Ethics, Evidence-based Practice and Socially Important Outcomes in ASD: Using the Right Intervention at the Right Time and in the Right Context

Cambridge Center for Behavior Studies
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The EPIC School

Educational Partnership for Instructing Children
What are Socially Important Outcomes for Adults with Autism Spectrum Disorders?


They concluded that the evidence base about services for adults with an ASD is underdeveloped and can be considered a field of inquiry that is relatively unformed.

As a result of analyzing data from the NLTS-2 it is clear that “young adults with autism have a difficult time following high school for almost any outcome you choose - working, continuing school, living independently, socializing and participating in the community, and staying healthy and safe. To complicate matters, many of these youth begin their journey into adulthood by stepping off a services cliff. Access to needed supports and services drops off dramatically after high school – with too many having no help at.” Roux, et al, 2015, p. 8

You may not know this but...

Nearly everything “systems-focused” in the adult services world is based on philosophical orientation and not on any scientifically valid determination of the best, or most appropriate or effective outcomes.

“Residentially, the outcome literature on group care is scant, and current knowledge about its effect on targeted outcomes is mostly based on studies with small non-representative samples, and weak study designs, lacking control groups and standardized measures.” (James, 2011. p. 308)

Some Basic Characteristics of Adulthood in the U.S. Include:

- Employed and able to maintain personal needs.
- Independence across environments.
- Able to make and maintain friendships.
- Able to make both simple and complex choices and make preference known if a functional way.
- Recognizes and responds to challenges to safety.
- Maintains patience and flexibility.
- Learns from mistakes.
- Capable of managing temper and anger.
- Able to distinguish between ‘needs’ and ‘wants’.
- Handles pressure in a socially appropriate manner.
- Recognizes that actions have consequences.
- Has leisure skill repertoire.
- Engages in diverse, yet consensual, sexual relationships.
Some Characteristics NOT Generally Regarding as Defining Adulthood in the U.S.:

- Responding to a timer on a 5-minute interval
- Naming all 50 states
- Sorting 500 colored beads
- Demonstrating unearned compliance to authority
- Correctly answering the questions, “How old are you?” and “When is your birthday?”
- Completing worksheets during “downtime”
- Responding to greetings only if presented in the same way every time
- Identifying the stages of the moon
- Reading 500 sight words
- Factoring a binomial equation.
- Identifying weights and measures but cannot apply either to cook a meal.
Into this fray steps the Behavior Analyst
The need to be a generalist

If you work with young kids you get to be a specialist. Whether you’re a special educator, speech pathologist, occupational therapist, or board certified behavior analyst, you get to be a specialist. When working with adolescents and young adults you don’t get to be a specialist and, instead, need to be something of generalist. In other words, you need a good working knowledge of ABA, Education Law, Labor Law, Mental Health concerns, medication side effects, sexuality, menstrual care, job development, job coaching, community-based instruction, generalized systems of communication, staff training, community training, and that’s just to start.
Thankfully...

Applied behavior analysis has myriad applications far beyond ASD so my knowledge, expertise, and experience in the ABA/ASD field is pretty generalizable these other areas of need.
But within our own field, while much of the skill acquisition research in children with ASD may be directly applicable in adolescence and adulthood, this is not true across all adult aspects and environments. This is because many of the skills associated with independent adulthood (e.g., personal safety, sexuality, etc.) are complex behavior chains that may, or may not, be repeated the same way every time.
For example, chaining has been demonstrated as being an effective way to teach a young student the necessary behavior sequence for zipping up a jacket (e.g., Walls, Zane, & Ellis, 1981)

Classroom TA - Zippering

1. Grasp the bottom edges of the front of the jacket at the base sides of the zipper with left and right hands, one of each side of opening and pull edges horizontal till zipper ends close.

2. Use left thumb and forefinger in pincer grasp on zipper above larger inset tooth at the bottom of the zipper.

3. Grasp zipper pull on the right side of the jacket with right thumb and forefinger in pincer grasp.

4. Line up the edges of the zipper, and then move the zipper pull side under the left teeth.

5. Guide the zipper pull hole on the left side of the pull-tab onto large guide tooth of the left side of the zipper.

6. Push with your right middle finger braced under the base of the zipper pull while holding the left side of the zipper so it does not move. OR hold the right zipper pull stationary while pushing the left tooth down into the zipper pull hole.

