Transition to Employment & Life in the Community: Targeting Skills and Competencies

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Educational Partnership for Instructing Children

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FYI

A complete copy of the handouts for this talk can be on the website of the EPIC School.

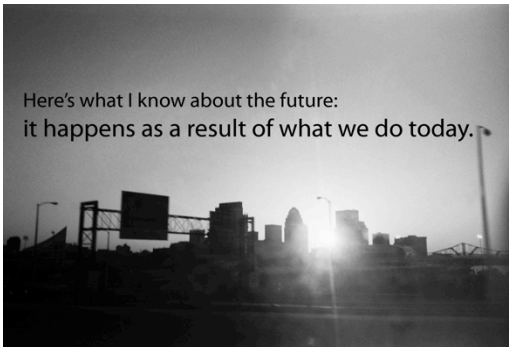
www.epicschool.org

The Basic Premise

Sometimes I think I am an autism professional who works in field of applied behavior analysis. At other times I think I am a behavior analyst who works in autism. The truth is that I am both.

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.



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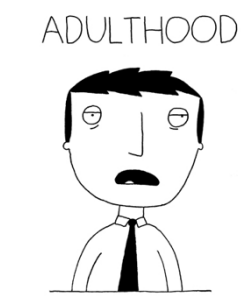


So we have a very complex, challenging, yet inevitable outcome called adulthood. And while we know much of what constitutes "best practices" in the transition transition to adulthood, we keep repeating the same mistakes we have been making for the past 30 years. For example…

Skill	Taught for the last 30 years	Occasionally taught for the last 15 years	The skills we need to consider now and looking ahead
Purchasing	Cash	Credit or Debit	Apple Pay
Travel Training	Mom drives you	Mom drives you	Uber, Self-Driving Cars
Organization	Velcro picture schedule	Velcro text schedule	Increasingly sophisticated Smart Phone Apps
Sex	"Never"	"He/she can masturbate if they have to"	Dating, relationships, sex, break ups, heartaches, etc.
Competence Defined As…	Safe and well cared form	90% accuracy across 3 consecutive sessions	What is the actual community standard for the skill
Safety	"Never let him out of your sight"	Inclusion and Supported Employment	Independence taught via Virtual Reality and monitored electronically

What does the research say?

Roux, et al (2013)

There is general acknowledgement that post-graduation outcomes for adults on the autism spectrum are, underwhelming at best. Most recently Roux, et al (2013) reported that only *half of young adults with ASD have ever worked for pay [emphasis added] since leaving high school and when they do work they earn significantly lower wages than those of age-referenced peers.* On an annual basis growing numbers of individuals with ASD are completing their 18+ years of publically funded education and graduating into unemployment, underemployment, or into poorly funded adult programs. Outcomes such as these represent a national economic and societal crisis of immense proportions.

Roux, A.M., et al. (2013) Postsecondary employment experiences among young adults with an autism spectrum disorder. *Journal of the American Academy of Child and Adolescent Psychiatry* 52(9), pp. 931-939.

Shattuck, et al (2012)

- Shattuck, et al, (2012) conducted a comprehensive literature review regarding original research on services and interventions aimed at supporting success in work, education, independence, and social participation among adults aged 18 and older with an ASD published between 2000 and 2010.
- 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.*

Shattuck, P., et al, (2012). Services for adults with autism spectrum disorders. *Canadian Journal of Psychiatry*, 57, 284-291.

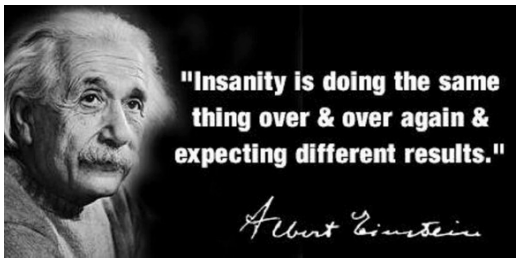
- Howlin, et al (2004) surveyed 68 adults with autism with an IQ of above 50 and found a majority (58%) were rated as having poor or very poor outcomes. With regards to employment status they found
  - 8 were competitively employed
  - 1 was self employed earning less than a living wage
  - 14 worked in supported, sheltered or volunteer employment
  - **42 had "programs" or chores through their residential provider.**

Sadly, over 30 years after Gary Mesibov said this, it remains true today.

"A major difficulty confronting those interested in adolescents and adults with autism is a lack of empirical data."

