**Slide 1**

Changing the Behavior of Behavior Analysts to Improve Adult Outcomes: Independence is More Important than Perfection

**EPIC SCHOOL** STEPS TO SUCCESS

Peter Gerhardt, Ed.D., The EPIC Programs
ABA Today Conference
October 15th, 2021

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**Slide 2**

## Disclaimer
**Unpaid Affiliations**

Dr. Gerhardt has an association with the following programs or organizations but receives no compensation for that association. None of the information contained in this presentation is relevant to those associations

O·AR ORGANIZATION FOR AUTISM RESEARCH          ACE 4.0 ABA Software System

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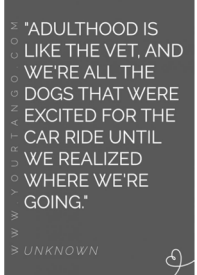
ENDICOTT COLLEGE  Department of Applied Behavior Analysis

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**Slide 3**

## Note

This talk discusses the support and intervention needs of individuals on the Autism Spectrum and co-occurring Intellectual Disability (i.e., Autism 2 or 3 in DSM-V). While much of what I will discuss can be applied to support more cognitively able individuals with ASD, they are not the group with whom I work.

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**Slide 4**

"ADULTHOOD IS LIKE THE VET, AND WE'RE ALL THE DOGS THAT WERE EXCITED FOR THE CAR RIDE UNTIL WE REALIZED WHERE WE'RE GOING."

UNKNOWN

Adult Outcomes

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**Slide 5**

After analyzing data from the NLTS-2, Roux and colleagues reported "**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

Roux, AM, Shattuck, P, Rast, JE. Rava, JA, & Anderson, KA. (2015) *National Autism Indicators Report: Transition into Young Adulthood.* Philadelphia, PA: Life Course Outcomes Research Program, A.J. Drexel Autism Institute, Drexel University

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**Slide 6**

And for many young adults and their families

6

According to Shattuck, et al, (2018):

Based on data from the National Longitudinal Transition Study-2012 (NLTS- 2012) and the National Survey of Children's Health 2016 (NSCH 2016).

- About one in three teens with ASD could not get to places outside the home very well or were not allowed to do so at all.
- Almost two-thirds (64%) of teens with ASD were taking prescription medications, and nearly half (48%) were taking medications for attention, behavior, or mood. These rates were much higher than teens with ID.
- About one in six (16%) did not receive needed healthcare
- One in four households of teens with ASD received at least one form of public assistance.

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2018 National Autism Indicators Report
(Shattuck, et al, 2018)

- 23%-33% percent of teens with ASD lived in a household that received Supplemental Nutrition Assistance Program (SNAP, also known as food stamps) within the previous two years.
- Black or African American teens were more likely to have difficulty than their peers in several areas:
  - Communication
  - Self-care and adaptive behaviors
  - Independently getting to places outside the home
- Black or African American teens had the highest rate of taking medication for emotion, concentration or behavior.
- Black or African American teens had the highest rate of unmet health care needs.

Shattuck, P. T., Rast, J. E., Roux, A. M., Anderson, K. A., Benevides, T, Garfield, T, McGhee Hassrick, E, & Kuo, A. *National Autism Indicators Report: High School Students on the Autism Spectrum.* Philadelphia, PA: Life Course Outcomes Program, A.J. Drexel Autism Institute, Drexel University, 2018.

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## In additiion

"Many young adults with autism spectrum disorder experience poor transition outcomes in key areas, including postsecondary employment, higher education, health care, social connectedness, and independent living." (Anderson, et al, 2017)

Quality of Life for adults with ASD is lower than that of typically developing adults, when measured with tools designed for the general population. There are no comprehensive ASD-specific QoL measurement tools validated for use with representative samples of adults on the autism spectrum. (Ayres, 2017)

The very variable findings reported in this review reflect the problems of conducting research into lifetime outcomes for individuals with a condition as heterogeneous as ASD. Much more systematic research is needed to delineate different patterns of development in adulthood and to determine the factors influencing these trajectories. (Howlin & Magiati, 2017)

The transition into adulthood is a critical period in the life course that shapes later outcomes. Many adults on the autism spectrum fare poorly across a wide range of quality-of-life indicators. (Anderson et al, 2017)

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## As to our research on adult services and ASD...

