

Preparing for Adolescence and Adulthood: How to Embed Functionality, Choice, and Quality of Life into Programming for Learners with ASD

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With thanks

- To Eden
- To my mentors, colleagues, supervisees, and students
- To the people with autism I have been honored to work with

Goals for today

- Define meaningful outcomes for for adolescents and adults with ASD
- Discuss meaningful education and meaningful employment
- Discuss how to
 - Enhance choice
 - Ensure skills are functional
 - Attend to quality of life issues

Topics for discussion

- Are we moving/shifting with learners as they age
- Are we preparing for transition appropriately
- Think about
 - Ratios
 - Choices of instructional programs and targets
 - Play skills
 - Age at which transition talks begin

ABA: A Definition

- “Applied Behavior Analysis is the science in which tactics derived from the principles of behavior are applied systematically to improve socially significant behavior and experimentation is used to identify the variables responsible for behavior change.”
- Cooper, Heron, & Heward, 2007



Critical elements of the definition

- Improve *socially significant* behavior
 - What does this mean?
- Identify variables responsible for behavior change
 - Why is this challenging in the teaching of social skills? How can this be done?



Are the changes we are making socially significant for adolescents and adults?



Seven horizontal lines for writing.

Lifelong Perspective

- Shattuck, et al, (2012) conducted a comprehensive literature review on individuals with ASD 18 and older (published between 2000 and 2010.)
- Evidence base about services for adults with an ASD *is underdeveloped and can be considered a field of inquiry that is relatively uninformed.*

Seven horizontal lines for writing.

National Autism Indicators Report: Transition into Young Adulthood 2015

- **Transition Planning**
 - 58% of youth with autism had a transition plan in place by the federally required age (according to special education teachers)
- **Services**
 - Approximately 26% of young adults on the autism spectrum received **no services** after high school
- **Adult Outcomes and Disconnection**
 - Over one-third of young adults were disconnected during their early 20s, meaning they never got a job or continued education after high school

Seven horizontal lines for writing.

Sobering news

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 all!” Roux, et al, 2015, p. 8

And more...

• “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)

Data...

- **Health, Mental health and Health Care**
 - 60% of youth had at least two health or mental health conditions in addition to ASD
- **Postsecondary Education**
 - 36% of young adults on the autism spectrum never attended post secondary education
- **Employment**
 - 58% of young adults on the spectrum worked for pay outside the home between high school and their early 20s – a rate far lower than young adults with other types of disabilities

More data....

- **Living Arrangements**
 - One in five young adults on the autism spectrum ever lived independently (away from parents without supervision) between high school and their early 20s
- **Social and Community Participation**
 - Approximately one in four young adults with autism were ENTIRELY socially isolated.
- **Safety and Risk**
 - Nearly 1/3 of the youth on the spectrum were victims of bullying during high school
 - Over 27% engaged in some type of wandering behavior
 - Low rates of criminal justice involvement reported

WHAT DO THESE DATA MEAN....

- Outcomes are sobering and indicate poor outcomes
- Outcomes include social isolation, lack of engagement, and vulnerability
- We must do better in earlier years
- We must transition effectively
- We must incorporate elements of programming that result in social significance

QUESTIONS TO ASK

- Where is this individual going to be in five years? Ten years?
- What needs to be done to get him or her ready?
- What are the obstacles to independence?
- What can be taught and what can be adapted?
- What are this person's social survival needs?



Where is this person going to be in 5 years?

- Likely target environments
- Ratio expected in those settings

What needs to be done to get ready?

- Fade level of supervision
- Thin schedule of reinforcement
- Sample tasks that are likely to be needed
- Identify preferences where applicable
- Plan for generalized responses for differing environmental arrangements and presentations of stimuli

What are the obstacles to independence?

- Challenging behaviors
- Stigmatizing behaviors
- Behaviors that make others uncomfortable
- Low expectations

What can be taught and what can be adapted?

