Adolescents and Adults with Autism: Evidence-based Practice, Adaptive Behavior, and Quality of Life

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What’s ahead?

“The current economic slowdown may well lead to significant cutbacks in services and supports for people with developmental disabilities” [1]. “Overall, the demand for community services is growing rapidly due to aging family caregivers, litigation promoting access to community services, the increasing longevity of persons with developmental disabilities, and the downsizing of public and private institutions. This growing demand is frequently unanticipated by federal, state, and local agencies, resulting in a crisis for families and state and local service delivery systems.”

David L. Braddock, Ph.D., Executive Director
Coleman Institute for Cognitive Disabilities
Source: http://www.aaid.org/index.cfm

What’s ahead?

• The next decade or so is Hurricane Katrina for adults with developmental disabilities. Every state has cut Medicaid services in response to the economic crisis and, historically, when states cut Medicaid services they are cut for a long time.” (Ellen Blackwell, CMS, 2010).
• Outcome studies of adults with ASD document that, independent of current ability levels, the vast majority of adults with ASD are either unemployed or underemployed. Some reports indicate under- or unemployment at 90%.
• The vast majority of adults with autism continue to live with parents, siblings or older relatives.

So perhaps a better mission statement would be:

The mission of autism education is to provide comprehensive, integrated, individualized, and data-based services to adolescents with autism resulting in independent employment, social inclusion, and community competence. As such, graduates will exit the program:

• Not just employable but employed a minimum of 20 hrs/wk;
• Not just with social skills but with a social support network centered around where they live, work, and recreate;
• Not just with the ability to follow directions but with the ability to initiate actions on their own, and;
• Not just under our stimulus control but under the stimulus control of the environment and their ability to manage their own behavior.
As individuals with ASD grow up, there remains this tendency to try and understand them in relatively simple terms. For example:

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

When in reality life 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...

"Let’s go to work"

So the challenge is to

Not look for simple solutions to complex problems...

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

Understanding ABA intervention 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)

Understanding ABA as applied to competent adulthood

- Contrary to what some might have you believe ABA is, in fact, the most person centered intervention that we currently have available.
- ABA represents a teaching methodology with tremendous versatility beyond discrete trial instruction
  - Fluency/Rate-based instruction → Instructional Intensity
  - Shaping & Chaining
  - Task Analysis
  - Functional behavior analysis/assessment
  - PBIS or MTSS
  - Incidental strategies, Group contingencies
  - CRM, Precision Teaching, Verbal Behavior, Relational Frame Theory, Acceptance Commitment Therapy, Behavioral Economics
  - Video Modeling - Environmental/Curricular Modifications, Yada, yada, yada
Understanding ABA as applied to competent adulthood

Behavior analysts recognize the power of positive reinforcement.*

*(though we often fail to use to this power well or wisely)

A favorite autism quote

“...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?

Active Student Responding Exercise 1

• ABA based interventions are highly effective in promoting behavior change (i.e., desirable outcomes) in our students and clients. Unfortunately much of what is understood as ABA translates into DTI which may have somewhat limited applicability with older learners. Among the behavioral based instructional interventions that may be more relevant are:
  1. Rapid Prompting Method (RPM)
  2. Precision Teaching
  3. Sensory Integration
  4. Shaping and Chaining
  5. Both 2 & 4
  6. Both 1 & 4

You need to download and read this article. Really. You do.
A few of the many challenges to evidence-based practice leading to improved quality of life.

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

And I would note that the beauty of science is not that I get to be right all the time but that I get to know when I am wrong and change direction.

"A failure is not always a mistake, it may simply be the best one can do under the circumstances. The real mistake is to stop trying.”

B.F. Skinner

I just want to point out

• that, particularly in autism 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 sh*t up.

“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:

<table>
<thead>
<tr>
<th>Publication Year</th>
<th>Publication Year</th>
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</thead>
<tbody>
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<td>Number of “Hits”</td>
</tr>
<tr>
<td>126</td>
<td>1,429</td>
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Same search using "autism" and "adolescent or adult" in the title & bounded by year of publication resulted in:

<table>
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<tr>
<th>Publication Years</th>
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<td>1990-2011</td>
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<td>Number of “Hits”</td>
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<tr>
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</tr>
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</table>

III

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
ASD is more than the sum of its parts -- even its behavior analytic parts


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

<table>
<thead>
<tr>
<th>Setting Type</th>
<th>Number of Studies</th>
<th>Average Rate</th>
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<tbody>
<tr>
<td>Residential/In-home</td>
<td>11</td>
<td>53.6%</td>
</tr>
<tr>
<td>Vocational/Day</td>
<td>6</td>
<td>46.0%</td>
</tr>
<tr>
<td>Both</td>
<td>9</td>
<td>48.1%</td>
</tr>
<tr>
<td>Combined Average</td>
<td>26</td>
<td>50.0%</td>
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Active Student Responding Exercise 2

- The volume of peer reviewed autism intervention research has grown exponentially in the past decade in almost all areas except:
  1. Development of joint attention
  2. Effective early intensive behavioral intervention
  3. Chelation
  4. The needs of adolescents and adults with ASD
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 Outcomes & Adaptive Behavior

• 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 that 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).