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Shattuck, P.T., Garfield, T., Roux, A.M. *et al.* Services for Adults With Autism Spectrum Disorder: a Systems Perspective. *Current Psychiatry Reports* **22,** 13 (2020).

- Approaches to characterizing impairments and severity, sample demographics and socioeconomic position distributions, and co-occurring conditions were highly variable across studies and sometimes missing altogether.
- Healthcare for adults with ASD emerged as a relatively new area of focus. For example, it was revealed that many autistic adults experience significant barriers to healthcare.
- Most studies included information about sex, but description of gender and non-binary/transgender gender identities was not presented.
- The articles included in the review involved samples that were predominantly male and white.

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Shattuck, P.T., Garfield, T., Roux, A.M. *et al.* Services for Adults With Autism Spectrum Disorder: a Systems Perspective. *Current Psychiatry Reports* **22,** 13 (2020).

- The field of research on services for adults on the autism spectrum remains small and generally lacks unifying conceptual frameworks or consistent methodological approaches. These lacks undermine the potential for knowledge to accumulate and be applied to help specific subgroups of people

- Moving forward, a life course systems perspective emphasizing the complex and evolving interactions among culture, history, institutions, organizations, policies, funding, and families that impact service accessibility, delivery, coordination, and effectiveness is essential
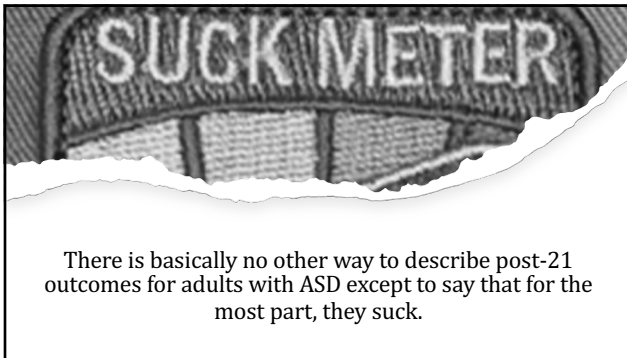
12

## On the upside

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Recently, Marsack-Topolewski, Samuel, & Tarraf (2021) documented the simple fact that parental caregiver burden was decreased when their adult child with ASD was more independent with daily living skills. The researchers concluded that there is a need for "family-centered interventions to improve the capacity of adults with ASD to perform ADLs independently". (p.1)

Marsack-Topolewski, CN, Samuel, PS, & Tarraf, W., (2021). Empirical evaluation of the association between daily living skills of adults with autism and parental caregiver burden. PLoS ONE 16(1) e0244844.

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There is basically no other way to describe post-21 outcomes for adults with ASD except to say that for the most part, they suck.

15

## But "good outcome" is a weirdly difficult term to define in any generalizable way.

- From my point of view, I think we need to consider characteristics of a good outcome to include, but not be limited to:
  - Choice
  - Control
  - Competence
  - Freedom from harm
  - Interpersonal respect

16

But poor outcomes continue, at least in part, because:

17

Behavior analysts are trained in the effective application of behavior analytic principles to increase or decrease behavior. Unfortunately, we are not trained in identifying which behaviors, beyond the most obvious, to target for increase or decrease.

18

In other words:

*Effective, behavior analytic intervention targeting the wrong skill is no better than ineffective, pseudoscientific intervention targeting the right skill.*

Neither results in any socially significant outcome for the student/client.

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Please note that evidence-based Practice in ABA & ASD does not require the development of a set of rigid, unyielding, and unalterable instructions governing interactions. In fact, evidence-based practice in ABA & ASD often requires one to modify interventions in response to a slew of conditions, settings and contingencies while maintaining a commitment to data-based decision-making.

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In other words, evidence-based practice in ABA/ASD is a combination science, experience, and a sophisticated understanding of context. In that way, EVP is sort of, well, "zen-like"

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## Application of Social Validity In ABA

*"At the same time that I was having to wrestle with the problems of subjective measurement in JABA, my colleagues and I in the Achievement Place Research Project were having some problems with unsolicited subjective feedback on similar issues. Colleagues, editors, and community members were asking us about the behavioral goals that we had chosen for training the teaching-parents and the youths participating in the community-based, family-style, behavioral treatment program at Achievement Place. They would ask us: "How do you know what skills to teach? You talk about appropriate skills this and appropriate skills that. How do you know that these are really appropriate?" (Wolf, 1978, p. 206)*