- Daily Living Skills
 - Shoe closures
 - Paper plates
- Community independence skills
 - Debit card
 - Using GPS on phone
 - Voice activation devices

What are this person's social survival needs?

- Vulnerability
 - Risk training
 - Safe behaviors and plans
- Perceived threat
 - Training on appropriate and inappropriate behaviors
 - Social validity checks

How should we be selecting and teaching?

- WHAT TARGETS?
- What is the VISION?
- Are we seeing through a lens of functionality?
- Are we thinking about social skills enough?



What are social/survival skills?

- Ensure behaviors do not frighten
- Ensure behaviors do not offend
- Ensure behaviors do not make others wary
- Make sure they are responsive
- Make sure they have positive interactions
- Make sure they will be accepted



Red flag skills

- Appropriate Proximity
- Approaches in the normative range
- Inhibition of unusual social overt and verbal behaviors
 - Social initiation to strangers
 - Staring
 - Odd topics
 - Fixations
- Capacity to accept both verbal and nonverbal cues

Functionality in this context

- FOCUS ON SKILLS THAT MATTER
- MAKE SURE LEARNER DOES NOT HAVE RED FLAG ISSUES



Is it a functional skill?

1. If the learner can't do it, will someone else have to?
2. Is the skill age-appropriate for the learner?
3. Is the skill needed immediately?
4. Will it continue to be needed in the future?
5. Is the skill needed frequently?
6. Will the skill be needed in multiple environments?
7. Can it be maintained by naturally occurring events?
8. Will the skill enhance the learner's quality of life?

Based on Brown, et. al (1980)

How are we determining skills to be worked on?

- Is it the "next item on the list?"
- Are you doing it because it is in the IHP?
- Are you following a curricular sequence?



HOW SHOULD WE BE DETERMINING GOALS?

- Individual assessment
 - Preferences
 - Skills
 - Next environments
 - Family input
 - Vision



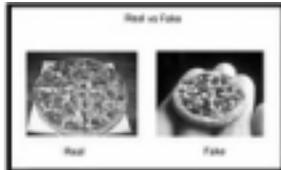
What are other elements of functionality?

- How are we teaching?
- Where are we teaching?
- What materials are we using?
- How are we evaluating progress?



Where are we teaching?

- In the segregated vocational setting (classroom)? At home? In the community?
- Where are we teaching the skill?
 - In the CONTEXT in which we wish to see it demonstrated
 - Requesting
 - Safety skills
 - Laundry skills
 - Cleaning tables
 - Greetings
 - Purchasing



How are we evaluating progress?

- Acquisition criterion only?
- What about maintenance?
- What about generalization?
- Spontaneous display?
- What about in the absence of or with faded adult supervision?
- What about with natural contingencies of reinforcement?

What kind of data?

- Data on Independence
- Data on Interference/Disruption
- Data that influences employment success
- Social Validity Data



Independence/Prompting

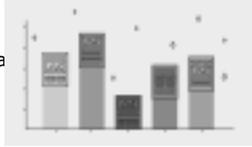
- These data can be compared to the assistance provided to a typical learner in that environment
- how discrepant?
- These data can guide decisions about supports and about the fading of supports
- These data can be a powerful measure of change

DATA

- Collect data
 - Generalization of skills
 - Social behaviors (initiations, responses)
 - Behavioral data/DISRUPTION
 - Engagement/CONNECTION
 - Conversation
 - INDEPENDENCE (prompts)
 - Other qualitative elements (speed, thoroughness)

What can data help with?

- Making adjustments in instruction
 - Add reinforcement
 - Change prompts
 - Change goal
- Decide about supports based on data
 - Need for intervention?
 - Need for additional supports?
 - Systematic fading plans



Very closely related: How do we ensure that the skills are generalizable?

