



**Bridges to Adulthood for
Learners With Autism Spectrum
Disorders: Targeting Skills for the
Next Environment**

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The Organization for Autism Research

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



What is applied Research?

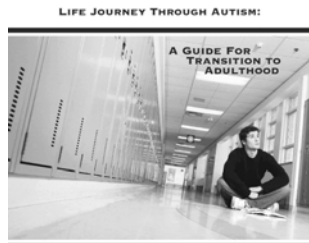
- *Applied research is direct, systematic research in support of individuals and families impacted by an autism spectrum disorder diagnosis and the systems charged with educating these learners across their lifetimes. Applied research addresses issues of practical importance, social significance, and 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.*

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.

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*
 - Parent's Guide to Assessment (2008)
- Annual "Applied Autism Research and Intervention" Conference
- The 2006 and 2008 OAR Autism Research Convocations
- www.researchautism.org website



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

The Organization for Autism Research

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
- But please note, 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

So in summary...

- ABA is an individualized, person centered approach
- The usefulness of ABA in both skill acquisition and behavior reduction is very well documented
- ABA uses both proactive and reactive intervention strategies, often concurrently
- Treatment outcome is often measured in terms of generalization and maintenance in real life environments
- Assessment in ABA is ongoing
- Attempts at skill acquisition and behavior reduction are both highly individualized

Transition Planning for
Competent Adulthood

To start with...

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

(Mesibov, 1983, p.37)

A search of the PsychINFO data-base using "autism" in the title & bounded by the year of publication resulted in:

Publication Years 1994-1995	Publication Years 2003-2004
Number of "Hits" 385	Number of "Hits" 2,400+

But, a search of the PsychINFO data-base using "autism" and "adolescent or adult" in the title & bounded by 5 years of publication resulted in:

Publication Years 1990-1995	Publication Years 2000-2005
Number of "Hits" 45	Number of "Hits" 234

It's more complex than you think...

"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 understanding 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

In other words, you need to become a conditioned reinforcer.

With adults, sometimes, we just don't understand what the standard should be...

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

- Jim Sack

There continues to be limited interest in adults and a persistent belief that they have "maxed out" in terms of skill development

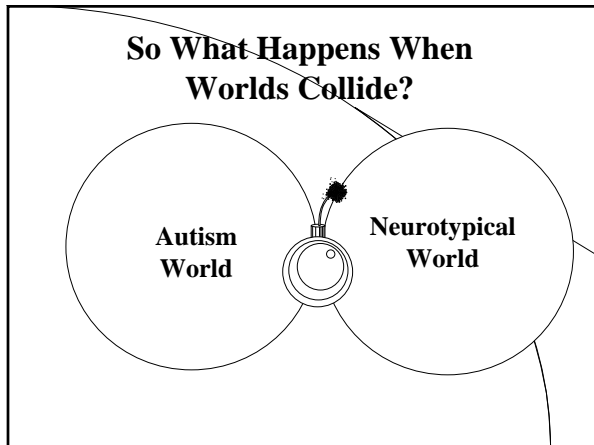
Nobody, it seems, goes to college to work with adults with autism.

Kids with autism? Sure. Adults with autism? Not so much.

Despite how evidence-based your interventions are...

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

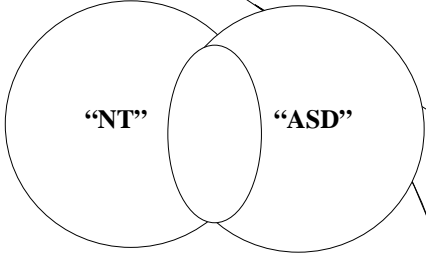
So it seems we need to do it different, and do it better



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

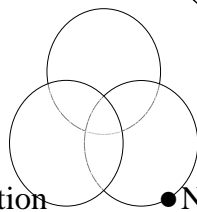
The diagram shows a single circle centered in the lower half of the box, labeled "NT".

This, however, may not be the most efficacious approach. Instead:



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.

Skill Sets Have Three Parts



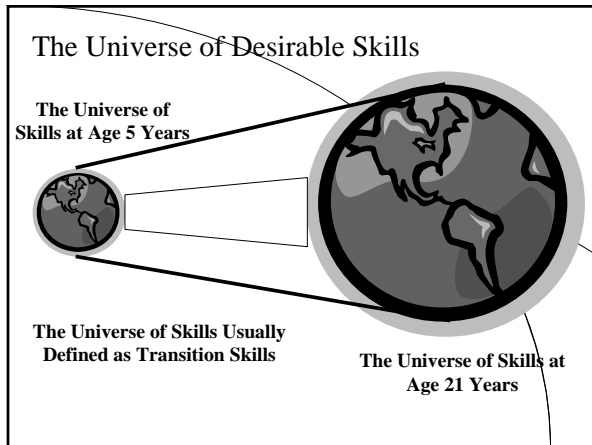
- Social
- Production
- Navigation

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.