A focus on adaptive behavior is not a move toward simplifying curriculum

• Adaptive behavior competencies:
  • Are not characterized by ADL skills
  • Supplement academic skill instruction.
  • Are more complicated than inferential calculus
  • Involve both simple and complex decision making skills
  • Central to application of academic competencies
  • Are not always highly preferred skills but, then again, some are.

Adaptive behavior is important because the world does not always play by the rules

Adaptive Behavior Intervention

The parameters of effective intervention in adaptive behavior would appear to include:
1. Context – Where instruction takes place
2. Intensity – How often instruction takes place
3. Efficiency – What is the response effort/equivalence associated with instruction
4. Transfer of control – Where does stimulus control lie
5. Value – Why might this skill be important to the student
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.

With the following definitions

- **Functionality**: the degree to which a skill, if acquired, can be applied across multiple environments, domains, or toward accessing individual preferences, interests, or desires.
- **Degree of Independence Granted**: the degree to which the acquired skill reduces dependence upon another individual across multiple environments.
- **Acceptable Error Rate**: the level of error that would be expected under typical conditions for a skill to be considered mastered.
- **Acceptable Level of Risk**: the level of risk to self or others, if error level is exceeded or that may be present during training. The risk of not providing instruction may be considered as separate level.
- **Individual Enjoyment**: the extent to which an individual will be able to access reinforcement through the participation in, or demonstration of, the skill.
- **Relationship to Community Inclusion**: The extent to which mastery of the skill allows the individual to navigate increasingly diverse and complex environments or communities.

Can we maybe relook at, say, generalization of adaptive behavior in ASD?

- Research indicates that individuals with ASD demonstrate challenges in generalization.
- Yet, we all know kids who generalize operation of the DVD/Blue Ray player from unit to unit, from house to house, and from home to school without any intervention.
- The question then becomes to what extent the absence of generalization of other skills is due to:
  1. Our failure to attend to context as a critical variable?
  2. Our failure to provide sufficient opportunities to respond that may be necessary for true mastery?
  3. Our failure to consider the relationship between skill value and the effort needed to complete the skill?
  4. Our failure to transfer control from the classroom environments to the world outside?

Sexuality: 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.
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. they engaged in stalking).

So if insanity is repeatedly doing the same thing while expecting a different outcome, perhaps we need to consider some changes in our behavior.

• Second, maybe we should expand our sphere of intervention to include skills that are valuable but difficult, and perhaps even a little risky to teach..

Active Student Responding Exercise 3

• In providing intervention in the area of adaptive behavior instruction:
  1. It is always best to teach out of context.
  2. The “value” of the skill (i.e., the usefulness of the skill in obtaining reinforcement) can play a role in acquisition, maintenance and generalization.
  3. Only primary reinforcers should be used.
  4. It is generally best to provide instruction where the behavior is most likely to be displayed.
  5. 2 and 4 but mostly 4.

First, maybe we should expand sphere of intervention to include community members.

"I thought something wasn’t quite right with him, but I didn’t think it was as bad as that autism thing.”
Rite Aid Cashier

• For example, 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 (and safe) including, but not limited to:
  • No Student Left Untested Standards of Learning
  • Sorting, collating, packaging, assembly
  • Worksheets in all their many forms
  • 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 in adulthood)

So to my ABA colleagues please remember that despite how evidence-based your interventions are, teaching inconsequential skills well is really no better than teaching essential skills poorly. What we teach needs to be as important as how we teach.

• Third, maybe we should expand our sphere of intervention such that we are providing our students and adults sufficient learning opportunities need to acquire a given skill or skill set. For 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.

• Fourth, 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.

Active Student Responding Exercise 4

• In providing behaviorally based intervention to adolescents and adults on the spectrum parameters and/or targets of intervention should include:
  1. The community in which the person lives.
  2. Complex and/or potentially risky skills.
  3. A sufficient number of opportunities so that a skill may be acquired.
  4. A commitment to data-based decision making.
  5. Have some direct relationship to the overall goals for each individual.
  6. All of the above.
Quality of Life as a Transition Outcome

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
What is quality of life?

• 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)

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

<table>
<thead>
<tr>
<th>Stage</th>
<th>Choice</th>
<th>Control</th>
<th>Competence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Childhood</td>
<td>Simple “either/or” choices</td>
<td>Limited</td>
<td>Access to tangibles</td>
</tr>
<tr>
<td>Middle School</td>
<td>Development of choice making skills &amp; repertoire</td>
<td>Intermittent</td>
<td>Access to tangibles, self scheduling &amp; monitoring</td>
</tr>
<tr>
<td>Transition</td>
<td>“Dignity of Failure” becomes issue</td>
<td>Intermittent across multiple settings</td>
<td>Job sampling outcomes, access to tangibles x settings, self-sched.</td>
</tr>
<tr>
<td>Young Adult</td>
<td>Options &amp; opportunity re: self sufficiency - Risk/Benefit Analysis becomes critical</td>
<td>Moderate across settings &amp; routines</td>
<td>Job of career path, access to tangibles x settings, self sched., desired social life</td>
</tr>
<tr>
<td>Adult</td>
<td>Where to work, live, play, eat, worship, who to vote for, sleep with, work with, etc.</td>
<td>Significant but still variable</td>
<td>Areas of success and accomplishment – An actual life.</td>
</tr>
</tbody>
</table>

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!

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

Selected References


Selected References