7. When the large left tooth reaches the bottom of the zipper pull hole (you can turn over the zipper pull and see the tooth edge when it is all the way into the zipper pull), hold the base of the jacket next to the large left tooth with your left forefinger and thumb, and with your right forefinger and thumb in a pincer grasp (with middle finger removed from the base of the zipper), pull with the zipper pull tab up along the zipper until the slide reaches neck height.
However, the TA for grocery shopping is more complex with variability at multiple steps resulting in a significantly more complex skill acquisition challenge impacting the effectiveness of simple chaining.

### Community Referenced Grocery Shopping Task Analysis

<table>
<thead>
<tr>
<th>Step</th>
<th>Level of variability</th>
<th>Production Skill – Low Difficulty</th>
<th>Social Skill - Difficult</th>
<th>Navigation Skill – Medium Difficulty</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Low</td>
<td>Low</td>
<td></td>
<td>Enter store</td>
</tr>
<tr>
<td>2</td>
<td>Low</td>
<td>Check shopping list</td>
<td></td>
<td>Locate and hand basket</td>
</tr>
<tr>
<td>3</td>
<td>Medium</td>
<td></td>
<td>Throughout store avoid bumping other shoppers</td>
<td>Head to first aisle</td>
</tr>
<tr>
<td>4</td>
<td>High</td>
<td></td>
<td>Throughout store respond to social courtesies</td>
<td>Stop at correct spot</td>
</tr>
<tr>
<td>5</td>
<td>Low</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>Medium</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>Low</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>Low</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
So what are essential skills?
A draft definition of “essential skill”

- Any skill that, when acquired, enables the individual to independently complete a variety of relevant tasks and engage in desired activities, AND

- Any skill that is used with sufficient frequency to remain in the individual’s repertoire. The exception here are safety skills which, ideally, are low response frequency skills AND

- Any skill that can be acquired within a reasonable time frame*. 

* Time frame is to be defined by further study and consultation.
## FREQUENCY OF USE

<table>
<thead>
<tr>
<th></th>
<th>Objective</th>
<th>≥ 1X/day</th>
<th>1X/day</th>
<th>2-3X/Wk</th>
<th>1X/Wk</th>
<th>1-2X/Mnt</th>
<th>Less Frequent</th>
<th>Importance*</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>“When is your birthday?”</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>X</td>
<td>0</td>
</tr>
<tr>
<td>2</td>
<td>“Where do you live?”</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>X</td>
<td>2</td>
</tr>
<tr>
<td>3</td>
<td>Wiping after BM</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>2</td>
</tr>
<tr>
<td>4</td>
<td>Make a meal with recipe</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>X</td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>5</td>
<td>Make meal with Microwave</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>X</td>
<td></td>
<td>2</td>
</tr>
</tbody>
</table>

0 = Not Important; 1 = Maybe important but not essential; 2 = Important
The Essential Eight
(McGreevy, Fry, & Cornwall, 2012)

1. Making requests (EFL, Domain 1):
2. Waiting after making requests (EFL, Domain 1):
3. Accepting removals, making transitions, sharing, and taking turns (EFL, Domain 1):
4. Completing 10 consecutive, brief, previously acquired tasks (EFL, Domain 1):
5. Accepting ‘No’ (EFL, Domain 1):
6. Following directions related to health and safety (EFL, Domain 2):
7. Completing daily living skills related to health and safety (EFL, Domain 4):
8. Tolerating situations related to health and safety (EFL, Domain 6):

But a simpler approach can be found outside of Behavior Analysis

What you do EVERY DAY matters more than what you do ONCE IN A WHILE.

— Gretchen Rubin

Can our Professional Ethics Guide Us Here?