Mesibov, G.B. (1983). Current perspectives on issues in autism and adolescence. In E. Schopler & G Mesibov, (Eds). Autism in Adolescents and Adults. Springer: Philadelphia. p.37

So it seems the only way things will be better for your son, daughter, or student than they were for those who already transitioned to the adult world is if we collectively do something to make "better" happen. And that means thinking 10-years down the road, moving from the classroom to the community, promoting independence and accepting reasonable risk all while meeting the requirements of the IEP, using evidence based practices, and addressing state standards. Easy, right?



So then let's all agree on a few things…

Everyone is capable of living and working in the community with the proper supports.

Nobody has to earn the right to be in the community.

If individuals with ASD tend not to generalize well then we need to teach where the skill is most likely to be used and that NOT in the classroom.

The potential of individuals with ASD to have fulfilling, included and employed adult lives is limited more by our vision than their skill deficits.

Lastly, there are some behavioral barriers and inviolable community norms that need to be addressed if the first four statements can be fully implemented. These are:

- *High rates of severe challenging behavior can limit community participation.*
- *Poor hygiene and age inappropriate clothing restricts social inclusion.*
- *Poor eating skills restricts inclusion on many levels.*
- *Inappropriate sexual behavior tends to fall under community zero tolerance policies*
- *Not being bowel or urine trained presents an overall challenge.*

But anyway, this is how this talk developed over the past few years.

Part I

Part II

How come no one ever taught you this?

Having worked with a large number of adolescents and adults who could identity the sight word "poison" but would still drink the poison, it dawned on me that no matter how evidence-based your intervention may be, using it to teach the wrong skill is no better than teaching the right skill poorly.

Part III

MY QUASI-EXPERIMENT

- Location: A private, behaviorally-based school for individuals with autism located in NYC.
- Two classrooms each with 5 adolescents with autism each student provided ABA-based instruction in a 1:1 ratio.
- A timer was placed in the classroom and all instructors were told to move away from their students when it rang.
- Data were then collected on what the students did in the absence of the instructor.
- What do you think the students did?

Nothing

They did nothing

So what does this tell us?

- Everything we were doing was teacher directed. In other words, all student behavior was prompted, mediated, and reinforced via the instructor.
- Student engagement was maintained, at least in part, by negative reinforcement (i.e., If I do this you will stop badgering me).
- None of the skills we were teaching were viewed as being of use of value by my students.

Yet at the same time in dens and bedrooms across the country

- The average American spends **142 hours per year** (3.5 standard work weeks) playing video games. Worldwide, the total is somewhere around **3.2 Billion** hours annually. I find this fascinating as game players have access to multiple, competing schedules of reinforcement that maintained an alternative behavior set prior to accessing to MMPGs.

Why?

"When you strip away the genre differences and the technological complexities, all games share four defining traits:

- *A goal,*
- *Rules,*
- *A feedback system, and*
- *Voluntary participation."*

Jane McGonigal (2011, p. 21)
Reality is Broken: Why Games Make Us Better and How They Can Change the World

The 7 Dimensions of ABA

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

Baer, D.M., Wolf, M.M., & Risley, T.R. (1968). Some current dimensions of applied behavior analysis. *Journal of Applied Behavior Analysis*, *1*, 91-97.

So we clearly have goals, rules, and a system of feedback

So maybe we need to consider generality, (voluntary participation) with adolescents/adults with ASD if we are to teach skills & skill sets that are initiated independently, generalizable, and maintained across time & environments.

ABA as Evidence-based Practice

The term evidence-based practice, as used in ASD, is an evolving concept involving both empirically supported interventions and the clinical expertise by which such interventions are selected, applied, and analyzed on on case by case basis. Smith (2013), for example, has defined evidence-based practice is a service offered by a provider to help solve a problem presented by a consumer highlighting the role of the clinician in an evidence-based process. Evidence-based intervention, on the other hand, generally refers to a set of proven interventions independent of one's ability to use them.

Smith, T. (2013). What is evidence-based behavior analysis?. *The Behavior Analyst*, **36**, 7-33..

Today we are expanding our knowledge of, and expertise in, ABA for use in the complex area of adulthood and ASD. A major challenge, however, is that we still view adults with ASD i very simplistic terms.

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

But all adults are complex

Hans Asperger on Complexity and ASD

"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 under-standing 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

Understanding ABA beyond the classroom and in support of older individuals

For our purposes today, ABA is:

- Analytical – Effective intervention requires us to understand points of view other than our own.
- Socially Important – Effective, generalized, and maintained intervention requires the selection of targets that of value beyond the classroom.
- Contextual/Generalizable - Effective intervention requires us to teach where the skill is most likely to be displayed.

