

## Adolescents and Adults with Autism: Evidence-based Practice in Support of Competence and Quality of Life

Peter F. Gerhardt, Ed.D.  
The McCarton School  
Pgerhardt@Mccartonschool.org

Unfortunately, the application of ABA with adolescents and adults with ASD is often understood in very simple terms:

Antecedent (yelling) → Behavior (crying) → Consequence (R+ comfort OR R- yelling stops)

### When in reality it is much more complex

**EOs/Setting Events**

- Learning history
- Adolescence & its impact
- Communication challenges
- Social challenges
- Mental health challenges
- Physical health
- Medication side effects
- Environmental stressors
- Curriculum considerations
- Boredom
- Sexuality
- Sleep issues
- Aging in & of itself
- Yada, yada, yada...

**Noncompliance**

**Professional**

"Huh?"

"Let's go to work"

### So the challenge is to

- Not look for simple solutions to complex problems...

$$\begin{aligned}
 x &= \frac{-b \pm \sqrt{b^2 - 4ac}}{2a} \\
 &= \frac{-3 \pm \sqrt{9 + 40}}{4} \\
 &= \frac{-3 - \sqrt{49}}{4} \quad \text{or} \quad \frac{-3 + \sqrt{49}}{4} \\
 &= -2.5 \text{ or } 1
 \end{aligned}$$

### So the challenge is to

- While not forgetting that sometimes simple solutions work best. Easy, right?

### Understanding ABA as applied to competent adulthood

ABA is a field of inquiry dedicated 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)

### Why are interventions based upon the principles of AB A effective with older individuals?

- ❑ Applied Behavior Analysis is a vast scientific discipline based upon over 35 years of published research.
- ❑ Interventions based up Applied Behavior Analysis recognize the power of positive reinforcement
- ❑ By the way, you should know that in supporting adolescents and adults there are times where previously accepted "prompt hierarchies" may have to be modified as a function of community standards and normative behavior.

### Why are interventions based upon the principles of AB A effective with older individuals?

- ❑ Behavior Analysts respect the role of significant others in the individual's life as *central* to the implementation of an effective intervention
- ❑ Behavior Analysis represents a teaching methodology with tremendous versatility beyond discrete trial instruction
  - Fluency/Rate-base instruction → Instructional Intensity
  - Shaping & Chaining
  - Task Analysis
  - Functional behavior analysis/assessment
  - PRT or NET
  - Incidental strategies
  - OBM, Precision Teaching, Verbal Behavior, Relational Frame Theory
  - Peer Modeling – Environmental/Curricular Modifications

### Why are interventions based upon the principles of AB A effective with older individuals?

- ❑ Instruction based upon Applied Behavior Analysis **DOES NOT** represent a rigid, unyielding, and unalterable set of instructions and/or interactions. In fact, good behavior analysts modify their instructional interventions in response to a slew of conditions, settings and contingencies while maintaining a commitment to data-based decision-making.

