us to Discuss Some of the Issues Related To:

PROBLEMATIC BEHAVIOR IN ADOLSCENTS AND ADULTS!

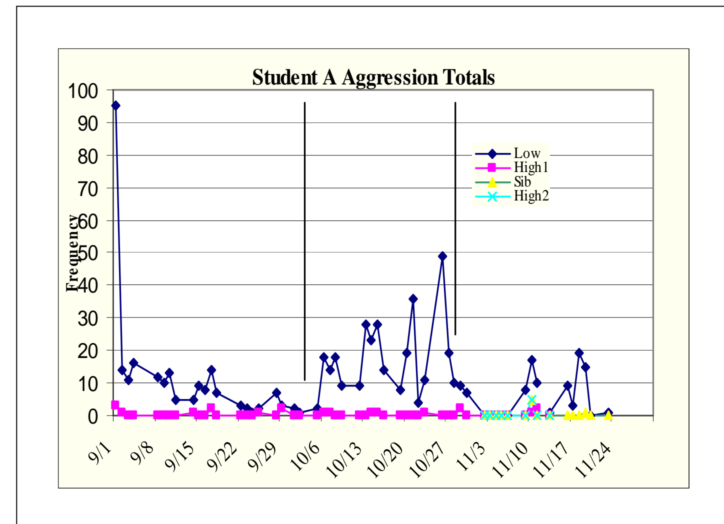
There cannot be a crisis next week. My schedule is already full.
Henry Kissinger (1923 -)

Specific Deficits That May Predispose Individuals to Engage in Problematic Behavior

- Limited access to reinforcement
- Low tolerance to change
- Difficulties with unstructured time
- Restricted leisure skills repertoire
- Selective attention by support staff
- Confusion
- Difficulties with waiting or delaying R+
- Poor environmental congruence
- Inability to exercise appropriate control over their environment

Issues in Behavioral Intervention With Adolescents & Adults With ASD

- The importance of the appropriate use of positive reinforcement remains significant.
- Function, function, function!
- Why do I think I have to intervene?
- To what extent does the display of the behavior limit his or her life?
- When is a “behavior” an “idiosyncrasy”?
- Control is the issue.



Today…

- His is supported as an adult at less than 1/3 the cost of his educational program
- He volunteers at the food bank
- He regularly goes out to restaurants for a sit down lunch
- Regularly exercises in the community (walking) 2-3 times per week
- He works with a wide number of staff with whom he feels comfortable
- In 2006 he was selected as Elk of the Year. He is well liked by all the Elks members!

The Transition Process

Deciding upon the components of an effective transition plan

Accepting that all of us have far fewer skills than we don't have, and that the skill need for learners with ASD is great, how do we decide upon what to teach?

Priorities of Instruction in Transition Programming

- Solicit student and family input as to where they want to be in 1 year, 5 years, 10 years, etc.
- Survey current and potential future environments.
- Assess skill needs across environments in terms of work, social and navigation skills.

Adapted from: Wehman, P. (1992). Life Beyond the Classroom: Strategies for young people with disabilities. Baltimore: Paul H. Brookes.

And …

- Prioritize skills that occur across multiple environments
- Attend to safety skills
- Attend to skills that reduce dependence
- Attend to skills you will need to provide the NT cohort

The Ultimate Transition Strategy

- When speaking about skill development always remember that for a specific skill

If you can teach the skill, teach it

If you can't teach the skill, adapt it

If you can't adapt it, figure out some way around it

If you can't figure out some way around it, teach the NT's to deal

So, In Brief, We Can Then Define Functional Transition Programming As:

- Relevant across multiple environments
- A continual programmatic focus through the functional use of skills
- Aware of individual and family preferences, as well as community demands
- Focused on the pragmatic use of communication
- Including attention to the social skill dimension of most activities
- In general, extremely hard work

Criteria of Ultimate Functionality

According to Lou Brown (1983), the ultimate test of functionality of specific IEP goals is to ask:

"If the student does not learn to do the task, will someone else have to do it for them?"

Sample Goal Sheet

- **Student:** Mark Doe **Age:** 14 years
- **Transition to Employment Goal:** To obtain employment in a field where; 1) there are clear completion criteria, 2) he will be able to listen to his music on a walkman, 3) he will be able to access transportation to, and 4) he will work directly with one primary supervisor.
- **Short Term Objectives (3 Months):**
- Investigate employment opportunities meeting these criteria – School Staff
- Assess appropriate opportunities in terms of production, social, and safety demands – Transition Specialist
- Obtain bus pass for ride to work - Parents
- Obtain state issued non-driver's driver's license for purposes of identification - Parents
- and so on….

Support in the workplace

"I continue to be amazed that you function as an independent adult."

Jim Sack

I first met Max about 10 years ago at a meeting to determine employment options. "So tell me Max," I said after the introductions were completed, "what type of job do you think you would like?" He thought for a moment and then proceeded to describe what he envisioned as the perfect job. "First" he said, "I don't want to get up early. Second, I don't want to sweat." He thought a minute longer then added, "Oh yeah, and I want to make a lot of money." Fine, I thought, he wants the same job as I do.

Main Entry: **in·de·pen·dent**
Pronunciation: "in-de-'pen-dent
Function: *adjective*
1 : not dependent: as a (1) : not subject to control by others : (2) **:** not affiliated with a larger controlling unit <an *independent* bookstore> **b (1) : not requiring or relying on something else : not contingent <an *independent* conclusion>** (2) **:** not looking to others for one's opinions or for guidance in conduct (3) **:** not bound by or committed to a political party **c (1) : not requiring or relying on others (as for care or livelihood) <*independent* of her parents>** (2) **:** being enough to free one from the necessity of working for a living <a person of *independent* means> **d :** showing a desire for freedom <an *independent* manner>

Does an individual have to be independent to be employed? Certainly not but there does need to be some degree of interdependence.

Main entry: interdependent

Pronunciation: In-ter-di-pen-duh nt

Function: *Adjective*

1. mutually dependent; 2. depending on each other.

Employment Outcomes…

- Howlin, et al (2004) surveyed 68 adults with autism with an IQ of above 50 and found a majority (58%) were rated as having poor or very poor outcomes. With regards to employment status they found
  - 8 were competitively employed
  - 1 was self employed earning less than a living wage
  - 14 worked in supported, sheltered or volunteer employment
  - 42 had "programs" or chores through their residential provider.