The 2015 Behavioral Science Insight Policy Directive

On September 15 2015 President Obama ordered government agencies to use behavioral science insights to "better serve the American People." In his executive order, the President directed federal agencies to find program areas where the behavioral sciences could improve "public welfare, program outcomes, and program cost effectiveness. This order reflects the evidence that people often fail to make rational choices. Such deviations from rationality, well documented in the decision-making literature, are consistent across time and populations. For example, the typical person would dislike losing $50 more than he would enjoy gaining $50, which would not be the case if he were fully rational. And when making decisions, people tend to give disproportionate weight to information that readily comes to mind (a recent discussion, for example) and overlook more pertinent information that is harder to retrieve from memory. Again, this shouldn't happen to so-called "rational agents."

Why Is Behavior Analysis Relevant to Improving Quality of Life?

"When done correctly, there is not a field of intervention that is more person centered than applied behavior analysis"

-Gina Green, Ph.D., BCBA-D
Personal Communication

Why Is Behavior Analysis Relevant to Improving Quality of Life?

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. Yoda, was probably a behavior analyst.

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

A Few Challenges to Evidence-based Practice with Older Individuals

One

The prevalence of pseudoscientific or simply unproven interventions leading up to adulthood competes with evidence-based practice.

Sadly, ASD is a bit of a fad magnet

There are, however, a variety of challenges to evidence-based practice

- Seeing is not believing.
- Correlation does not automatically mean causation. We know this but we generally don't act accordingly (the say/do phenomena).
- There is a tendency to make the facts fit our personal theories rather than make our personal theories fit the facts.
- There is well established tendency to opt for low response effort interventions (e.g., meds) over high response effort ones (e.g., ABA). While at the same time, evidence from social psychology indicates that how well we perceive an outcome is, at least in part, related to how difficult it was to achieve.
- 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 so superstitious learning is, to some extent, inevitable.

If you want to try an unproven intervention, this is the best way to go about it (Kay & Vyse, 2005)

1) Clearly define the target of the intervention. What exactly is it that you expect this intervention will do?
2) Develop decision rules to help you decide if, or when, the intervention worked.
3) Get some baseline data before you start. For families, they should try to get an hour or two (in "random" 15-min intervals) of video of their son/daughter

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But if you want to try some unproven interventions, here is a reasonable way to go about it (e.g, Kay & Vyse, 2005)

4) Implement the intervention to the best of your ability (i.e., with fidelity)
5) Collect data on both positive changes (i.e., your defined expectations) and negative changes (i.e., side effects).
6) Evaluate objectively using your decision rules.

Kay, S., & Vyse, S. (2005). Helping parents separate the wheat from the chaff: Putting autism treatments to the test. In Jacobson, J.W., Muliek, J.A., Foxx, R.M. (Eds.), *Controversial therapies for developmental disabilities: Fad, fashion, and science in professional practice* (pp.265-277). Hillsdale, NJ: Lawrence Erlbaum Associates.

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two

Time Is Not On Our Side

- School Days/Year (NJ) **211.0**
- Hours/day **6.0**
- Hours/day actual engagement **4.5**
- Total hours/year engaged **949.5**
- Total hours 17to 21-years **4,747.5**
- Goals in average IEP **30.0**
- Total goals across 5 years **150.0**
- Hours/goal available **31.65**

But that really is best case scenario defined as:

- Student fully engaged 4.5 hours/day;
- NO staff or student absences;
- NO holiday or birthday parties
- NO field trips;
- NO challenging behavior
- NO weather closures, and;
- NO late arrivals or early dismissals…

Since we don't have best case scenario we can include a "fudge factor" of .3 which means we actually have

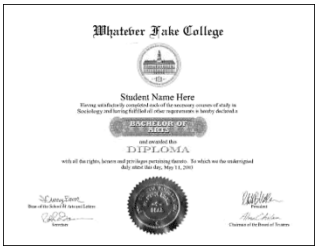
5

school days to teach each goal to mastery and generalize to untrained environments and novel people.

Which means, time is not on our side.

three

Nobody, it seems, goes to college to work with adults with autism. Kids with autism? Sure. Adults with autism? Not so much.