### And lastly

"...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

### Happiness? What does behavior analysis have to do with happiness?



- Reid, D. H., Green, C. W., & Parsons, M. B. (1998). A comparison of supported work versus center-based program services on selected outcomes for individuals with multiple severe disabilities. *Journal of the Association for Persons with Severe Handicaps*, 23(1), 69-76.
- Parsons, M. B., Reid, D. H., & Green, C. W. (2001). Situational assessment of task preferences among adults with multiple severe disabilities in supported work. *Journal of the Association for Persons with Severe Handicaps*, 26(1), 50-55.
- Green, C. W., & Reid, D. H. (1996). Defining, validating, and increasing indices of happiness among people with profound multiple disabilities. *Journal of Applied Behavior Analysis*, 29(1), 67-78.
- Green, C. W., Reid, D. H., Rollyson, J. H., & Passante, S. C. (2005). An Enriched Teaching Program for Reducing Resistance and Indices of Unhappiness Among Individuals With Profound Multiple Disabilities. *Journal of Applied Behavior Analysis*, 38(2), 221-233.
- Green, C. W., Gardner, S. M., & Reid, D. H. (1997). Increasing indices of happiness among people with profound multiple disabilities: A program replication and component analysis. *Journal of Applied Behavior Analysis*, 30(2), 217-228.
- Green, C. W., & Reid, D. H. (1999). A behavioral approach to identifying sources of happiness and unhappiness among individuals with profound multiple disabilities. *Behavior Modification*, 23(2), 280-293.
- Green, C. W., & Reid, D. H. (1999). Reducing indices of unhappiness among individuals with profound multiple disabilities during therapeutic exercise routines. *Journal of Applied Behavior Analysis*, 32(2), 137-147.
- Bannerman, D. J., Sheldon, J. B., Sherman, J. A., & Harchik, A. E. (1990). Balancing the right to habilitation with the right to personal liberties: The rights of people with developmental disabilities to eat too many doughnuts and take a nap. *Journal of Applied Behavior Analysis*, 23(1), 79-89.

Some basic challenges to evidence-based practice with older learners

**1**

The prevalence of pseudoscientific or simply unproven interventions leading up to adulthood

Sadly, ASD is a bit of a "fad magnet"

So real science, in the form of peer-reviewed research, is critically important because:

- Seeing is not believing
- Correlation does not mean causation
- With a population of 310,000,000 people, one in a million occurrences happen to 310 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.

I just want to point out

- that, particularly in autism and behavior analysis, we need to exercise caution whenever anybody says you need to "think outside of the box". Why? Because unless they really, really know the box they are just making shit up.

And further...

- The field of ABA is a really, really, really big box with more than enough room for creative thinking without the threat of magical thinking.

*"If more and more people can be convinced that a system of belief is correct, then clearly it must, after all, be correct" (Festinger, Riecken, & Schachter, 1954)*

# 2

“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 Year 1990	Publication Year 2010
Number of “Hits”  126	Number of “Hits”  1,243

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

Publication Years 1990	Publication Year 2010
Number of “Hits”  4	Number of “Hits”  14

Publication Years 1990-2009 Autism and Residential Number of “Hits”	Publication Year 1990-2009 Autism and Employment Number of “Hits”
11	15

Publication Years 1990-2009 Quality of Life Number of “Hits”	Publication Year 1990-2009 Adaptive Behavior Number of “Hits”
12	23



■ The parameters defining successful outcomes for adults are, well, vague at best.

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

- Jim Sack



Providing evidence-based intervention to adults is a more complex process than you might 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 if you are to be an effective behavior change agent.*

### Or some actual data...

McLaughlin, D. M., & Carr, E. G. (2005). Quality of Rapport as a Setting Event for Problem Behavior: Assessment and Intervention. *Journal of Positive Behavior Interventions*, 7(2), 68-91.

Relationship quality (rapport) between people with developmental disabilities and their caregivers has long been suggested as an important variable influencing the likelihood of problem behavior. However, to date, the association between rapport and problem behavior has not been systematically investigated. The authors evaluated a multi-method strategy for assessing rapport and then used the assessment information to develop a multi-component intervention for problem behavior. *In Study 1, a descriptive assessment was carried out in which rapport was operationally defined, and good and poor rapport dyads consisting of staff members and participants were identified. Then, a functional analysis of each participant's problem behavior was conducted with respect to the interaction of two factors: quality of rapport and task demands. The results of the assessment study indicated that when rapport was poor, levels of problem behavior were high; when rapport was good, levels of problem behavior were low. In Study 2, the authors evaluated the effectiveness of a multi-component intervention package designed to improve rapport between the person with disabilities and his or her caregiver. When rapport improved, participants showed a decrease in problem behavior and an increase in task completion in the presence of staff members who had previously been identified as having poor rapport with participants.* The multidimensional nature of rapport assessment, as well as the unique contribution that rapport-building can make to multi-component intervention, are discussed. (PsycINFO Database Record (c) 2010 APA, all rights reserved)

five

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.