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## Social Validity in ABA

*"The suggestion seemed to be that society would need to validate our work on at least three levels:*

1. *The social significance of the goals. Are the specific behavioral goals really what society wants?*
2. *The social appropriateness of the procedures. Do the ends justify the means? That is, do the participants, caregivers and other consumers consider the treatment procedures acceptable?*
3. *The social importance of the effects. Are consumers satisfied with the results? All the results, including any unpredicted ones?*

***We have come to refer to these as judgements of social validity."*** *(Wolf, 1978, p. 207)*

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In their review of articles published in JABA between 1999 and 2016, Ferguson, et al (2018) analyzed 1,209 articles for measures of social validity. Of the 1,209 articles evaluated, only 141 (i.e., 12%) reported measures of social validity. Additionally, of the articles that did not report social validity measures, only 4% recommended future researchers assess the social validity of the goals and procedures. The authors' results are similar to earlier findings in that social validity is rarely measured and/or reported within JABA

Ferguson, J.L., Cihon, J.H., Leaf, J.B., Van Meter, S.M., McEachin J. & Leaf, R. (2018): Assessment of social validity trends in the journal of applied behavior analysis, *European Journal of Behavior Analysis,* **20**, 146-157.

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*"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)*

25



If we are going to change outcomes it seems we need to make a few changes to our own behavior starting with:

26

Providing intervention as if we are running out of time, because we are.

27

## Time is not on your side.

- In New Jersey there are:
  - 210 School Days/Year
  - Typical School Day is 6 hours in length
  - If we subtract time spent at lunch, on break, in the bathroom, etc. we conservatively end up with 5 hours of active programming/intervention each day.
  - # of School Days X # of hours/day of intervention = 1,050 hours
  - Across 5 years (ages 16-21 years) that gives us 5,250 hours.
  - Sounds like a lot, doesn't it.?

28

## Time is not on your side.

- If there are 30 goals/objectives in your student's/client's IEP
  - That results in 150 instructional targets across 5-years
  - 5,250 available hours divided by 150 instructional targets leaves you with 35 instructional hours available for each instructional target.
  - We know there are 5 instructional hours during each school day.
  - This means you only have 7 School Days to provide sufficient intervention to bring each instructional target to mastery, let alone ensure generalization outside of the instructional environment with your student/client.

29



- Given the limited number of intervention hours available, the question then becomes, "What should be my priorities for intervention?" Do I spend 100 hours providing instruction in tacting US currency or do I spend that time teaching the much larger skill of shopping independently for preferred items?

30

The numbers don't lie.  For outcomes to change we need to prioritize intervention and target those skills with the potential for the greatest impact.

31

To do this, we need to rearrange the established contingencies supporting our behavior in such a way that the following set of behaviors become reinforced.

32

We need to modify our contingencies of reinforcement, so we stop thinking in terms of "functional skills" and, instead, think in terms of "applied skills"

| Functional | Applied |
|---|---|
| Functional refers to some arbitrary characteristic of the skill | Applied refers to the extent to which the individual will use the skill once acquired. |
| Mastery of functional skills often translates into "responds to the Sd" | For an applied skill, initiation is occasioned by some environment stimuli. |
| Functional skills are generally limited to activities of daily living (ADLs) | Applied skills cross instructional domains so long as they are used by the individual |
| Functional skills are, unfortunately, too often taught outside the natural context | Applied skills are best acquired by practice in the natural context |
| Functional skills tend to fairly static | Applied skills are more dynamic with some acceptable variations in demonstration between individuals |

33

We need to modify our contingencies of reinforcement so that skill acquisition targets are as congruent as possible with the individual's interests, preferences, and idiosyncrasies.

- As an example, if self-talk occurs at a high frequency when the individual is taking a break, could he/she engage in self talk when acquiring a new, work-related skill (if it didn't interfere with skill acquistion)?
- Or during grocery shopping, don't freak out if the individual puts a bag of Hershey's kisses in the cart.  He or she is communicating that Hershey's kisses are a good reason to go shopping in the first place.  We can refer to this process as "finding value."