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

PROBLEMATIC BEHAVIOR IN ADOLESCENTS 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

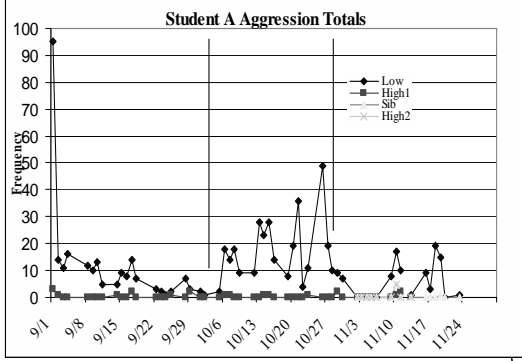
- Limited access to reinforcement
- Low tolerance to change
- Difficulties with unstructured time/Restricted leisure skills repertoire
- Selective attention by support staff
- Confusion
- Difficulties with waiting or delaying R+
- Poor environmental congruence
- Inability to exercise appropriate control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

Indicators of a Medical Correlate to Problematic Behavior

- The unexpected appearance of a new behavior or the significant increase in an existing, defined behavior
- Identifiable patterns of behavior associated with certain biological phenomena, e.g., menstrual cycle, allergies, constipation, medication reaction etc.
- The identification of external correlates is elusive
- Family history of medical challenges
- R/O the possibility of a secondary psychiatric diagnosis including depression, bi-polar disorder, obsessive-compulsive disorder, etc.



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!

**Transition Planning for
Competent Adulthood**

**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 (contextual)
- A continual programmatic focus through the functional use of skills (socially valid)
- Aware of individual and family preferences, as well as community demands (contextual)
- Focused on the pragmatic use of communication (socially valid)
- Including attention to the social skill dimension of most activities (contextual)
- In general, extremely hard work (i.e. requires significant response effort)

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?”

Some Useful Transition to Community Skills

Personal Mobility	Safety Skills
Seeking Assistance	Endurance
Quality Control/ Self Checking	Functional Communication
Self Monitoring of Behavior	Age Referenced Clothing & Hygiene

So Why These Skills?

Because they are all skills that are useful across multiple environments.

**Four Basic Transition Skills
Relevant to All Students**

1. The ability to assess themselves including skills and abilities and the needs associated with their disability
2. Awareness of the accommodations they might need
3. Knowledge of their rights to these accommodations, and
4. The advocacy skills necessary to express their needs across multiple environments.

This, in other terms, is self advocacy. Self advocacy is global term for an individual's ability to effectively and appropriately argue on their own behalf for change that is directly relevant to their own lives. Given that, perhaps the more correct term for this ability is simply, advocacy.

Specific Areas of Advocacy Instruction

- Legal and civil rights
- Service acquisition and choice
- Personal safety
- Social relationships
- Sexual relationships
- Choice and control

Some Poorly Understood Forms of Advocacy

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

Support in the workplace

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

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.

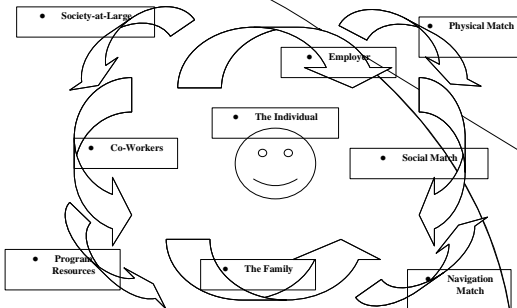
Considerations toward successful employment for learners with ASD

- 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
- Autism Awareness needs to promote competence over disability
- Attend to the social dimension of the job
- Job match considerations

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?

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.

**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?”

More Threads ...

- There is little potential for distinction between who they are and their status as a person with AS.
- It’s not so much knowing the skill but using the skill.
- Reports of social isolation are prevalent
- What about empathy between group members?

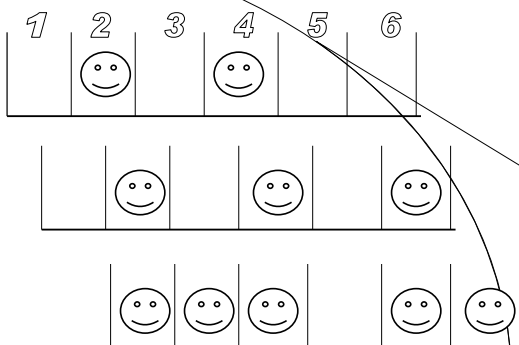
The Increasing Demands of the Social World

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

The Increasing Demands of the Social World

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

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

<i>Task</i>	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)
<i>Riding Mass Transit</i>	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
<i>Lunch with co-workers</i>	Eat Neatly	Respond to interaction from co-workers	Initiate interactions with co-workers
<i>Hallway Greeting</i>	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
Direct Instruction – Video Modeling	Generalization Training	Meta-cognitive Strategies
Provide opportunities to use the skills taught	Naturalistic 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/Video Modeling

- 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

Self Monitoring

- Self monitoring involves providing individual learners with specific strategies for monitoring their own social interactions. This may involve counters, check sheets, palm pilots or timers and may be used in conjunction with other strategies.

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.

Naturalistic 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.