Which is further "complicated" by the fact that no one stays in the field.

**Direct Service Turnover in Residential/In-Home and Vocational/Day Services, 1998-2003\***

Setting Type	Number of Studies	Average Rate
Residential/In-home	11	53.6%
Vocational/Day	6	46.0%
Both	9	48.1%
Combined Average	26	50.0%

\*Source: The Supply of Direct Service Professionals Serving Individuals with Intellectual Disabilities and other Developmental Disabilities. Report to Congress (2004). Department of Health and Human Services; Washington DC. Available on line at [http://www.ancor.org/issues/shortage/ispe\\_stp\\_11-09-04.doc](http://www.ancor.org/issues/shortage/ispe_stp_11-09-04.doc).

Given all that, it should come as no surprise that what we do know about adult outcomes should not make us all that happy...

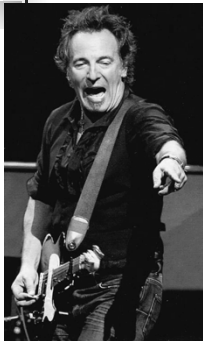
**Adult outcome research**

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

**Adaptive Behavior**

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

**Adaptive Behavior by way of Jersey**

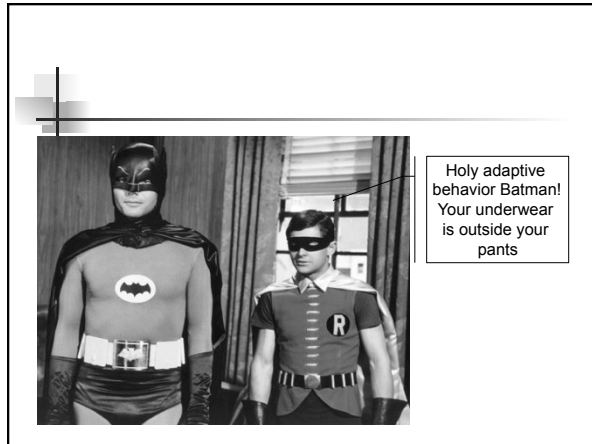


*"We busted out of class. Had to get away from those fools. We learned more from a 3-minute record baby, than we ever learned in school"*

Bruce Springsteen "No Retreat, No Surrender"

**Adaptive behavior and ASD**

- Adaptive behavior is not considered one of the core symptoms of ASD and, as such, receives significantly less attention in terms of effective intervention and current research.
- Despite the exclusionary criterion of "no clinically significant delay in [ ] the development of age appropriate self-help skills [and] adaptive behavior (other than social interaction)" in diagnosing Asperger Syndrome, research indicates that for this group of learners the gap between IQ and adaptive behavior can be marked. (Lee & Park, 2007; Myles, et al, 2007)



## Adaptive Behavior Intervention

SOCS

The parameters of effective intervention in adaptive behavior include:

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

SOCS

## Context

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

## Intensity

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

## Intensity

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

## Efficiency

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

## Transfer of Control

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

## Value

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

## Adaptive behavior and adult outcomes

- In a group of 20 adolescents with Asperger syndrome, Green, et al (2000) found that despite a mean IQ of 92 only half were independent in most basic self care skills including brushing teeth, showering, etc. None were considered by their parents as capable of engaging in leisure activities outside of the home, traveling independently, or making competent decisions about self care.

- 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.

## Two under-researched areas of adaptive functioning in adults



## Sexuality

- 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.

## Sexuality

- 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. they engaged in stalking).

## 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.

## Adaptive Behavior and Incarceration

- Professionals have been aware of high rates of learning and behavior disorders among incarcerated youth for some time (Moffitt, 1990) leading some professionals to characterize the juvenile justice system as a default system for special needs learners with more complex emotional and behavioral challenges (Quinn, et al, 2005)

## Adaptive Behavior and Incarceration

- Paterson, (2008) looked at two adults with Asperger Syndrome incarcerated in the U.K. Both individuals faced challenges understanding the complex formal and informal social hierarchies of prison life and accepting unfamiliar or non-preferred rituals and routines. Both were ultimately placed in a modified form of secure custody for their own safety.