These less than positive outcomes, however, are best understood as systems failures rather than the failure of individuals with ASD

Job Description

- Job Title: Autism Professional
- Salary: Often less than you deserve if you do this right
- Hours: Whatever is needed
- Expectations:

CHANGE SOMEONE'S LIFE!

A major challenge to facing adults with autism is that nobody goes to college to work with adults with autism. Kids with autism? Sure. Adults with autism? Not so much.

Other challenges include, but are not limited to:

- Insufficient transition planning
- Limited training opportunities
- Poor job/instructional match
- Historical misconceptions regarding the employability of persons with disabilities
- Discontinuous services
- Dearth of services
- Limited public interest
- Limited professional interest
- Inadequate autism awareness and continued misconceptions
- Splintering of our limited resources

"A major difficulty confronting those interested in adolescents and adults with autism is a lack of empirical data."

(Mesibov, 1983, p. 37)

Considerations toward successful employment for learners with ASD

- There is a need to redefine work readiness
- Job sampling with sufficient instructional intensity to develop competencies is critical
- Developmental jobs v. Career Development
- A service economy requires one to be proficient at job carving
- Co-worker training and/or personal advocacy
- Job match considerations
- Autism Awareness needs to promote competence over disability
- Attend to the social dimension of the job

Skill Sets Have Three Parts

- Social
- Production
- Navigation

What is Job Match?

- Job Match is the extent to which a particular job meets the individual's needs in terms of challenge, interest, comfort, camaraderie, status, hours, pay & benefits. Ideally, as we move through the job market, we get closer and closer to our ideal job match.

Components of The Physical Job Match

- Hours of employment
- Acceptable noise levels
- Pay, benefits, vacations, holidays, etc
- Acceptably activity levels
- Physical requirements of the job (e.g. Lifting)
- Quality control requirements
- Production requirements

Components of the Social Job Match

- Acceptable level of interaction
- Clear job expectations
- Navigation skills
- Grooming and hygiene
- Communication skills relevant to environment
- Personal space
- Phone/vending/cafeteria
- Co-worker training and support

A Guide to Employers

When working with employers:

- Know your limitations and your clients strengths
- Move from "doable" to more challenges tasks
- Obtain specific job description
- Obtain specific assessment information
- Obtain specific "chain of command" information
- Don't waste their time
- Always be honest and open… Do not promise more than you can deliver

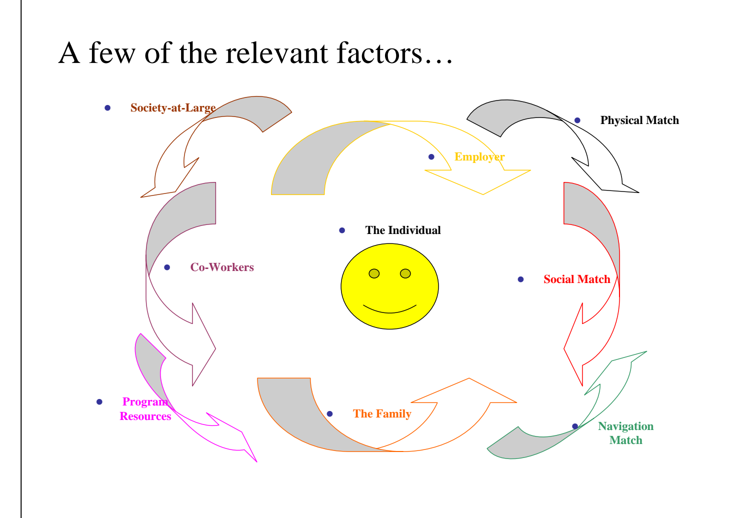
Coordinating with the Business Community: The Business Advisory Council

- Access to the needs of the business world
- Access to the business to human services dictionary
- Networking, networking, networking
- Allows for direct consumer input
- Ongoing consultation and support
- Generates good will

In the end, effective employment development and support requires a reconceptualization of who our constituents are to include:

- *Individual with an autism spectrum disorder*
- *Their family*
- *Their employer and coworkers*
- *The community-at-large who benefits from their work.*

A few of the relevant factors…



The Individual

- Was there adequate and intensive transition programming provided prior to graduation?
- What are the individual's interests?
- What are the individual's areas of strength? Of deficit?
- What are their current communicative competencies?
- What level of support will the individual need in the areas of life, social, and navigation skills?
- What safety skills do they possess?
- What job experience (if any) does the individual possess?
- What was the experience of the employer and the individual prior to graduation.

The Physical Match

- Is the space accessible and other individuals willing to accommodate
- Challenging work that is, in effect, "doable".
- Job site that will not make the individual anxious..such as loud noises, smell, lights etc.
- Does the job require the individual to stand or to sit? Walk or remain in one place? Start early or start late?
- Is the job environment too hot, cold, loud, dark, etc.?
- Are the physical demands of the job compatible with the abilities/preferences of the individual (i.e. heavy lifting, etc.)?

The Social Match

- What social skills need to be assessed prior to employment (based upon on-site observation)?
- Will there be ample time for social interactions with other employees?
- Does the job require too much social interaction with co-workers? Customers?
- Does the employer offer after hours social activities such as softball, bowling, etc.
- What type of dress code does the job require?
- How might the physical environment affect the social demands of the job (cubicle vs. desk, seat near a doorway, etc.) Can they be modified?

The Navigation Match

- Safe and manageable environment
- Close proximity to home or accessible by reasonable transportation options.
- Can the individual navigate all components of the environment (elevators, stairs, cafeteria, restrooms etc.)?

The Family

- Families are full partners in the process
- What is the family's overall vision of employment for the individual?
- Maintain high (yet reasonable) expectations for their son or daughter in terms of employment
- Support and encourage the individual to remain employed
- Assurances and commitment of attendance
- Keep channels of communication open
- Be willing to provide transportation in a pinch.
- Is there someone in the family who has an "in" at a potential place of employment (ex. Family business)?