- Teaching in natural contexts
- Assessing for generalization
 - Analogs
 - Natural environment probes
- Teaching smartly
 - Using multiple exemplars
 - Training loosely

The Right to Personal Liberties

- Bannerman, Sheldon, Sherman, & Harchik, 1990
- People should have a variety of available options, and should be free to choose from among them
- "Uncoerced" choices: there are no implicit or explicit consequences for selecting one alternative over the others (except for the characteristics of the alternatives themselves)

Things people decide.....

- ◆when to take a shower
- ◆what to eat, when to eat
- ◆with whom to spend time
- ◆whether to take a day off from work
- ◆whether to take a nap
- ◆what to watch on tv

Are we compromising liberties to achieve habilitation?

- ◆1. Clients may have little input regarding treatment goals or instructional methods
- ◆2. Behaviors may be taught without regard to preferences or past learning in the area
- ◆3. Choice making is often not taught
- ◆4. Opportunities for choice are limited

Is there reason to be wary of allowing maximal choice?

- May make "bad" choices
 - may need intensive teaching first
 - judgement may be poor/ safety concerns
- May interfere with development of other skills
 - choosing a leisure skill vs. a vocational task
 - choosing to be dressed vs. to dress independently

Why should we allow more choice?

- ◆ Legislative mandate: People with disabilities are guaranteed same basic rights of other citizens
- ◆ May help individuals better prepare to live in the larger community

Benefits of Choice

- ◆ Situations in which choice is available are preferred
 - children prefer to choose their own rewards and prefer tasks in which they will get to choose rewards
- ◆ Participation increases in situations in which choice opportunities are provided
 - more likely to do exercise of your choice vs. assigned exercise

Benefits of Choice

- ◆ Opportunities to make choices may increase performance
 - weight loss is better if individuals choose the treatment program vs. receiving the identical treatment without choosing it
 - Some mixed data

Benefits of choice

- Problem behavior is reduced when choices are given
 - Dyer's work supports that children with autism demonstrate improved behavior when they can choose tasks, materials and reinforcers
 - Also engage in less social avoidance while engaged in preferred activities

Some implications

- ◆ Preferences of clients should be assessed
- ◆ Client input should be considered in the selection of goals, methods, materials, etc.
- ◆ Choice-making skills should be taught
- ◆ Choice-making should be available both within and between scheduled activities
- ◆ Creativity and flexibility are needed to determine how to honor choices

Conclusions

- ◆ Everyone should have the same rights
- ◆ We need to help individuals exercise freedoms responsibly

How do we help ensure that others have positive impressions and experiences with people with ASD?

- Showcase Strengths
 - Find ways to highlight with fellow students
 - Video resumes for work placements
- Be creative about how supports are provided
 - Bluetooth
 - Camera systems for vocational monitoring
- Build social skills that are functional

Qualitative aspects of social behaviors

- Clarity
- Appropriateness
 - Think red flags
- Independence
 - Think proximity reduction
- Endurance
 - Think competitive employment
- Latency
 - Think social norms

How do we address these issues?

- Clarity and Appropriateness
 - Use shaping
 - Use differential reinforcement
 - Specifically teach discrimination of appropriate and inappropriate
- Independence
 - Guard against prompt dependency
 - Program for generalization
 - Use proximity fades systematically
 - Transfer to self monitoring for social responses and initiations

And that responses are readily available.....

- Increasing the likelihood that learners will have skills when they need them



INCREASE REAL EMPLOYMENT

- Reduce barriers
- Community relationships
- VIDEO RESUMES



Addressing endurance

- Focus on duration as a dimension of response
 - Length of time in leisure skill
 - # conversational exchanges

How are problems in fluency manifested in learners with autism?

- Effortful, laborious motor responses
- Long durations of responses
- Long latencies to respond

What is the social significance of dysfluency?

- Missed social opportunities
- Missed opportunities to participate in group instruction

WAYS TO ATTEND TO FLUENCY

- Being a fluency builder vs. blocker
- Attend to latency, shape it
- Attend to duration, build systematically
- Check peers for norms and for real-world aims

Addressing Issues of Latency

- Focus on latency as an aspect of responding
 - Measure it and work to reduce it
 - Include it as part of criteria for mastery
- Achieve Fluency through Rate Building
 - What is Fluency: "The fluid combination of accuracy plus speed that characterizes competent performance." (Binder, 1996)

When does latency have social consequences?