Apparently we need to do things different, do them better, and have more research on which to base our interventions.

First, we tend to focus on the "production" component of adaptive behavior to the detriment of the social and navigation components (i.e., context)

Elevator Behavior

Up and Then Down by Nick Paumgarten. The New Yorker, April 21, 2008, pp. 106-115. Proxemics and US Culture by Judie Haynes. Retrieved from [http://www.everythingsl.net/inservices/proxemics\\_elevator.php](http://www.everythingsl.net/inservices/proxemics_elevator.php) on April 19, 2008.

You Are In An Elevator ...

- What are the rules are for standing in the elevator? Where do people stand when there are only two or three people? What happens when a fourth person enters the elevator?

You Are In An Elevator ...

- What are the rules are for standing in the elevator? Where do people stand when there are only two or three people? What happens when a fourth person enters the elevator?
- If there are only two or three people on an elevator, each person usually leans against the walls. If a fourth person boards the elevator, the four corners are normally occupied.

You Are In An Elevator ...

- What happens when the elevator becomes more crowded and there are now four or more people?

You Are In An Elevator ...

- What happens when the elevator becomes more crowded and there are now four or more people?
- When there are more than four people on an elevator, the occupants begin to follow a complex set of rules for behavior. Everyone turns to face the door. Hands, purses, and briefcases hang down in front of the body. People usually scrunch up, rounding their shoulders, so that they take up as little space as possible.

## You Are In An Elevator ...

- How close will people stand? What is allowed to "touch?"



## You Are In An Elevator ...

- How close will people stand? What is allowed to "touch?"
- People don't touch each other in any way unless the elevator becomes very crowded, and then they only touch at the shoulders or upper arms. If you see an overcrowded elevator, you will probably choose to wait for the next one.

## You Are In An Elevator ...

- What do people look at in a crowded elevator?



## You Are In An Elevator ...

- What do people look at in a crowded elevator?
- Everyone usually looks at the floor indicator located above the door.

## You Are In An Elevator ...

- When is it permissible to talk to the other people?




"You talkin' to *me*!"

## You Are In An Elevator ...

- When is it permissible to talk to the other people?
- It is unusual for strangers to speak to each other in an elevator unless they are sharing some kind of similar experience (such as a conference). People who do know each other will usually speak softly. When a group of people enter the elevator and do not follow these rules, other occupants usually feel very uncomfortable.

**You Are In An Elevator ...**

- If you think this behavior is exaggerated, the next time you are on an elevator, don't face the door. Turn around and face toward the other occupants. See what their reaction is. If you really want to upset everyone, give them a big grin.



With the resulting task analysis looking something like this...

Production (Non-context)	Social (Context)	Navigation (Context)
		Locate elevator
Press correct button		
	Wait	
	When door opens, wait for others to leave	
		Enter elevator
		Turn around
Press correct button or ->	Ask for button to be pressed	
		Adopt appropriate distance from others
Number identification ->		Monitor floor(s)
		Exit elevator at correct floor
		Proceed to destination

- Second**, our repertoire of evidence-based interventions are often used to teach inconsequential skills because they are either easy, safe, or both.

- Anecdotally, there are few skill excesses or deficits that the community-at-large cannot be taught to, if not accept, then tolerate. These include:
  - Extreme aggression/self injury
  - Inappropriate eating/mealtime behavior
  - Inappropriate toileting/restroom use
  - Inappropriate sexual behavior
  - Poor hygiene

- Yet we continue to focus on a subset of skills that we assume to be functional including (but not limited to):
  - Sorting, collating, packaging, assembly
  - Shoe tying
  - Money concepts v. Purchasing skills
  - School-based activities v. Community-based activities
  - Nonfunctional academics (few of us really need to differentiate between a horse and a zebra on a regular basis)

So it seems...