Program Resources

- Highly trained, dedicated and qualified staff and administration
- Commitment to career development v. job placement
- Able to offer training to employers and co-workers
- Understands that businesses are not nonprofits.
- Commitment to data-based decision making and evidence-based practice
- Reasonable staff to client ratio
- Access to reliable transportation
- Assurances and commitment of attendance
- Intensive support in early stages of employment followed by data driven and structured fading
- Clear, high expectations of the individual.

The Employer

- Willing to commit to time and sensitive to accommodations
- Does the employer have experience of employing individuals with disabilities?
- Is willing to be part of the team on a regular basis
- Are able to define clear expectations and duties for employee.
- Able to promote equality and fairness to all employees.
- Able to empower the individual
- Does not look at this job as a "Token" or favor (i.e., Realistic and needed job, not one made up for the individual)
- Is willing to allow training for co-workers?
- Can identify areas of need for the employer/business?

Supervisory Support…

- Hanger & Cooney (2005) interviewed the supervisors of 14 successfully employed individuals with autism to examine their supervisory practices and their perceptions of employees with autism. Supervisors evaluated their employees with autism highly, and qualitative analysis found that a set of specific supervisory accommodation strategies were commonly associated with successful supervision. These included:
  - maintaining a consistent schedule & set of job responsibilities;
  - using organizers to structure the job
  - reducing idle or unstructured time
  - being direct when communicating with the employee, and
  - providing reminders and reassurances.

Co-workers

- Willing to participate in training
- Are there co-workers who can be counted on for support if needed (i.e. "natural supports)?
- Willing to treat all coworkers the same
- Willing to be honest and candid
- Sensitive to, and accepting of, any special accommodations.

Society-at-Large

- Accept the individual as a contributing member of the community
- Avoid "feeling sorry" for the individual.
- Empower the individual
- Accept the "gifts" the person has to offer
- Respect the person as any employed adult in a job that is job socially significant, of value to the community, and personally fulfilling/significant for the individual?

The Social World

What do we mean by the term "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. Please note that social behavior is reinforced by the response to the behavior (i.e., we are only social for a reason)

The Hidden Curriculum

- The values, strategies, beliefs and behaviors that are necessary but untaught parts of successful learning have been called the "hidden curriculum." Unfortunately, those who did not pick up these habits are less successful. The solution, say some educators, is to provide plenty of opportunities for direct instruction in the attitudes and skills needed for good performance.

- Indiana State University Center for Teaching and Learning

  http://www.indstate.edu/ctl/tips/tip2_7.html

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.

Issues Effecting Social Skills

Nonverbal Interactions
Reciprocal Interactions
Theory-of-Mind Deficits
Abstract or Inferential Thinking
Problem Solving Abilities
Working Memory Deficits
Attribution Patterns
Stress
Lack of Self-Awareness
Ability to Self-Regulate Behavior
Language Comprehension Problems
Ability to Generalize
"Show me the money"

Reference: Social Skills Training, Jed Baker, Ph.D., Autism Asperger Publishing Company, 2003

Necessary, Preferred and Marginal Skills

Task	**Necessary: Skills upon which independence may depend (social survival)**	**Preferred: Skills that support independence but may not be critical**	**Marginal: Skills that, while valuable, may be negotiable (social competence)**
Riding Mass Transit	Wait until others get off before you get on	Whenever possible, chose a seat where you are not sitting next to someone	Whenever possible, put a row between you and other passengers
Lunch with co-workers	Eat Neatly	Respond to interaction from co-workers	Initiate interactions with co-workers
Hallway Greeting	Respond to the greeting with acknowledgement (head nod)	Orient briefly toward the person and offer acknowledgement	Orient, acknowledge and answer greeting including use of person's name

Some Recommendations as to Research Questions Relative to Community Employment

Research Questions Related to Employment

- **The Individual**
  - Evidence-based practices in transition planning inclusive of CBI
  - Assessing personal preference (e.g., Lattimore, Parsons & Reid, 2002) relative to employment (e.g., job sampling).
  - Assessment of effective communicative competences on the job.
  - Determining parameters of job match & job carving.
  - Skills or skill sets which may be most closely related to employment success (i.e., work readiness).
  - Strategies to promote generalized community safety skills.
  - Strategies to promote social and behavioral inclusion on the job for learners across the spectrum.
  - Quality-of-life as an outcome measure in employment research
  - And so on…

Research Questions Related to Employment

- **The System**
  - Employment statistics inc. hours, wages, benefits and type of job.
  - Access to, and utility of, SSA Work Incentives for adults with ASD.
  - Employer characteristics most closely associated with employment success.
  - Analysis of employer financial benefits beyond tax incentives.
  - Effective methods of staff training and long-term support.
  - Effective methods of co-worker training and support.
  - Assessment of cost-effectiveness in supporting individuals across the spectrum in actual employment
  - And so on…

Research Questions Related to Employment

- **The Family**
  - A state by state assessment of the challenges families face in accessing post-21 services in general.
  - Family expectations and concerns regarding community employment.
  - Congruence of family goals with type and extent of community employment.
  - Evidence-based practices in support of family inclusion in the transition and post-transition process and programs.
  - Multicultural differences which may impact family comfort with, and participation in, supported employment initiatives.
  - Identification and development of effective support services or systems for families of adults with ASD.
  - And so on…

Quality of Life as a Transition Outcome

Quality of Life is Not a New Concept

Not life, but good life, is to be chiefly valued.

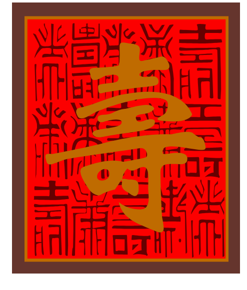
Socrates (469 BC - 399 BC)

QOL as a human right?

All persons enjoy the "right to be left alone, [ ] the privilege of an individual to plan his own affairs,… to shape his own life as he thinks best, do what he pleases, go where he pleases [ ] the freedom to walk, stroll or loaf."