How important are ethics in today’s society?
Ethics defined

**Ethics** – 1) the discipline dealing with what is good and bad and with moral duty and obligation.
2) A set of moral principles: a theory or system of moral values often. 3) *the principles of conduct governing an individual or group.*

What Ethics Isn’t

1. The same as “feelings” although our feelings may help inform our ethical choices.
2. Synonymous with religion. Many people are not religious, but ethics applies to everyone.
3. Defined by following the law. A good system of law does incorporate many ethical standards, but law can deviate from what is ethical.
4. Simply following culturally accepted norms. Some cultures are quite ethical, but others become corrupt or blind to certain ethical concerns.
5. A science, although social and natural science can provide data to help make better ethical choices.

Values and Ethics are NOT the Same

**Values** are the basic beliefs an individual holds to be true. In that way, values can be said to constitute the guiding principles of an individual’s life.

**Ethics** is a set of rules formulated by a country, company, profession, or organization designed to guide the behavior of its members. Ethics is not focused on the individual but rather on the entire organization.
To outsiders, our terminology can trigger a “values alarm” that has nothing to do with the actual ethics of the situation. For example:

- Punishment
- Control, aversive control, stimulus control
- Conditioning
- Abolishing Operation
- Avoidance
- Time-Out
- Shaping

Evidence-based intervention, or more accurately, empirically validated intervention, refers to those treatments or interventions that have attained a recognized standard of research validation. These stand independent of one’s ability to utilize such interventions.

Evidence-based practice, on the other hand, is commonly understood as the integration of empirically validated interventions with clinical expertise. To be engaged in evidence-based practice requires an extensive knowledge of the field, extensive experience working in the field, and a commitment to remaining current with the research in the field. Evidence-based Practice focuses entirely on one’s ability to appropriately utilize evidence-based interventions.
In real life, context is critical

“Behavior analysts often emphasize the need to study the effects of ABA procedures in the context of typical practice settings (e.g., Johnston, 1996). However, reviews indicate that the large majority of our research focuses on interventions delivered by study personnel, usually in tightly controlled environments such as laboratories, specialized ABA classrooms, or distraction-free areas set up to provide one-to-one instruction [ ]. This discrepancy may reflect a dilemma that behavior analysts have had trouble resolving: We recognize that conducting studies in practice settings may require sacrificing some scientific rigor because the primary mission of such settings is to deliver services rather than conduct research (Johnston, 1996), yet we regard the quality of many studies in these settings as unacceptable (Johnston et al., 2006).” (Smith, 2013)

So this whole topic is annoyingly complex
A few basic choices regarding valued and socially important adult outcomes?

- Community employment versus Day Habilitation Program
- Live at home versus live in a group home versus independent living.
  - If live in group home, what size? 4 residents? 8 residents?
- Live in the country versus suburbs versus metropolitan area?
- Full-time supervision versus part-time supervision versus sporadic or no supervision.
- Kept protected from risk versus exposed to some level of risk versus full exposure to risk.
- Allowed full sexual expression within boundaries of law versus sexual expression moderated by various restrictions.
Just these simple values choices result in:

486 different combinations of what constitutes a valued outcome for an adult with ASD. Your choice guides your ethical practice.
When approached with a questionable situation or ethical concerns, behavior analysts should rely on three (3) specific questions (Cooper, Heron, & Heward, 2007).

• What's the right thing to do? – *This, essentially, is a question of values and evidence-based practice and the point where discussion often gets bogged down.*

• What's worth doing? – *This, too, is a question of values as the answer can only be arrived at by assessing personal effort leading to expected client outcome.*

• What does it mean to be a good BCBA? - *This is the question that forms the core of our professional ethics.*
The 7 Dimensions of ABA

- **Applied**: Deal with problems of social importance.
- **Behavioral**: Deal with measurable behavior or reports if they can be validated.
- **Analytic**: Require an objective demonstration that the procedures caused the effect.
- **Technological**: Are described well enough that they can be implemented by anyone with training and resources.
- **Conceptual Systems**: Arise from a specific and identifiable theoretical base rather than being a set of packages or tricks.
- **Effective**: Produce strong, socially important effects.
- **Generality**: Designed from the outset to operate in new environments and continue after the formal treatments have ended.