Despite how evidence-based your interventions are, teaching inconsequential skills well is really no better than teaching essential skills poorly.

■ **Third**, in community-based instruction of adaptive skills, there may be a tendency for professionals to focus on the wrong contingencies. That is, there may be greater professional reinforcement available for the absence of "problems" in the community than for any actual skill development by their students

■ **Fourth**, we may need to think and read outside the literature base with which we are most comfortable and most familiar. For example:

**ABA beyond JABA...**

Hagner & 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; (activity schedules/task analysis)
- using organizers to structure the job (visual supports)
- reducing idle or unstructured time (Differential R+ of Alternative behavior - DRA)
- being direct when communicating with the employee, and (present a clear and accurate Sd or instructional directive)
- providing reminders and reassurances (prompting and reinforcement)

**ABA beyond JABA...**

- In the literature on emotional intelligence, social competence is generally described as existing along a continuum from social survival to true social competence and is, to a very large degree, understood as being context bound (Topper, Bremner & Holmes, 2000). This would tend to indicate that teaching social skills (or social adaptive behavior) out of context might be a necessary, but not a sufficient criterion, for future social competence. In addition, their concept of *social survival* implicates response effort as one of the many parameters impacting social competence.

**ABA beyond JABA:  
Social competence & response effort**

	<b>Competence Response Effort</b>		
	Necessary: Skills upon which independence may depend (low response effort or social survival)	Preferred: Skills that support independence but may not be critical	Marginal: Skills that, while valuable, may be negotiable (high response effort or social competence)
<b>Skill</b> <i>Lunch with co-workers</i>	Eat Neatly	Respond to interaction from co-workers	Initiate interactions with co-workers
<i>Halfway 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

**ABA beyond JABA...**

- Adkins, et al, (2002) demonstrated that the behavior plans developed and written by certified behavior analysts were written at a reading level well above those staff whose job it was to implement the plans. Further, the authors found that modifying the readability level of these plans resulted in enhanced treatment outcomes for all individuals in the study. *And the moral to this story is when it comes to training, you are only as competent as your audience will allow you to be.*

Sixth, we need to figure out creative ways to use our technology to get around the boulder...



The Use of Bluetooth® Technology to Promote Independent Responding in the Community: The Reduction of the Stigma of Prompting

**PAAL**

*Preparing Adolescents  
for Adult Life*

Satriale, G., et al, (2008)

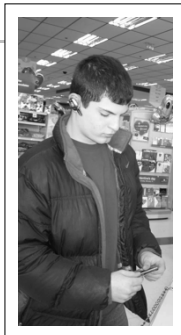
## Purpose

- To examine the extent to which the Bluetooth technology can be used in lieu of gestural prompting during community based instruction.



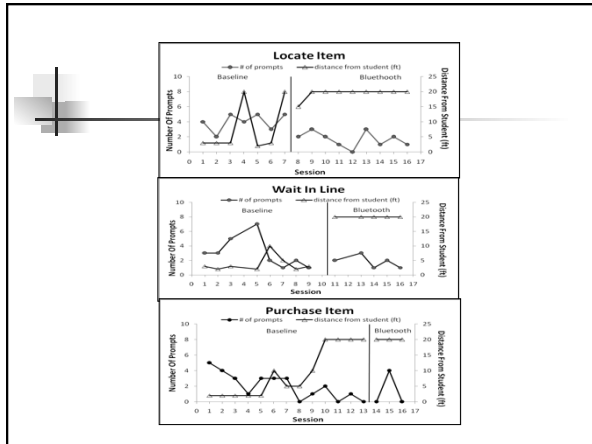
- The use of Bluetooth technology allowed prompting to be delivered from increasingly greater distances.

- Reduced levels of physical and gestural prompting lead to greater independent functioning and reduction of stigma thereby promoting greater levels of social acceptance within the community.