Whatever Fake College

Student Name Here

BACHELOR OF ARTS

and awarded the

DIPLOMA

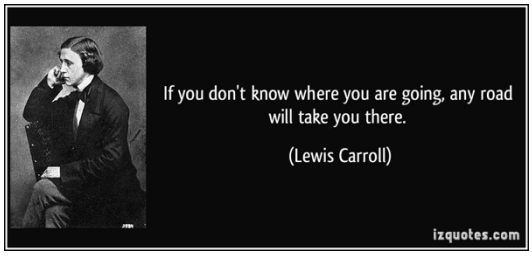
Which is further "complicated" by the fact that no one stays in the field.

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/aspe_dsp_11-09-04.doc.

So what do we do?



*Actually, this is a paraphrase of a conversation Alice has with the Cheshire Cat. If I were to be accurate, this quote can actually be attributed to George Harrison.

"You Cannot Make a Transition Plan without Defining the Outcome of your Plan"

-Peter Gerhardt

"Transition Services" Under IDEA:

The term "transition services" means a coordinated set of activities for a child with a disability that: (1) Is designed to be within a results-oriented process, (2) that is focused on improving the academic and functional achievement of the child with a disability (3) **to facilitate the child's movement from school to post-school activities, including postsecondary education, vocational education, integrated employment (including supported employment); continuing and adult education, adult services, independent living, or community participation**; (4) Is based on the individual child's needs, taking into account the child's strengths, preferences, and interests; and Includes instruction, related services, **community experiences, the development of employment and other post-school adult living objectives, and, if appropriate, acquisition of daily living skills and functional vocational evaluation.** [34 CFR 300.43 (a)] [20 U.S.C. 1401(34)]

So start with an outcome statement

Upon graduation A will be living in a small well, supervised residential setting in NYC with 24-hour, 1:1 support. He will have part time (no more than 20 hours/week) employment at a job he enjoys, where there is social interaction and support from a job coach. His free time will be spent shopping, walking, exercising, etc. Social opportunities are important to A so he will have access to both typical and adaptive events (e.g. movies, religious services, Mets games, etc.). As part of his leisure life A will have regular breaks during which he can choose a preferred activity (e.g., leafing through a magazine, books, doing puzzles, using his I-Pad/Touch screen computer, etc.). This should be considered very important to A's emotional stability. The important people in his life will consist of his family, extended family and close friends, at least one good friend, and a variety of acquaintances.

And then there are a couple of ways to figure out what you need to do to help your student get there.

Priorities of Instruction in Transition Programming

- Solicit student and family input as to desired 1 year, 5 year, 10 year outcomes.
  - But you really need to try and be specific here. Not just that he should have a job but a job doing what? When does he do this job? Who does he do this job with? What might make employment worthwhile to him?
  - And then do the same for where/how he will live and his leisure skills, public social circle and private social circle.

Adapted from: Wehman, P. (1992). Life Beyond the Classroom: Strategies for young people with disabilities. Baltimore: Paul H. Brookes.

Priorities of Instruction in Transition Programming

- Solicit student and family input as to desired1 year, 5 year, 10 year outcomes.
- Survey current and potential future environments based upon these outcomes.
  - You need to then get out of your classrooms and homes and see what skills are really needed.
  - Are there any connections you can use to give you son or daughter a more expanded educational experience?

Adapted from: Wehman, P. (1992). Life Beyond the Classroom: Strategies for young people with disabilities. Baltimore: Paul H. Brookes.

Priorities of Instruction in Transition Programming

- Solicit student and family input as to desired1 year, 5 year, 10 year outcomes.
- Survey current and potential future environments based upon these outcomes.
- Assess skill needs in these environments in terms of production, social and navigation skills.
  - Remember, production skills are easy. Social and navigation skills are really difficult.

Adapted from: Wehman, P. (1992). Life Beyond the Classroom: Strategies for young people with disabilities. Baltimore: Paul H. Brookes.

Priorities of Instruction in Transition Programming

- Solicit student and family input as to desired1 year, 5 year, 10 year outcomes.
- Survey current and potential future environments based upon these outcomes.
- Assess skill needs in these environments in terms of production, social and navigation skills.
- Prioritize skills that occur across multiple environments
  - More often than not these will fall into the category of Social or Navigation skills but not always.

Adapted from: Wehman, P. (1992). Life Beyond the Classroom: Strategies for young people with disabilities. Baltimore: Paul H. Brookes.

Priorities of Instruction in Transition Programming

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- Survey current and potential future environments based upon these outcomes.
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- Prioritize skills that occur across multiple environments
- Attend to safety skills
  - Significantly overlooked but very important to consider.