34

Modify your contingencies of reinforcement so task analyses are individualized for each student in a way that  targets the most efficient, simplest way to complete the chain.

| Instead Of This | Try this |
|---|---|
| Measuring laundry detergent | Use Tide Pods |
| Sorting laundry | Don't |
| Laminated/Velcro schedule | Smart Phone |
| Cooking | Microwaving |
| Picking out clothes | Pre-organized sets of clothes |
| Tying shoes | Converse slip-ons |
| Write full name | Write your initials |

35

# This, BTW, is my signature

36

**Slide 37**

Light Hiker (Retro Stripe) - Crew

BTW, the web is full of potential short-cuts and accommodations

37

**Slide 38**

Modify your contingencies of reinforcement such that you can work outside of the controlled environment and in the natural environment.
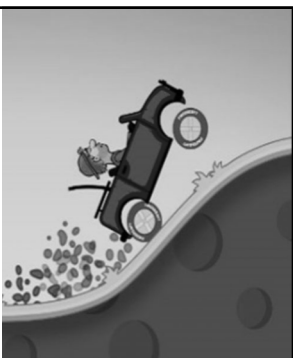
**CHALLENGING BEHAVIOR**

Inattention | Aggression | Self Stimulation | Sensory Issues | Rigidities | Non-Compliance

• Source: The Autism Partnership: http://www.autismpartnershipsg.com/en/service/our-method-and-approach-aba/

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**Slide 39**

Challenging Behavior in the Less Controlled Environment

We now have over 50-years of behavior analytic research focusing on the assessment and intervention of challenging behavior. However, the vast majority of this research has been conducted in well-controlled environments with little attention paid to generalization and long-term maintenance. This means, unfortunately, that the research base for assessment and intervention in less-well-controlled environments such as the individual's home or in the community is lacking.

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**Slide 40**

Is this the hill I want to die on today?

40

**Slide 41**

When a challenging behavior occurs in the less controlled environment, you have 3 options from which to choose initially

**Option 1:** Continue with what you are doing in an attempt to work through the challenging episode.

**Option 2:** Briefly continue what your doing, provide reinforcement for some positive behavior, and then terminate what you are doing allowing everything to end on a positive note.

**Option 3:** Terminate activity or accede to demand and vacate the environment ASAP.

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**Slide 42**

As a function of myriad factors, any one of the 3 options might be the best option at that particular time given that particular situation with that particular student.
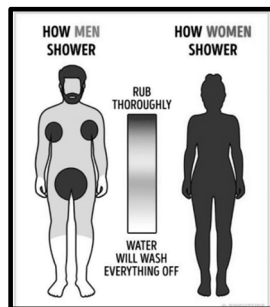
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Don't just act like a behavior analyst, think like a behavior analyst.

43

We need to modify our contingencies of reinforcement such that insignificant errors do not preclude your student's or client's independence.

- On any given day I think I probably vary somewhere between 70% to 100% accurate implementation of everything I am expected to do. While people may laugh when I screw up, no one ever says "I am sorry, we have to practice that again." or "I am sorry, I don't think you can do that by yourself anymore."
- Your goal should not be trying the teach the perfect chained response. Your goal should be for your student/client to complete the chain in a way the achieves the desired end goal.
- This can be referred to a "_normative mastery_"

44



45

At the end of the day, independence is more important than perfection

46

There are , of course, some exceptions

- COVID19 sanitary protocols
- Street crossing
- Medication self-administration
- Privacy
- Personal safety
- Some aspects of sexual behavior
- Menstrual care
- Sword swallowing
- Etc.

47

We need to modify our contingencies of reinforcement in such a way to (safely) allow for errors when teaching safety skills.



48

But it goes without saying, don't be stupid about it. Well, maybe it doesn't go without saying. Touching the hot stove is just an example. It is not a recommendation.

49

We need to modify our contingencies of reinforcement in such a way that we can recognize and, ideally, define the concepts below with reference to each student/client and his or her family:

| | |
|---|---|
| Relationship | Compassion |
| Partnership | Happiness |
| Friendship | Joy |
| Self Esteem | Respect |
| Concern | Empathy |

50

It seems when it comes to working with adults with autism, we are more often a science of probabilities, than a science of certainties.