Supreme Court Justice William O. Douglas (1973)

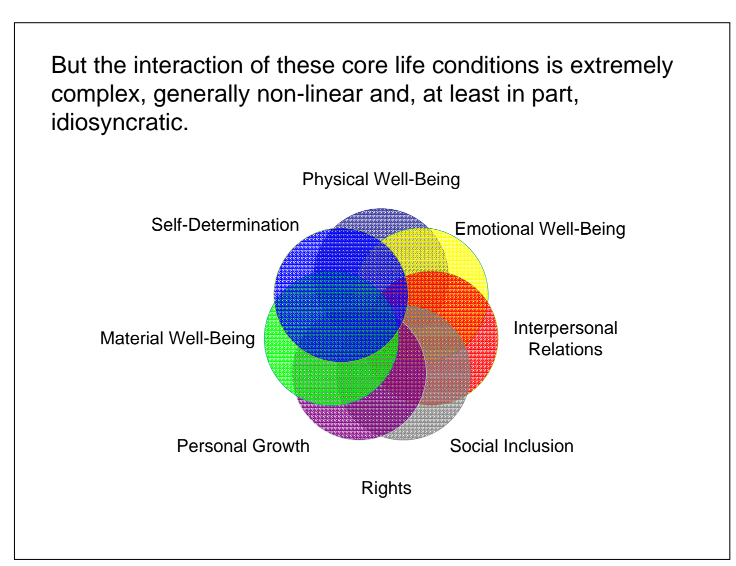
But what is meant by "Quality of Life?"



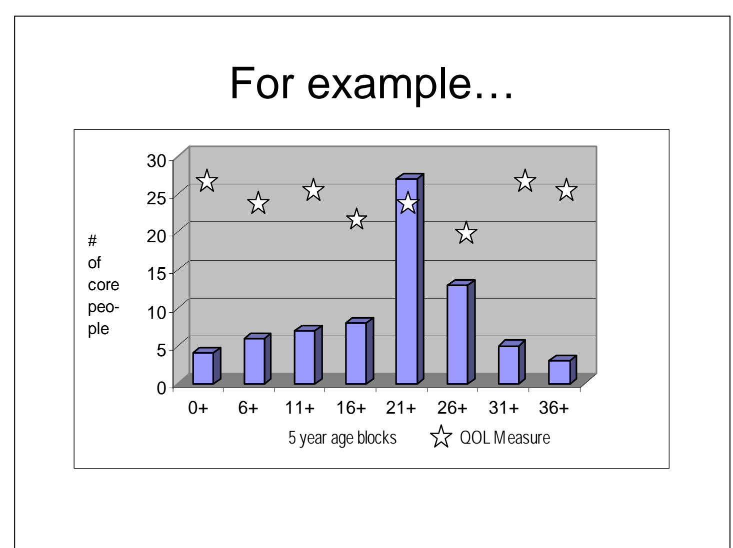
What does QOL mean? (R. Schalock, 2001)

- Quality of life 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.*

But the interaction of these core life conditions is extremely complex, generally non-linear and, at least in part, idiosyncratic.



For example…



We subsequently can operationally defining QOL by what it is by using certain "core indicators" For Example:

Life Condition	Physical Well-Being	Social Inclusion	Material Well-Being	Self-Determination
Examples of Core Indicators	Physical Health	Community Participation	Finances	Autonomy and Control
	Access to Health Care	Community Roles	Employment	Choices
	Access to Leisure	Social Supports	Housing	Person Centered

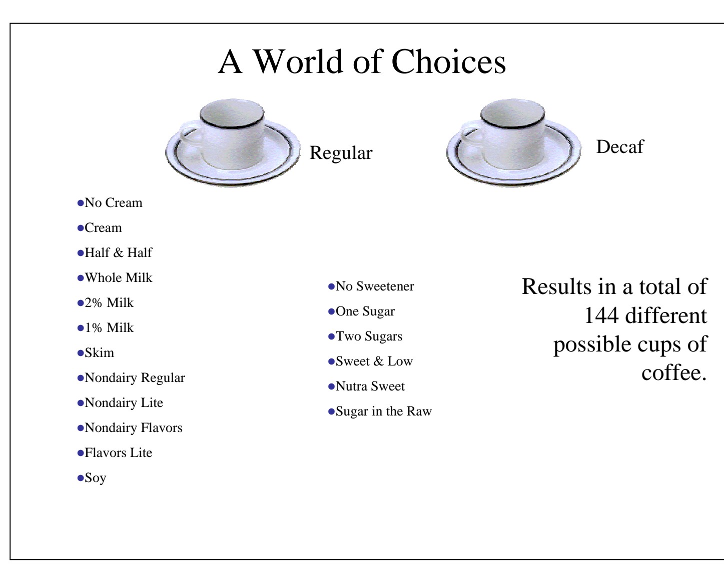
Schalock, Robert (2001)

Choice, control and competence in QOL…

Choice, Control, and Competence in QOL: CHOICE

- The ability to make uncoerced choices and have those choices honored is integral to one's perception of QOL. From the moment we wake up each day we are presented with choice making opportunities that may impact our lives. Should I hit the snooze? Should I have breakfast? What should I wear today? And so on … How well we make these choices, and how frequently our choices are, if not granted, at least acknowledged, greatly contributes to our personal sense of well being: our Quality of Life

A World of Choices



Choice, Control, and Competence in QOL: CONTROL

- We all desire some degree of control over our fates. Much of this sense of control we get by making or, at least, participating in decisions that directly impact us. The more control we exhibit over decisions relevant to our lives, the more satisfied we feel as a person and the greater our sense of well being: our Quality of Life.

Choice, Control, and Competence in QOL: COMPETENCE

- The interplay between choice and control is an area called competence. We generally chose to engage in tasks where we have some demonstrated or emerging level of proficiency. We may control the situation along such parameters as how long we work on a task, whether we work in public or in private, or whether we give up on a task all together. The better we are at some personal and public assortment of tasks, the better our sense of well being: our Quality of Life.

What variables are most likely to enhance the QOL of different individuals at different times in their lives?

	Choice	Control	Competence
Childhood	Simple "either/or" choices	Limited	Access to tangibles
Middle School	Development of choice making skills & repertoire	Intermittent	Access to tangibles self scheduling & monitoring
Transition	"Dignity of Failure" becomes issue	Intermittent across multiple settings	Job sampling outcomes, access to tangibles x settings, self sched.
Young Adult	Where to work, live, eat, vote, etc. Risk/ Benefit Analysis	Moderate across settings & routines	Job w/ career path, access to tangibles x settings, self sched., desired social life
Adult	Where to work, live, eat, vote, sleep with, etc.	Significant	A life

Some final thoughts on QOL

"…happiness among people with profound multiple disabilities can be defined, reliably observed, and systematically increased" supporting the fact that "the contributions of behavior analysis for enhancing the quality of life among people with profound and multiple disabilities may be increased significantly."