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- Prioritize skills that occur across multiple environments
- Attend to safety skills
- Attend to skills that reduce dependence
  - Sometimes just being less dependent is an excellent goal.

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- Survey current and potential future environments based upon these outcomes.
- Assess skill needs in these environments in terms of production, social and navigation skills.
- Prioritize skills that occur across multiple environments
- Attend to safety skills
- Attend to skills that reduce dependence
- Attend to skills you, or the student, will need to provide the NT cohort.
  - The best way for others to help, support, or just get to know your son or daughter.

Adapted from: Wehman, P. (1992). Life Beyond the Classroom: Strategies for young people with disabilities. Baltimore: Paul H. Brookes.

A Short Cut

When speaking about skill development always remember that for a specific skill

If you can teach the skill, teach it

If you can't teach the skill, adapt it

If you can't adapt it, figure out some way around it

If you can't figure out some way around it, teach the NT's to deal

A Shorter Cut

"If the student does not learn to do the task, will someone else have to do it for them?"

Lou Brown, 1985

Which leads to something like this…

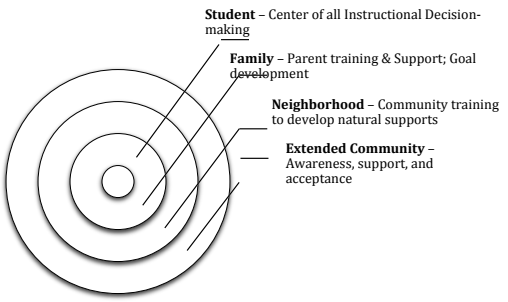
Transition Profile
[Student]
[Date]

Peter Gerhardt Associates, LLC

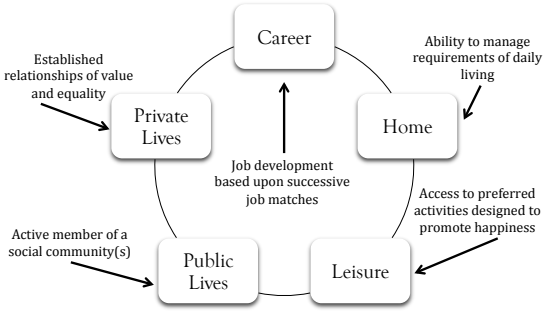
Student's Transition Statement

At 23 years Student will be living in a small well, supervised residential setting in NYC with 24-hour, 1:1 support. He will have part time (no more than 20 hours/week) employment at a job he enjoys, where there is social interaction and support from a job coach. His free time will be spent shopping, walking, exercise, etc. Social opportunities are important to Student so he will have access to both typical and adaptive events (e.g. movies, religious services, Mets games, etc.). As part of leisure life Student will have regular breaks during which he can choose a preferred activity (e.g., leafing through a magazine, books, doing puzzles, using his I-Pad/Touch screen computer, etc.). This should be considered very important to Student's emotional stability. The important people in his life will consist of his family, extended family and close friends, at least one good friend, and a variety of acquaintances.

Transition Profile Recommended Areas of Intervention



Transition Profile Areas of Focus



Sphere of Intervention: Career

In order to be gainfully employment Student needs the following programs/skills should be targeted.

Skill	Challenge	Recommendation
Student needs to be able to transition to work (bus or taxi) without any disruptions	A community setting, Restricted communication, Changes in bus schedules/ traffic. External variables	Listen to music on bus? Give a book/magazine. Sitting in the back of the bus. Orient self away from Student as volume increases. Adjust physical proximity
Student needs to increase his endurance at work from current 8.5 hours/week		Incorporate Negotiable-→ Nonnegotiable and 5 time rule
Student needs to increase the variety of work tasks he able to complete (clear onset/ offset)		
Student needs to be able to work with support staff up to 20 feet away.	Size of the work room.	

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Student needs to increase his endurance at work from current 8.5 hours/week		Incorporate Negotiable-→ Nonnegotiable and 5 time rule
Student needs to increase the variety of work tasks he able to complete (clear onset/offset)		
Student needs to be able to work with support staff up to 20 feet away.	Size of the work room.	

Sphere of Intervention: Home

Within his home, Student should be able to independently (or with minimal supports), accomplish the following.