51

EPIC's Critical Skills

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**Critical Skill - Toileting (Bowel and Urine)**

Goal – Independent use of a bathroom, when necessary, including locking the door, wiping seat, wiping self (if necessary), washing hands, exiting bathroom and return to "location"

53

Critical Skill - Dressing

- Goal – Closing door for privacy, independent selection of appropriate clothes, donning clothes in correct order and orientation and checking appearance before opening door and exiting area.
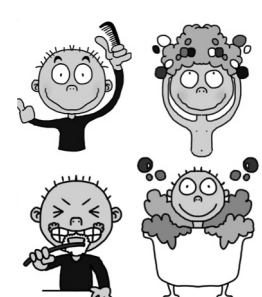
54

## Critical Skill - Independent Eating

Goal – Able to correctly use all appropriate utensils (knife, fork, spoon) to eat a variety of foods neatly and at a culturally accepted pace.

55

### Critical Skill – Bathing/Self Care

Goal – To demonstrate the ability to independently bathe/shower and complete relevant self care/hygiene skills (e.g., tooth brushing, grooming, etc.)

56

Goal – Independent completion of a variety of household chores or, in our field, "*ADLs*". The issue is not whether to target these skills but rather, when to target these skills.
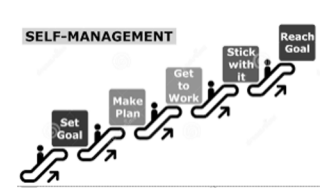
## Critical Skill – Household Participation

57

• Goal – To acquire new skills when presented via dyad or triad instruction at a rate of acquisition similar to that documented via 1:1 instruction.

## Critical Skill – Able to learn in a group

58

### Critical Skill – Self Management

Goal – To demonstrate the ability to identify one's own behavior as either appropriate or inappropriate deliver potential reinforcement in the absence of supervision.

59

Critical Skill – Problem Solving/Variable Responding

Goal – To demonstrate the ability to offer more than one potential solution when presented with a relevant problem or challenge.

60

## Critical Skill – Maintain Physical Safety

Goal 1 – Demonstrate the ability to identify and avoid potential "non-human" dangers in the immediate environment.

Goal 2 – Demonstrate ability to discriminate between "safe" and "unsafe" people and respond appropriately.

Goal 3 – Demonstrate a reasonable degree of noncompliance when presented with "privacy requests" from an unapproved person.

Goal 4 – Demonstrate ability to participate in healthcare management activities (e.g., doctor or dentist visits).

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## Critical Skill - Communication

Goal – Demonstrate the ability to make one's wants and needs known to naïve listeners across multiple environments.

62

## Self-Advocacy

One of the most important processes but, at the same time, my least favorite label for a process. Why? Because it automatically identifies the person as having a disability even though the general process is what I do challenge a charge on my credit card.

*Self-advocacy is the ability to speak-up for yourself and the things that are important to you. Self-advocacy means you are able to ask for what you need and want and tell people about your thoughts and feelings*

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ADULTHOOD

This was just a VERY brief introduction to the behavior change we, as behavior analysts, need to undertake if adult outcomes in ASD are to improve.
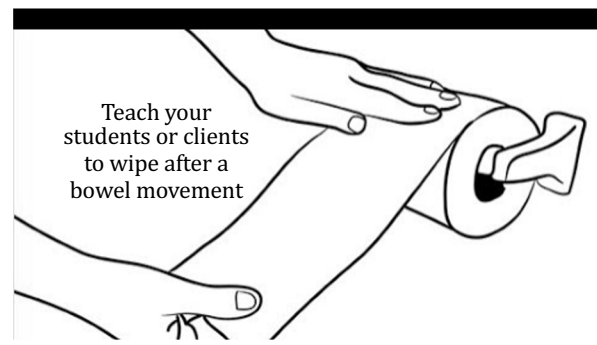
"IF YOU'RE NOT TIRED, YOU'RE NOT DOING IT RIGHT.

• We didn't even touch on such topics as:
  • Sexuality
  • Working with parents of older individuals
  • Behavior analysis and mental health
  • Healthcare transition
  • Aging and ASD
  • Employment
  • Transportation
  • Quality of Life
  • Leisure
  • And so on..

64

So, with that...

65

Teach your students or clients to wipe after a bowel movement

66

NOTHING IS PERFECT. LIFE IS MESSY. RELATIONSHIPS ARE COMPLEX. OUTCOMES ARE UNCERTAIN. PEOPLE ARE IRRATIONAL.

Adulthood is f*ck*ng complex. It is not that people are irrational (usually), it is just that you have no way of knowing all the relevant variables at any given time.

67



68

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

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