C. Green & D. Reid, 1996

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, now 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

Thank you!

Sexuality and Sexuality Education for Learners with ASD

Peter F. Gerhardt, Ed.D.

February 15, 2008 **1:00 pm - 3:30 pm**

About The Presenter

Dr. Peter Gerhardt is President of the Organization for Autism Research, a nonprofit organization, the mission of which is to fund applied research and disseminate the relevant findings in support of learners with Autism Spectrum Disorders and their families. Dr. Gerhardt has over 25 years experience utilizing the principles of Applied Behavior Analysis in support of adolescents and adults with Autism Spectrum Disorders in educational, employment, and community based settings. He is the author or co-author of articles and book chapters on the needs of adults with autism spectrum disorder, the school-to-work-transition process, assessment of social competence, and analysis and intervention of problematic behavior. He has presented nationally and internationally on these topics. Dr. Gerhardt received his doctorate from the Rutgers University Graduate School of Education. Dr. Gerhardt was recently awarded the John W. Jacobson Award for Significant Contributions to Effective Behavior Intervention by New York State ABA.

Dr. Gerhardt has been an active member of Maryland ABA since relocating to Maryland (from New Jersey) 6 years ago and he is currently the President-Elect. Previously, he had served on the Board of Directors on New York State ABA and was a founding director of Connecticut ABA.

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Training Description

Persons with an autism spectrum disorder (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 and at different stages in their lives. As such, there is a significant need for individualized, effective instruction for persons with ASD across the ability spectrum. Unfortunately, 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) in general, and autism spectrum disorders in particular. This presenation will address the potential translation of instructional strategies based upon behavior analytic principles to the area of sexuality instruction for learners with ASD. In addition, particular areas of instruction and challenges (both individual, familial, and systemic) will be discussed.

Training Objectives

On completion of this workshop, participants will be able to:

- Provide an overview of the components of sexuality education
- Recognize the importance of sexuality education as one component of community safety training
- Recognize some of the challenges to effective sexuality education specific to learners on the autism spectrum.

Sexuality & Sexuality Instruction with Learners with Autism Spectrum Disorders

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

Why ABA to teach sexuality?

- 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.

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.

Sexuality Defined

- "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)

Historical Considerations (Sobsey, 1994)

- Eugenics Movement
  - Starting in the late 1800's laws were passed banning marriage or sexual intercourse involving women with a developmental disability or epilepsy (Sobsey, 1994).
  - Between 1907 & 1957 (and later in some cases), some 60,000 individuals with a developmental disability were sterilized without their consent or, at times, knowledge.

Historical Considerations (Sobsey, 1994)

- Both programs were designed to 1) protect learners with a developmental disability from sexual abuse and 2) eliminate developmental disabilities by restricting reproduction.
- Until the mid-1960s such actions remained relatively commonplace with displays of sexuality by learners with developmental disabilities punished as inappropriate or deviant.

Myths about Sexuality

- In the community at large, there continue to exist a number of myths regarding sexuality and learners with ASD including:
  - Persons with ASD and other developmental disabilities have little or no interest in sex.
  - Persons with ASDs and other developmental disabilities are hypersexual.
  - Persons with ASD 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.

But consider this…

- Individuals with ASD may have sexual feelings that are out-of-sync with their level of social development and awareness
- As kids grow older, their social and sexual skill sets are likely to become more disparate with their chronological age and appearance
- Other people, however, will base expectations on their chronological age, NOT their developmental age

(American Academy of Pediatrics, 1996; Koller, 2000; Volkmar & Wiesner, 2004)

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.

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.

Some 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

Accessing 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

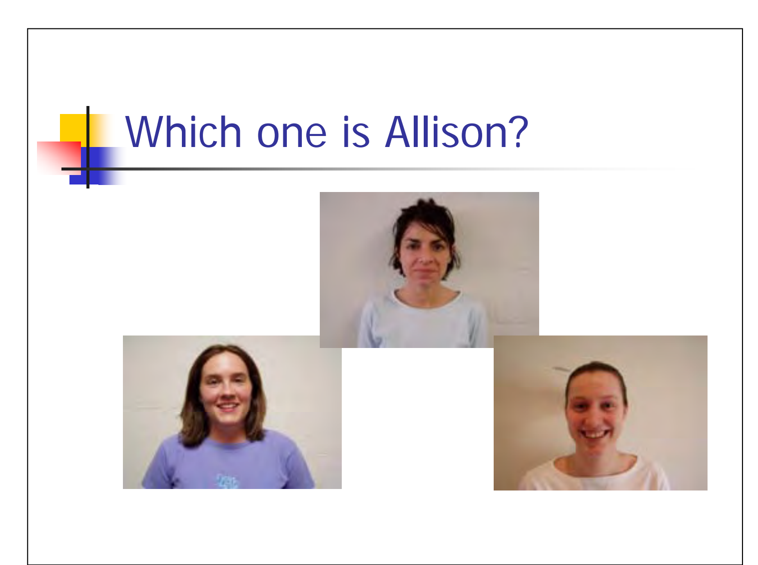
Teaching materials

- Creating your own is easy, less costly, and often more situationally appropriate
- 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)

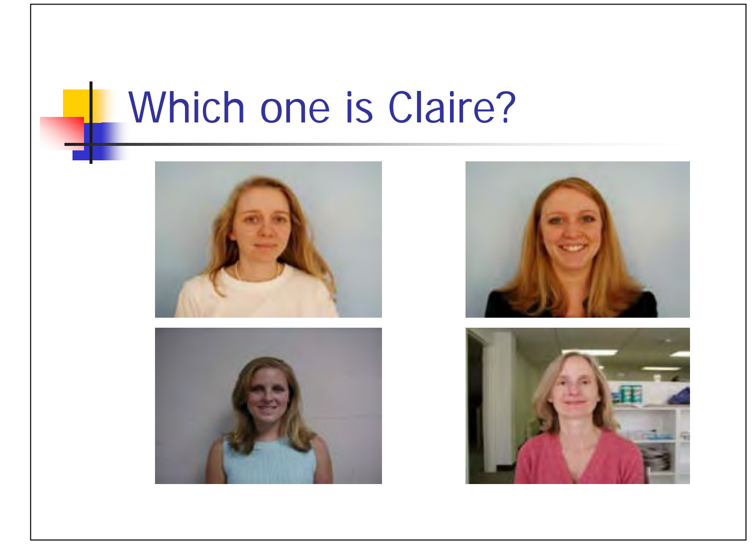
Guidelines for making materials

- Individuals with autism may attend to irrelevant details, so avoid visual clutter and make the relevant stimuli obvious
- Skills that are not generalized are not useful skills, so provide multiple examples of the same concept to aid generalization
- For example…