Skill	Challenge	Recommendation
Continue preparing and eating 3 meals/day, checking mail, taking our garbage, etc.	None for staff Systematically assess efficacy of GF/CF diet	Continuation of current programs.
Student should be able to request access to leisure preferences.	Developing communication skills to request. Ensure access during downtime.	See leisure section
Student will be able to shower/shampoo/dry with minimal staff supervision.	Long standing challenge. Understanding completion criteria.	Consider increase distance of parent or staff and see if reduces prompt cueing.
Student will be able to wipe effectively after a bowel movement.	Long standing challenge. Understanding completion criteria.	Consider increase distance of parent or staff and see if reduces prompt cueing.
Student will manage his own sleep/wake cycle.		Purchase and use alarm clock
Student will be able to respond to a knock and "Can I come in" when in bathroom/ bedroom.	Will require repeated practice	Provide sufficient opportunities to respond (no less than 5X day)
Student will be able to take his laundry to the cleaners and pick up when done.	General purchasing, navigating, carrying, etc.	Self explanatory

Sphere of Intervention: Leisure

Student should be able to independently (or with minimal supports), access and utilize the following leisure skills.

Skill	Challenge	Recommendation
Increase the variety of leisure skills Student has access to and enjoys (clear onset/offset).	Leisure skills need to function as such. Student is an experiential learner.	Introduce an actual jigsaw puzzle with age appropriate themes. Leisure sample 5X per activity
Increase Student's independent duration at a variety of leisure activities.	Finding new, age appropriate activities that will hold Student's attention.	Baseline current engagement at new activities. Leisure sample 5X per activity
Increase Student's exercise opportunities to include more group activities (aerobics).		Continue weight lifting. Locate/start integrated aerobics class. Walking.
Student will have regular access to YouTube and music via I-Pod	So as not to interfere with other life relevant activities	

Sphere of Intervention: Public Social

Student needs to be able to access, or utilize, the following skills with minimal prompting.

Skill	Challenge	Recommendation
Student needs to be able to transition to community activities (bus or taxi) without any disruptions	Structure and predictability are important to Student but contrary to many transitions	Provide a minimum of 1 such transition/day. Identify a reasonably powerful R+ for transitions.
Student will master the exchange process of purchasing.	Frequency of practice needs to be high	Student will purchase an item 2-3X day. Consider intro of Student to Cashier
Student will follow a shopping list at a small grocery store or deli.	Frequency of practice needs to be high	Student will shop for all items he needs to make his lunch and, upon return, make lunch with purchased agreement.
Basic social courtesies inc. Thank you, excuse me, Hello, Goodbye, social distancing, waiting in line	Frequency of practice needs to be high	Prioritize thank you, social distancing, and waiting for instruction and data collection. Incidental instruction for rest
Behavioral Expectations	This needs to be clarified by team	
Safety, Public men's room use, crossing street, personal info.	High priority but very difficult to teach	Prioritize high frequency skills inc. stop at all curbs. Have Student ALWAYS carry wallet with official photo ID, and GPS Smart Phone.

Sphere of Intervention: Private Social

Not directly applicable in this case as the necessary skills are subsumed under the four other areas of intervention

Skill	Challenge	Recommendation
Student needs to more effectively communicate his wants, needs, fears (dogs), concerns, etc.	Motivation to communicate needs to be established to promote communication	Consider systematic desensitization protocol for dog phobia. Increase number of communicative opportunities across the day
Transition from pajamas to t-shirt and sweat pants.	Student needs to wear sleepwear that is more age appropriate.	Make and reinforce change

Family Responsibility in Support of Transition Programing

AREA	RESPONSIBLITY
Career	• Use personal contacts to identify 3-5 potential employment or job training opportunities for Student • Identify 3-5 adaptive skills at home with clear onset/offset to work on with Student. • Continue coordination of team meetings.
Home	• Instruction in managing own sleep/wake cycle • Generalization and maintenance of all other skills in this section.
Leisure	• Identify a minimum of one new leisure opportunity/month. • Promote increasingly longer durations in preferred and non-preferred activities.
Public Social	• Coordinate "Shopping List" program • Generalization and maintenance of all other skills in this section. • Coordinate Resource Mapping
Private Social	• Provide a greater number of communicative opportunities. • Transition of age-relevant sleepwear (i.e., shorts and tee shirt).