While all 7 dimensions are essential independent of whichever behavior analytic field you might find yourself, the most difficult ones (at least for me) seem to get the least discussion. These are:

- **Applied**: Deal with problems of social importance.
- **Effective**: Produce strong, socially important effects.
- **Generality**: Designed from the outset to operate in new environments and continue after the formal treatments have ended.
Effective autism intervention is certainly a problem of social importance. So we are good here. But if we drill down a bit the complexities start to emerge.


- I would, therefore, suggest that mere act of providing autism intervention is insufficient to fulfil this dimension. This has nothing to do with effectiveness of our interventions. This has to do with, all things considered, teaching the wrong skills effectively is no better than teaching the right skills poorly.
**Effective:** Produce strong, socially important effects.

Behavior analytic intervention in ASD has produced a string of strong, socially important effects. I am pretty sure we can all agree on that so we are good here.

- However, since Lovaas, (1987) and the subsequent research/practice in EIBI, what can we point to as being a strong, socially important behavior analytic “discovery” in autism intervention? 30 years seems a long-time between “discoveries” for such a young field.

- There have, of course, been a number of significant publications on innovative behavior analytic interventions since 1987 (e.g., Iwata, et al, 1994 on FBA) that have positively impacted the lives of individuals with ASD.


Effective: Produce strong, socially important effects.

- But here is the challenge: Student A attends an excellent (and expensive) ABA-based private ASD school. Student B attends a public school program (at half the cost of the private school) where he “gets 5 hours of ABA” a week. If, at age 21 both individuals end up in the same Adult Day Program, to what extent have we produced strong, socially important effects?

- I would, therefore, suggest that despite our many triumphs -- far more than any other field of intervention -- there is a need to ask, and subsequently answer, bigger and more socially important questions regarding ASD intervention if we are to fulfill this dimension in 2016.
**Generality:** Designed to operate in new environments & continue after formal treatments have ended.

In other words, generalization and maintenance of acquired skills should be a direct result of our effective interventions. This is essential as neither generalization nor maintenance are automatically guaranteed and individuals with ASD tend to have problems with both.

- A challenge here is that research attention to generalization and/or maintenance has diminished. So far in 2016 there have only been two articles published in the peer reviewed literature with “generalization” and “autism” in the title. Only five such articles in 2015 while between 1991 and 2014 there were a total of 72 articles published (APA PsycNet search 7/30/16).
Generality: Designed [ ] to operate in new environments & continue after formal treatments have ended.

- Perhaps more bothersome is the tendency to attribute a lack of generalization as particular to autism. While this may be true, I think it has become a convenient excuse.

- And generalization & maintenance from school to home for a month or so is not our most pressing need. Rather, the pressing need is to understand generalization from school to the community, and then from one community to another and ultimately, generalization and maintenance of acquired skills from school to the adult service system over time.
Generality: Designed [ ] to operate in new environments & continue after formal treatments have ended.

- I would, therefore, suggest that despite a good understanding of the basics of both generalization and maintenance, our understanding of each process with older individuals, with more complex skills, across community environments, needs attention. Further, while ASD and lack of generalization may be connected this has not held back behavior analytic intervention in other areas where the same is true (e.g., verbal behavior, joint attention, etc.). more than any other field of intervention, there is a need to ask, and subsequently answer, bigger and more socially important questions regarding ASD intervention if we are to fulfill this dimension as of 2016.
The Behavior Analysts Ethical Code, as established by the Behavior Analyst Certification Board, is an essential document intended to guide the ethical conduct of practitioners in the field of Behavior Analysis.

My only concern today is that, perhaps, the code does not sufficiently address the issue of socially important treatment outcomes. For example...
Behavior Analyst Ethical Code
Sec. 2.09

(a) Clients have a right to effective treatment (i.e., based on the research literature and adapted to the individual client). Behavior analysts always have the obligation to advocate for and educate the client about scientifically supported, most effective treatment procedures. Effective treatment procedures have been validated as having both long-term and short-term benefits to clients and society.

(b) Behavior analysts have the responsibility to advocate for the appropriate amount and level of service provision and oversight required to meet the defined behavior-change program goals.