- Social responsiveness
 - Responding in a group context
- Long latencies to respond and slow response rates lead to missed opportunities for interaction and participation*

Characteristics of Fluent Behavior

- Automatic
- Low response effort
- Flowing
- Functional
- Expert



What other elements of social skill training are commonly discussed as clinical challenges?

- Following social rules
- Emitting complex social responses

Are these important?

- Related to success
- Related to avoidance of negative outcomes
- Related to quality of life



What would we use?

- Role plays and Behavioral Rehearsal
- Behavior Skills Training
- Scripts
- Teaching Interaction
- Cool vs. Not Cool
- Video Modeling
- EMBEDDED TEACHING
- NATURAL ENVIRONMENT

How do we get to more meaningful outcomes?

- TEACH IN CONTEXT OF RED FLAG PREVENTION
- CHANGE OUR INSTRUCTIONAL ENVIRONMENTS
- COMMUNITY BASED INSTRUCTION
- Increase real employment
 - How to secure jobs
 - Employment barriers
 - Showcasing strengths
 - How to provide on-site assistance/support
 - Remotesupervision through technology
- CREATIVE models of residential support
 - Shared living experiences
 - Working with government to help support such models

Are these important skills?

- MAYBE, for survival and acceptability
- REDUCE LIKELIHOOD OF OFFENDING OTHERS
- REDUCE LIKELIHOOD OF BEING ACCUSED OF INAPPROPRIATE BEHAVIOR
- REDUCE LIKELIHOOD OF IMPULSIVE RESPONSE THAT LEADS TO TROUBLE

What about other issues?

- Sexual Behavior
 - Ensuring safe behavior as a pursuer
 - Ensuring not victimized
- Bullying
 - What is the correct response to teach?
 - What is the correct behavior to emit?
- What about mental health challenges?
 - Detection
 - Treatment
 - Prevention of violence



What are some ways to address these concerns?

- Teach the individual to report behavior that is novel or unclear
- Do discrimination training for acceptable and unacceptable behaviors
- Present social rules and teach to the nuances
- Teach behavior regulation strategies
- Ensure consultative support

Partnering with other professionals

- Evaluation of comorbidity
- Risk assessment
- Sexual behavior issues or sexual trauma issues
- Educating first responders

QUALITY OF LIFE AND HAPPINESS

- What do we know about these elements of programming?
- Are we assessing them as outcomes?



What are components?

- DIMENSIONS
 - physical health
 - psychological state
 - level of independence
 - social relationships
 - personal beliefs
 - relationship to the environment



Happiness- operationally defined

- Happiness = Private Event
 - Self-Report
 - Indices
 - Overt behaviors
 - Observable



- Green, Gardner, & Reid, 1997; Green & Reid, 1996; Green & Reid, 1999; Green & Reid, 2005; Parsons, Reid, and Lattimore, 2012

Evaluate happiness

- Evaluate activities designed to promote happiness
- Identify unhappiness during events
 - Alter events?
 - Prevent distress?
- Evaluate behavior reduction interventions
- Resolve controversies within team
- Assess effects of teaching strategies



Our goal.....

- Our goal in targeting skills should be to create changes that
 - Are socially significant
 - Are meaningful
 - Occur in natural environments
 - Occur in generalized contexts
 - Occur spontaneously
 - Lead to a better quality of life



Another index of change: Social validity

- Are the changes making a meaningful difference in this child's life and in the lives of those he or she encounters?
 - More rewarding interactions
 - Fewer negative interactions
 - More independence
 - Fewer assists from adults
 - Positive reactions from other community members
 - Increased openness and real community integration
 - Happiness
 - Choice

Thank you

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