## A secondary benefit

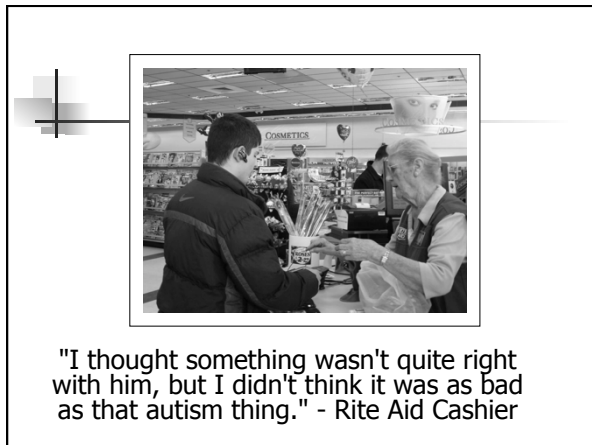
- The participant frequently exhibited non-contextual vocalization across settings. The implementation of the Bluetooth disguised his vocalization as functional communication thereby reducing the stigma associated with this particular behavior.



### And in terms of social validity

- Socially valid behavior interventions are those that
  - Are directed to problems of verifiable importance;
  - Are valued by designated target groups; and
  - Have sufficient impact to change the target behavior.

Winett, R.A., Moore, J.F., & Anderson, E.S., (1991). Extending the concept of social validity: Behavior analysis for disease prevention and health promotion. *Journal of Applied Behavior Analysis*, **24**, 215-230.



So it seems we may need to retire some inaccurate terms...

- Generally, the terms "high" or "low" functioning refer only to cognitive functioning or academic competencies and do not reflect the actual functional capabilities of an individual. "High functioning" individuals may actually function very poorly in terms of adult competencies while some "low functioning" individuals may be quite independent as a function of effective, targeted intervention.

What does ABA have to offer Quality of Life Considerations?



### In case you forgot


"...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

A very quick example re:  
*Happiness*

*Technology: Electronics*  
**MP4 player/ iPod™**

- Purpose:**  
 To reduce stigma associated with one-on-one instruction (close proximity and physical prompts) by providing auditory /visual cues via watch during the workout routines at the local fitness center

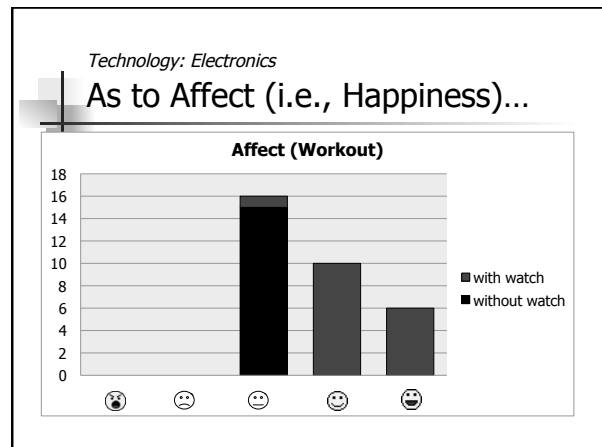
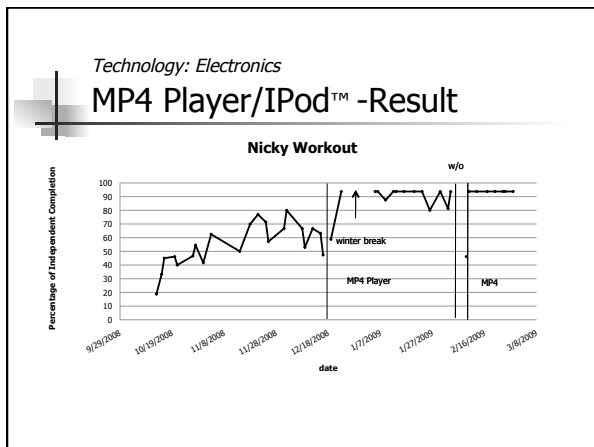