A very brief discussion of the concept of leisure skill instruction

Leisure and Recreation: The Ultimate Choice Activity

- Leisure and recreation skills, by definition, require choice in terms of activity, location, duration, time, partners & access.
- Without attention to any or all of these factors, what may appear to be leisure activities rapidly become work tasks.

Behavioral Indicators That an Activity Is Leisure Rather Than Work Include:

- Independent requests for the activity
- Independent initiation of the activity
- Unanticipated duration of activity
- Absence of problematic behavior during activity
- Individual demonstrates positive affect (calm → happy → joy → euphoria) during the activity
- Individual is reluctant to terminate the activity
- Termination of the activity is associated with negative affect (calm → anxious → agitated → meltdown)

Sexuality & Sexuality Instruction with Learners with Autism Spectrum Disorders and Other Developmental Disabilities

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

Why ABA?

- 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 sexuality.
 - 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.

However...

- 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

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.

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

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

Some guidelines for teaching

- 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

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 School to High School and Beyond..

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

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

- Can be used for sexuality education, 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)

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:
 - 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

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 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.

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 hour 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)

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)

Sexuality Education – Abuse and Exploitation

- As of now, the best defense we can offer individuals with developmental disabilities to be as free from sexual abuse as possible is...

A comprehensive sexuality education!

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

Challenges to Supporting Adults

- Discontinuous services
- Dearth of services
- Limited interest
- Staffing concerns
- Access to adequate medical services
- Issues with the criminal justice system
- Substance abuse issues

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)

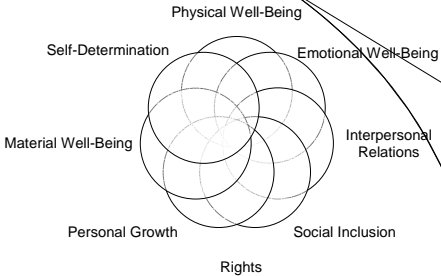
But what is meant by “Quality of Life?”

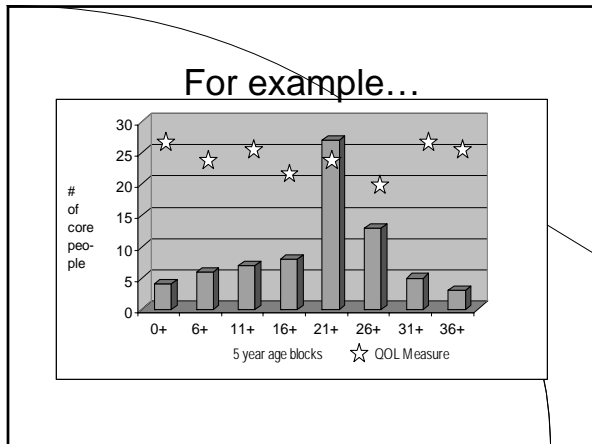


What does QOL mean?
(R. Schalock, 2001)

- 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.





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

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

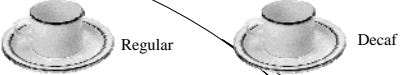
Schallock, Robert (2001)

Choice, control and competence in Quality of Life

Choice, Control, and Competence in QOL: CHOICE

- The ability to make un-coerced 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



- No Cream
- Cream
- Half & Half
- Whole Milk
- 2% Milk
- 1% Milk
- Skim
- Nondairy Regular
- Nondairy Flavors
- Nondairy Lite
- Soy

- No Sweetener
- One Sugar
- Two Sugars
- Sweet & Low
- Nutra Sweet
- Sugar in the Raw
- Splenda

Results in a total of 144 different possible cups of coffee.

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

And in summary...

- Interventions based on the principles of ABA are applicable across skill domains and across the lifespan.
- It is easy to be successful when you set the bar low so think big and have high expectations.
- Start planning early and, certainly, no later than age 16 years.
- To the maximum extent possible, work cooperatively with all involved in the process to the benefit of the teen/young adult with ASD.
- Remember that transition planning is a process and first drafts of ITPs are rarely the final draft.

- Keep your eyes on the prize of your long term transition goals for employment, living or postsecondary education. Frame all your discussions with reference to those desired outcomes. Involve extended family and friends in the process, particularly in the area of employment as they may have contacts and resources you do not.
- Remember, you are a critical part of this process no matter what title you have (parent, speech pathologist, transition specialist, etc.).
- With reference to community skills, remember to teach where the skills are most likely to be used. It is more effective to teach grocery shopping at an actual supermarket than it is to teach it in the classroom

- Identify the level of “risk” with which you are comfortable and then work to maximize independence within that framework. (For example, while you may be uncomfortable with him or her crossing the parking lot of supermarket without close supervision, he or she may not need the same intensity of supervision in the supermarket) As the teen/young adult gains greater independence across tasks and environments, reassess your acceptable level of risk.
- Good, effective transition planning is effortful and time consuming. There are, sadly, no known shortcuts but when it is done well, the outcomes are well worth the effort.

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, 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**

“You must be the change you wish to see in the world”
Mahatma Gandhi