Professional Responsibility in Support of Transition Programing

AREA	RESPONSIBLITY
Career	• Develop instructional programs and reasonable data collection systems for identified goals. • Ensure a high and consistent frequency of instruction (i.e., opportunities for Student to learn skill) for all identified goals.
Home	• Develop instructional goals and reasonable data collections systems for identified goals. • Many of these goals have a limited opportunity for instruction (e.g., only shower 1X day) so it is essential the every opportunity is seen as a teaching opportunity. • Consider the use of adaptive devices or modify, if appropriate, mastery criteria.
Leisure	• Identify a minimum of one new leisure opportunity/month. • Work with family to promote increasingly longer durations in preferred and non-preferred activities.
Public	• Develop instructional goals and reasonable data collections systems for identified goals. • Prioritize high frequency/high risk areas of intervention.
Private	

Desired community Responsibility in Support of Transition Programing

AREA	RESPONSIBLITY
Career	• Provide opportunity for employment • Provide frequent performance feedback to job coach • Provide for a brief "training" of co-workers on who Student is as a person and how he best communicates.
Leisure	• Provide access to a variety of activities • Acceptance of Student as a full part of leisure community associated with an activity
Public	• Acknowledgement of Student's autism and related challenges while, at the same time, be willing to learn about his strengths • Provide simple accommodations as necessary and possible • Respect Student's privacy while interacting with Student in an age appropriate and relevant manner.

Resource Mapping

Resource Mapping is a **process** of identifying and linking community resources with agreed upon individual goals and preferences. Resource mapping can be used to:

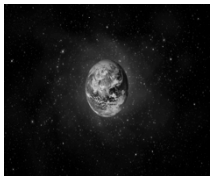
- ❑ Identify available community resources
- ❑ Enhance services
- ❑ Identify additional funding supports
- ❑ Align young adult with available community supports
- ❑ Use data to make informed decisions
- ❑ **Cultivate new partnerships and relationships over time by supporting or "giving back" to targeted organizations.**

Areas of Interest in Resource Mapping

AREA	POSSIBLE SOURCES
Leisure	YMCAs, Movie theaters, JCCs, Township Sponsored Adaptive Sports, Music classes or concerts, SNACK etc.
Financial Support	Social organizations such as Lions or Elks Clubs, Community Foundations, Communities of faith, etc.
Career	Retired Senior Volunteer Programs, Chambers of Commerce, Rotary Clubs, Local Businesses (particularly those with which you do business), Volunteer opportunities such as Meals on Wheels, Good Will, Salvation Army, Food Pantries, etc.
Social	Neighbors, friends, high school seniors (community service graduation requirement), Communities of faith, College fraternities or sororities, Community College, Local Arts organizations, SNACK, etc.

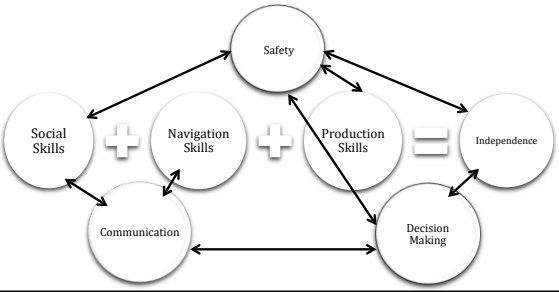
Transition, Adaptive Behavior and Adult Outcomes

The Universe of Skills at Age 5 (and those skills that we usually teach)



The Actual Universe of Adult Skill Competencies

The primary difference between the two views, and between independence and dependence is adaptive behavior.



Adaptive Behavior

"Adaptive Behavior is defined as those skills or abilities that enable the individual to meet standards of personal independence and that 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 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.

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.

Matson, Rivet, Fodstad, Dempsey, & Boisjoli, (2009) evaluated 337 adults using the Vineland Adaptive Behavior Scale to assess the differential impact of having 1) an Intellectual Disability (ID), 2) an ID plus ASD, or 3) an ID, ASD, and an Axis I mental health diagnosis. **Adaptive skills were greatest for the ID group followed by the ID plus ASD, and ID and ASD plus psychopathology. Thus, the greater the complexity of diagnoses, the greater the skills deficits observed, particularly where psychopathology was concerned.**

Matson, Hattier, & Belva, (2012) noted that work, self-help, leisure, and hygiene skill deficits are often associated with a diagnosis on the autism spectrum. **A number of interventions have been established to assist individuals with these impairments the most effective of which are interventions based upon applied behavior analysis (ABA)**

Adaptive Behavior Competencies:

- Are not simplified curricular goals
- Are not characterized by ADL skills
- 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

Chores (ADLs) that typical children can do.