*Technology: Electronics*  
**MP4 player/ iPod™**

- Baseline:**
  - Participants wore the MP4 player watch or iPod and earphones/headphones connected to the device
  - Use written schedule and a portable timer to follow the workout schedule (checking schedule, setting a timer,
  - Partial and/full physical prompts were provided as needed

*Technology: Electronics*  
**MP4 player/ iPod™**

- Intervention:**
  - Participants wore the MP4 player watch or iPod with earphones or headphones connected to the device
  - Verbal directions combined with highly preferred music were given via MP4 player or iPod
  - Partial/full physical prompts were provided as needed





## 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)



Can we really define “Quality of Life?”

## We can start here...

- 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.

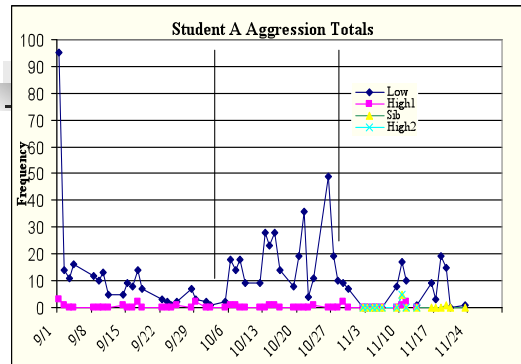
- R. Schalock, (2001)



Choice, control and competence in 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	Options & opportunity re: self sufficiency - Risk/Benefit Analysis becomes critical	Moderate across settings & routines	Job w/ career path, access to tangibles x settings, self sched., desired social life
Adult	Where to work, live, play, eat, worship, who to vote for, sleep with, work with, etc.	Significant	A life



Gerhardt, P.F., Weiss, M.J., & Delmolino, L. (2003). Treatment of severe aggression in an adolescent with autism: Noncontingent reinforcement and functional communication training. *The Behavior Analyst today*, 4, 386-394. Available on-line at <http://www.behavior-analyst-today.com/VOL-4/BAT-4-4.pdf>

### As of 2007...

- His was supported as an adult at less than 1/3 the cost of his educational program
- He was volunteering at the food bank
- He regularly went out to restaurants for a sit down lunches and dinners
- Regularly exercised in the community (walking) 2-3 times per week and at a local gym
- He worked with a wide number of staff with whom he felt comfortable
- In 2006 he was selected as Elk of the Year. He is well liked by all the Elks members!

### And as of 2011...

- His continues to be supported as an adult at far less than his educational cost
- He now works at the food bank
- He independently and safely navigates his home environment with 3-year old child present
- Continues exercising and now has a personal trainer
- Consistently accepts "no" as reasonable response to requests for high calorie foods
- Goes out to lunch with people other than his family
- Remains active in the Elks and other groups

*Be the change you wish to see in the world"*



*Mahatma Gandhi*



### Recommendations for Future Research and Practice

Assessment methods to identify functionally relevant skills (i.e., true adaptive behavior) for development in the community

Effective behavior analytic instruction in community-referenced safety skills. Issues related to long term maintenance

Retrospective studies of "successful v. unsuccessful" adults on the spectrum to help indentify effective strategies and interventions

Effective methods of community training to promote great levels of social inclusion for learners with ASD across multiple environments

### Recommendations for Future Research and Practice

Effective models of transition intervention resulting in more positive outcomes.

Cost-benefit analyses of current models v. less "facility-based" models of adult services and support

Issues related to staff recruitment and retention

Family support issues and intervention for parents of adults

## Recommendations for Future Research

Implications of fluency-based interventions on the development of adaptive responding with older learners

Competency-based models of staff training in the provision of community-based instruction

Implications of instruction in social survival skills v. more typical social competence skills.