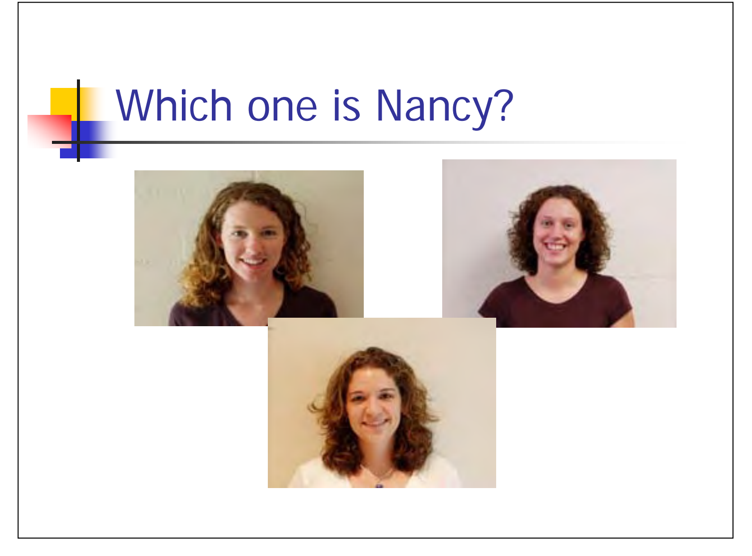
This is Allison


Which one is Allison?

This is Claire


Which one is Claire?

This is Nancy


Which one is Nancy?

Which is Nancy?

A final guideline

- 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

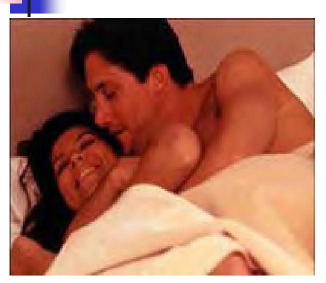
http://www.ural.ru/gallery/news/people/sex/bed.jpg

Q: What does this picture show?

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

(Konstantareas & Lunsky, 1997, p. 410)

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

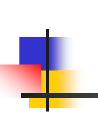


http://www.reuniting.info/images/0bedSM.jpg

Q: What is this man doing?

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

(Konstantareas & Lunsky, 1997, p. 411)



Goals of a comprehensive sexuality education

- Provide accurate information
- Develop personal values
- Develop the necessary social competence

Goals of Comprehensive Sexuality Education: 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

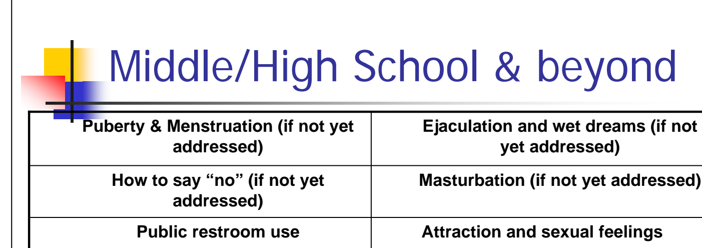
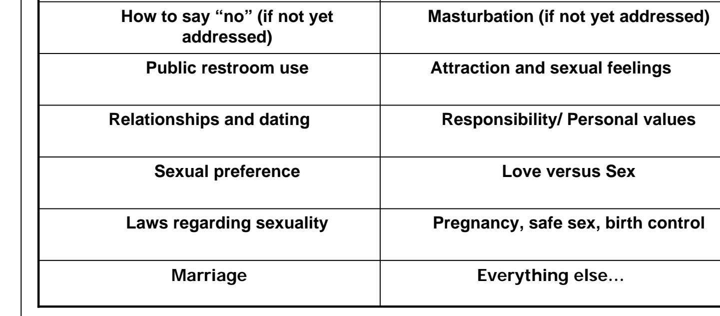
- Public versus private behavior
- Good touch versus bad touch ™
- Proper names of body parts
- "Improper" names of body parts
- Personal boundaries/personal spaces
- Masturbation
- Avoidance of danger/Abuse prevention
- Social skills and relationship building
- Dating skills
- Personal responsibility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

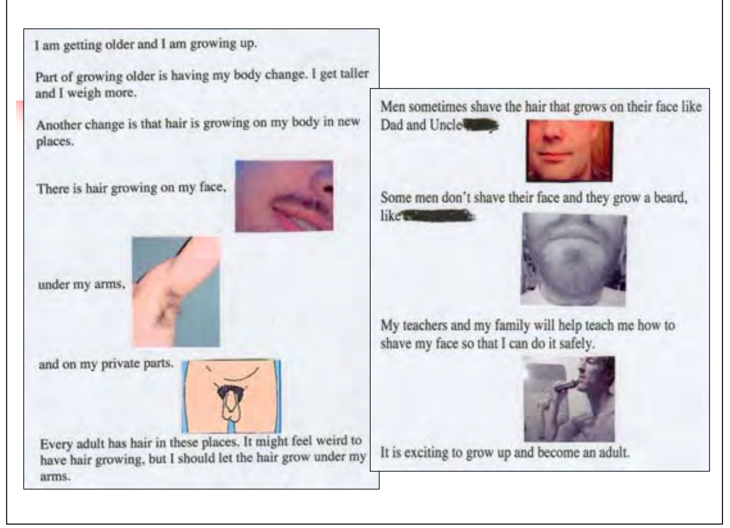
Middle/High School & beyond

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	**Responsibility/ Personal values**
Sexual preference	**Love versus Sex**
Laws regarding sexuality	**Pregnancy, safe sex, birth control**
Marriage	**Everything else...**

The same techniques we use to teach other skills...