Behavior Analyst Ethical Code Sec 2.0:  
(Behavior Analysts’ Responsibility to Clients)  
Sec. 2.09

(c) In those instances where more than one scientifically supported treatment has been established, additional factors may be considered in selecting interventions, including, but not limited to, efficiency and cost-effectiveness, risks and side-effects of the interventions, client preference, and practitioner experience and training.

(d) Behavior analysts review and appraise the effects of any treatments about which they are aware that might impact the goals of the behavior-change program, and their possible impact on the behavior-change program, to the extent possible.

Sec. 4.0
Behavior Analysts and the Behavior Change Program

“Behavior analysts are responsible for all aspects of the behavior-change program from conceptualization to implementation and ultimately to discontinuation.”

However...

At no place in the Ethical Code is any standard of “Socially Important Outcome” defined or discussed. The closest we get is:

“Sec. 4.05 Describing Behavior-Change Program Objectives.

Behavior analysts describe, in writing, the objectives of the behavior-change program to the client before attempting to implement the program. To the extent possible, a risk-benefit analysis should be conducted on the procedures to be implemented to reach the objective. The description of program objectives and the means by which they will be accomplished is an ongoing process throughout the duration of the client-practitioner relationship. “
A Proposal

Given all that, perhaps it is time to consider not a revision, but an addition, to the BACB Professional and Ethical Compliance Code such as

**11.0 Behavior Analysts focus on socially important and environmental valid outcomes.**

Behavior Analysts are expected to develop, implement, supervise, and modify as necessary behavior change programs that focus on socially important and generalizable outcomes.
11.1 – Goal Selection: Behavior analysts are expected to identify behavior change goals that take into account the chronological age of the client, his or her preferences and deficits, the demands of current and future environments, and that have the greatest potential to generalize and maintain after intervention as predicted by matching law.

11.2 – Location of Services: Behavior analysts are expected to recognize and minimize the challenges to behavior change programs that are inherent in less contrived environments such as a client’s home, community, or place of employment.
A Proposal

11.3 – Social Validity: Behavior analysts are expected to develop behavior change goals that are socially valid and to identify potentially effective intervention strategies that are evidence-based and acceptable to the community at large.

11.4 – Staff Training: Behavior analysts are expected to provide evidence-based training to non-behavior analytic staff in less contrived environments in a manner the best promotes the correct implementation of behavior change programs for their clients.
A Proposal

11.5 – Outcomes: Behavior analysts are expected to identify evidence-based interventions in such complex areas of human competence as independence, safety, self management, communication, time management, self care, employment, etc., the acquisition of which may be associated with more positive overall outcomes in adulthood.
Closing thoughts...
You need to download and read this article. Really. You do.
ABA as a three term contingency

- It seems that as a field we have had a multi-decade love affair with the terms “Behavior” and “Analysis”. The term “Applied” however has been treated more like a Friend-with-Benefits who we call upon when we think no one is looking.

- Yet the Applied aspect of our science is, in my opinion, equal in importance to Behavior or Analysis are.

- When our classrooms become indistinguishable from a clinic or research setting we are, perhaps inadvertently, diminishing the relevance and central importance of Applied in the development of generalizable skills that are maintained over time.
Recognize, Control For, but Accept Reasonable Risk

Risk, it seems, is unavoidable. However ignoring risk, under the guise of safety, invites greater risk for the individual in question. (This, btw, is why we do things like fire drills.) But Risk threatens things we typically value. What we do about risk depends on the options we have, the outcomes we value, and our beliefs about how our options may result in the outcomes we value. These outcomes can be certain or uncertain and our choices simple or complex (Fischhoff & Kadvany, 2011) so rarely is there one, correct choice about how to deal with risk.

Think Big...

John will be able to safely navigate his work environment allowing him to independently use the restroom, take a break in the staff room, and order/pay for lunch in the cafeteria. If he needs help at any point he will be able to seek out a coworker and ask for assistance using his ACS. Data will be collected on independent initiation of component skills and number/type of prompts necessary to complete the skill. Social validity data will be collected from co-workers on a bi-weekly basis.
A Mission Statement with Socially Important & Generalized Outcomes as the Focus

The mission of autism education is such that 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.
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
1904 - 1990