Effective instruction in the areas of sexuality and sexual safety

Models of therapeutic intervention in the criminal justice system

## Selected References

- Ceferlund, M., Hagberg, B., Billstedt, E., Gillberg, C., & Gillberg, C. (2008). Asperger syndrome and autism: A comparative longitudinal follow-up study more than 5 years after the initial diagnosis. *Journal of Autism and Developmental Disorders*, *38*, 72-85.
- Glennon, T.J. (2001). The stress of the university experience with students with Asperger syndrome. *Journal of Assessment, Prevention, and Rehabilitation*, *17*, 183-190.
- Green, J., Gilchrist, A., Burton, D., & Cox, A. (2000). Social and psychiatric functioning in adolescents with Asperger Syndrome compared with conduct disorder. *Journal of Autism and Developmental Disorders*, *30*, 279-293.
- Hagner, D., & Cooney, B.F. (2005). "I do that for everybody": Supervising employees with autism. *Focus on Autism and other Developmental Disabilities*, *20*, 91-97.
- Ivey, J. K. (2007). Outcomes for students with autism spectrum disorders: What is important and likely according to teachers? *Education and Training in Developmental Disabilities*, *42*, 3-13.

## Selected References

- Lattimore, L. P., Parsons, M. B., & Reid, D. H. (2006). Enhancing job-site training of supported workers with autism: A reemphasis on simulation. *Journal of Applied Behavior Analysis*, *39*, 91-102.
- Lee, H.J., & Park, H.R., (2007). An integrated literature review on the adaptive behavior of individuals with Asperger syndrome. *Remedial and Special Education*, *28*, 132-141.
- Mazefsky, C., Williams, D., & Minshew, N. (2008). Variability in adaptive behavior in autism: Evidence for the importance of family history. *Journal of Abnormal Child Psychology*, *37*, 921-928.
- McClannahan, L. E., McGee, G. G., MacDuff, G. S., & Krantz, P. J. (1990). Assessing and improving child care: A personal appearance index for children with autism. *Journal of Applied Behavior Analysis*, *23*, 469-482.

## Selected References

- Mesibov, G.B., Current perspectives and issues in autism and adolescence. In E. Schopler & G.B. Mesibov (Eds), *Autism in Adolescents and Adults*, (pp. 37-56). New York: Plenum
- Myles, B.S., Lee, H.J., Smith, S.M., Tien, Y., Swanson, T.C., & Hudson, J. (2007). A large scale study of the characteristics of Asperger syndrome. *Education and Training in Developmental Disabilities*, *42*, 448-459.
- Okuda, K. (2001). Toilet training for an adult with autism, severely disturbing behavior, and mental retardation 23-31. *Japanese Journal of Special Education*, *39*, 23-31.
- Quinn, M.M., Rutherford, R.B., Leone, P.E., Osher, D.M., & Poirier, J.M. (2005). Youth with disabilities in juvenile corrections: A national Survey. *Exceptional Children*, *71*, 339-345.
- Smith, M. D., & Belcher, R. (1985). Teaching life skills to adults disabled by autism. *Journal of Autism and Developmental Disorders*, *15*, 163-175.

## Selected References

- Stokes, M., Newton, N., & Kaur, A. (2007). Stalking, and social and romantic functioning among adolescents and adults with autism spectrum disorder. *Journal of Autism & Developmental Disorders*, *37*, 1969-1986.
- Topper, K., Bremner, W., & Holmes, E.A., (2000). Social competence: The social construction of the concept. In R. Bar-on & J.D.A. Parker, (Eds.), *The Handbook of Emotional Intelligence*, (pp. 28-39). San Francisco: Jossey Bass.
- Taylor, B. A., Hughes, C. E., Richard, E., Hoch, H., & Coello, A. R. (2004). Teaching teenagers with autism to seek assistance when lost. *Journal of Applied Behavior Analysis*, *37*, 79-82.
- Watanabe, M., Uematsu, T., Kobayashi, S., (1993). Teaching community skills (bus riding) to students with autism. *Japanese Journal of Special Education*, *31*, 27-35.
- 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