- Can be used for sexuality education, too. For example:
  - 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)

Just for the record…

- 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
- 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)

Goals of Comprehensive Sexuality Education: VALUES

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

Goals of Comprehensive Sexuality Education: SOCIAL

- Promote the development of adequate and effective social repertoires inclusive of:
  - Hidden curriculum items
  - Decision making skills
  - Personal advocacy
  - Peer refusal skills (i.e., a functional "no")
  - Avoidance of dangerous situations
  - Dating

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

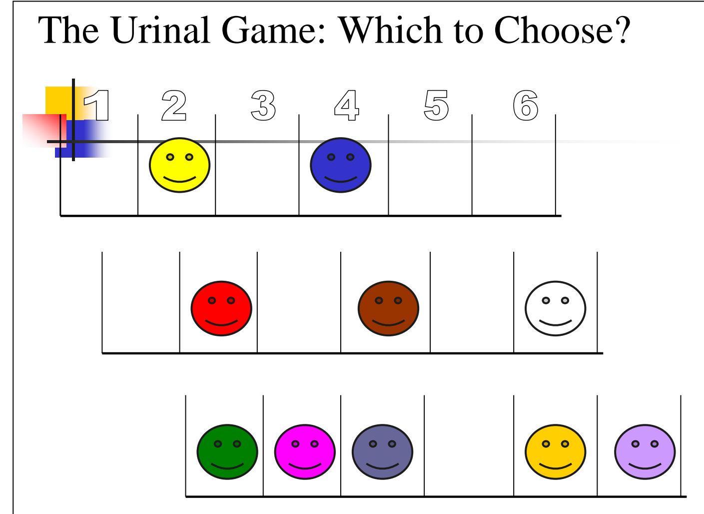
What do we mean by the term "SOCIAL SKILLS"?

- 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.

Social Threads of Discussion From the Douglass Group

- "I just want someone to show me the rules."
- Independence, and respect for one's independence are important.
- "If you NTs have all the skills, why don't you adapt for awhile?"
- Special interests are important.
- It's not so much knowing the skill but using the skill.
- Reports of social isolation are prevalent

The Urinal Game: Which to Choose?



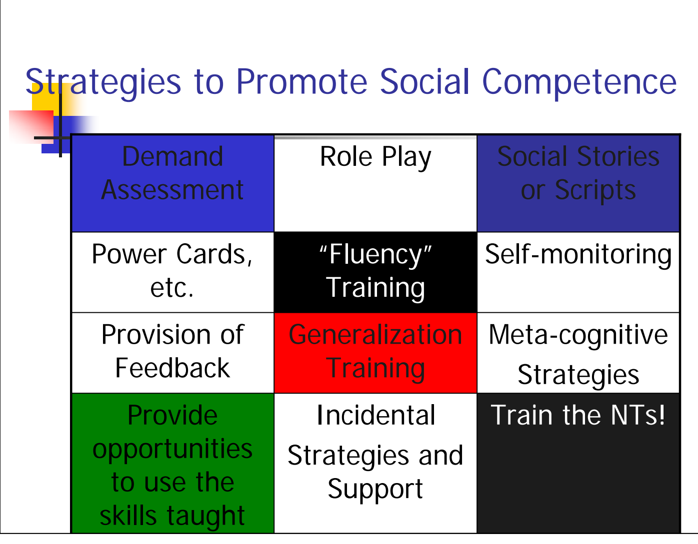
Challenges to Adequate Social Skill Instruction or Support

- The nature of ASD
- Social skills, by their very nature, are variable across environment, time, task, and people
- Social skills have diverse criteria of competence
- Social skill instruction involves both when and when not to use the skill as a function of multiple cues
- Failure, on the part of the instructor, to adequately assess social demands
- Failure, on the part of the instructor, to adequately prioritize social skill instruction
- Failure, on the part of the instructor, to provide sufficient examples and opportunities to use the taught skills
- Failure, on the part of the instructor, to consider providing social skill support and instruction to the NT cohort
- But there are some things that can be done …

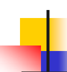
Necessary, Preferred and Marginal Skills

Task	Necessary: Skills upon which independence may depend (social survival)	Preferred: Skills that support independence but may not be critical	Marginal: Skills that, while valuable, may be negotiable (social competence)
Riding Mass Transit	Wait until others get off before you get on	Whenever possible, chose a seat where you are not sitting next to someone	Whenever possible, put a row between you and other passengers
Lunch with co-workers	Eat Neatly	Respond to interaction from co-workers	Initiate interactions with co-workers
Hallway Greeting	Respond to the greeting with acknowledgement (head nod)	Orient briefly toward the person and offer acknowledgement	Orient, acknowledge and answer greeting including use of person's name

Strategies to Promote Social Competence



Demand Assessment	Role Play	Social Stories or Scripts
Power Cards, etc.	"Fluency" Training	Self-monitoring
Provision of Feedback	Generalization Training	Meta-cognitive Strategies
Provide opportunities to use the skills taught	Incidental Strategies and Support	Train the NTs!

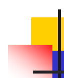


Demand Assessment

- Demand assessment requires that instruction mirrors the actual environmental demands of a particular situation or situations so that those social skills with the greatest functional relevance are those that are taught first.

Role Play

- Role play involves the repeated rehearsal of a particular social situation or situations. If role play is to be effective, it must:
  - Reflect the real environmental demands
  - Be practiced under a variety of conditions
  - Be practiced to a fluency level
  - Low frequency skills may need to be revisited on occasion



Social Stories or Scripts

- Popularized by Carol Gray, social stories or scripts provide a written "lesson plan" for particular social situations from the learner's perspective. Often times, social stories are focused on skill development for identified, challenging situations (e.g., haircuts).

Power Cards

- Power cards (Gagnon, 2001), involve the development of social stories or scripts that directly involve the individual learner's personal interests in an attempt to increase the "power" of the intervention. For example, if a learner with an ASD was a fan of a particular movie, reference to a preferred character in that movie might be included in the script.

Social Fluency

- Instruction in social fluency requires attention to not just the particular skill, but also to the timing with which the skill is most optimally utilized.

Direct Instruction

- Myles & Southwick (1999) discuss direct instruction as a viable method of social skill instruction and support. DI instructional sequence includes
  - Rationale: How and why
  - Presentation: Active and multimodal
  - Modeling: Show what to do (videotape)
  - Verification: Does the learner understand the skill (video modeling)
  - Evaluation: Does the learner use the skill during DI
  - Generalization: Does the learner use the skill outside DI

Meta-Cognitive Strategies

- Sometimes referred to as "learning to learn" strategies, meta-cognitive strategies focus more on teaching social problem solving than on direct skill instruction
  - SOCCSs – Situation, Options, Consequences, Choices, Strategies, <simulations> (Rosa, 1995)
  - STOP – Stop, Think, Options, Pick

Use the Skills

- In social skill instruction, try to focus primarily on those skills used 1) most often and 2) generate the biggest individual payback. Instruction in social skills that that are infrequently used or for which the payback is less obvious (or less desirable) may be particularly challenging for both the learner and the instructor.

Incidental Strategies

- Effective social skill instruction (and goal development) needs to take place across the day and, in particular, outside the context of the instructional settings. Look for opportunities throughout the day to promote and reinforce social competence (and approximations) and develop new, functionally relevant goals.

Train the NTs

- Remember, social skills are bi-directional. Attention may need to be paid to both ends of the interaction.

What about social decision making skills?

- The parameters of choice making go far beyond simple forced choice responses and include:
  - Where to…
  - With whom…
  - When to…
  - What to do before or after…
  - When to end…

Personal factors impacting competent decision making

- Individual's history of decision making
- Individual communicative competence
- Individual social competence
- Long and short term consequences of previous decisions
- Current risk/benefit analysis competencies
- Relationship between current skill sets, desires and rights
- Level of individual support, direction and oversight

Consent…

The Question of Personal Consent

- One's ability to give free and informed consent defines a consensual sexual relationship. Unfortunately, and particularly with reference to more able individuals, this this area is one where there is little consensus regarding the, 1) definition of consent, 2) assessment of competence to give consent, and 3) the implications of current guidelines (or lack thereof) regarding how families and other caregivers might best address an individual's desire to give consent while providing a degree of protection from abuse or exploitation.

Definitions of consent

- The ability to provide consent exists if the person demonstrates an understanding that his or her body is private, of the sexual nature of the act, and has the ability to say "no". (ARC, 1998)
- Other definitions (e.g., Ames & Samowitz, 1995) include the requirements that consent be informed, voluntary, and that the individual demonstrates the ability to act upon knowledge through responsible, interpersonal behavior.

Definitions of consent

- In New York State regulations are in place to ensure that individual rights to sexual expression are not restricted within the limits of ones consensual ability. Determination of ability to offer consent may include (but not necessarily be limited to), the use of some measure of sexual knowledge, an individual assessment and evaluation with particular attention to individual decision making competencies, family input, and input from involved professionals (e.g. psychologists, physicians, etc.).

Definitions of consent

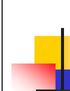
- However, laws as to who may offer consent vary on a state by state basis with some states using guardianship status as a determinant and others requiring specific, documented determinations of competency to offer consent.

Staff Training…

In supporting individuals with ASD in sexuality instruction and activities support staff require training in:

- The sexuality policy of the organization
- Who can teach what to whom
- How and what is being taught
- Definition of abuse, potential abuse situations and statistics on abuse
- What constitutes appropriate client/staff interactions across domains
- Training in respectful provision of personal care training and needs
- Ways to protect individual safety, privacy and personal freedoms
- Ethical decision making
- Training in reporting suspected or actual instances of abuse

The Issue of Sexual Abuse and Exploitation



Sexuality Education – Abuse and Exploitation

- Despite our best efforts, people with developmental disabilities are victims of sexual abuse and exploitation at a rate much higher than that of the NT population. While appropriate education in sexuality issues cannot assure that no person will be the victim of sexual abuse, failure to provide such training would certainly appear to increase the risk.

Sexuality Education – Abuse and Exploitation

- Mythologies related to sexual abuse:
  - There is no real risk
  - Well, he/she would never be in that situation anyway
  - I can ensure 24 protection and guarantee that he/she doesn't even have the opportunity for appropriate sexual relations (denial of individual rights) let alone inappropriate ones

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

We can teach 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)

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

Case Study Discussion I
(adapted from Watson, Griffiths, Richards & Dykstra, 2002)

- An 8 year old girl named Caroline has an autism spectrum disorder and a seizure disorder currently controlled though medication. Her receptive comprehension is greater than her expressive vocabulary although both are limited. She is generally independent in toileting, showering, and dressing but often requires supervision to ensure "quality control". Although she is only 8, staff have discussed with the family the possibility of starting menstrual care training with Caroline.

Case Study Discussion I
(adapted from Watson, Griffiths, Richards & Dykstra, 2002)

- Is it necessary to start menstrual care training now?
- What restrictions might be put on any such training?
- What might be taught regarding her need for some supervision in the bathroom, showering or dressing?
- Is Caroline potentially vulnerable to sexual abuse?
- Who has the final say?

Case Study Discussion II
(adapted from Watson, Griffiths, Richards & Dykstra, 2002)

- Peter is a 16 year old student with an ASD diagnosis. Peter attends high school where half his classes are in special education and half, including gym, in general education. Recently, there have been three reports of Peter masturbating after gym class. Peter has a girlfriend, Susan, who is 15 and attends the same school where she is enrolled, part time, in special education classes. Initially, Peter and Susan would see each other only at school as neither set of parents approved of their dating because of their ages and disabilities.

Case Study Discussion II
(adapted from Watson, Griffiths, Richards & Dykstra, 2002)

- Teachers have recently observed the couple becoming more intimate (e.g., holding each other closely for extended periods of time, kissing in the hallway). When approached about their behavior in school, they generally reply that "They are in love and everyone else is doing it."

Case Study Discussion II
(adapted from Watson, Griffiths, Richards & Dykstra, 2002)

- Should sexuality education be provided to Peter and Susan?
- Should it be done in the context of the special education or regular education curriculum?
- Should they be taught separately or together?
- What should be taught?
- To what extent should sexual intimacy be part of this instruction?
- Should staff receive training?
- To what extent should both families be involved?

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