AGE	CHORE
2-4 year olds	Help dust, Put napkins on table, Put laundry in hamper, Help feed pet
4-7 year olds	Set (or help set) the table, Put away toys, Help make bed, Help put dishes in dishwasher, Help clear table, Help put away groceries, Water the garden
8-10 year olds	Make bed, Set & clear table, Dust, Vacuum, Help wash car, Help wash dishes, Take out the trash
11 year olds and older	Above plus clean room, Mow lawn, Feed pets, Start doing own laundry, Make small meals, Shovel snow, Help with yard work, Empty and load dishwasher, etc.

Adaptive Behavior Intervention

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

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

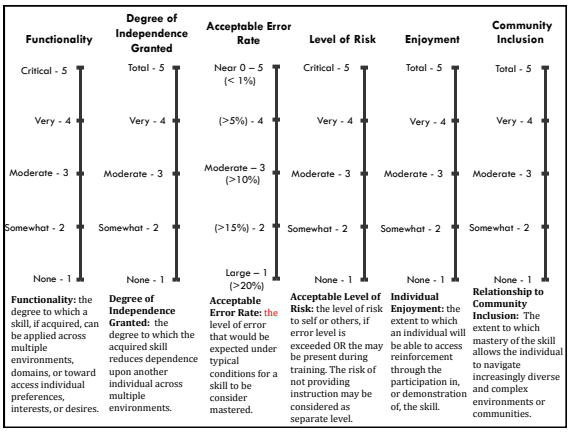
- A general goal of many ABA-based programs is for teachers to demonstrate stimulus control over their students and classroom.
- However, the ultimate goal of any transition program is to transfer such control from the teacher to both the environment (e.g., stop at the red light) and the individual themselves (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.

Using the following definitions

- **Functionality:** the degree to which a skill, if acquired, can be applied across multiple environments, domains, or toward access 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 consider mastered.*
- **Acceptable Level of Risk:** the level of risk to self or others, if error level is exceeded OR the may be present during training.
- **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.

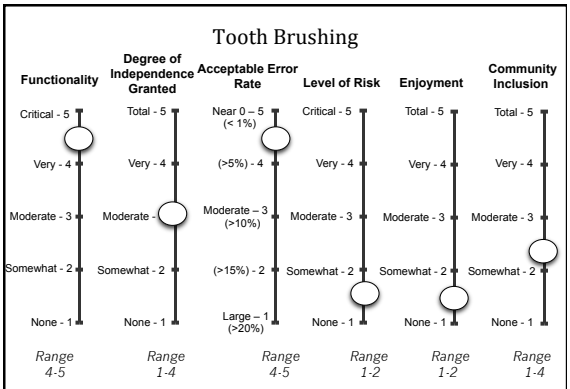


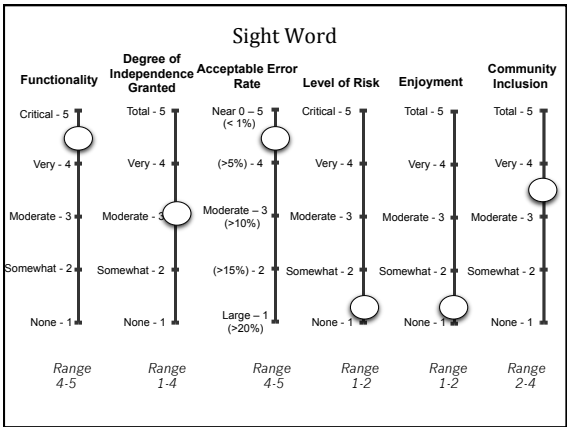
Testing the Application of the Functionality Index With Adolescents and Adults With Autism

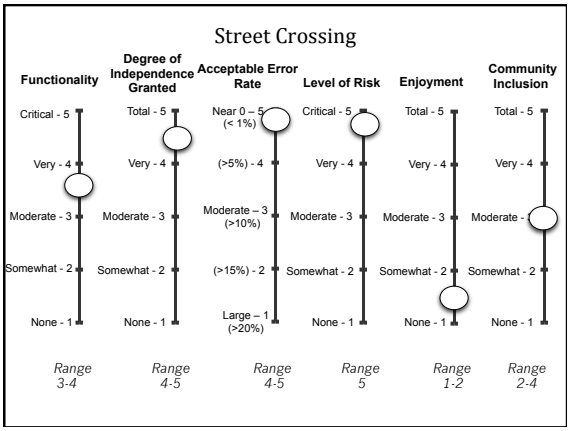
Peter F. Gerhardt, Ed.D.,
ABAI Conference, Minneapolis, MN
May, 2013

Rated IEP Goals

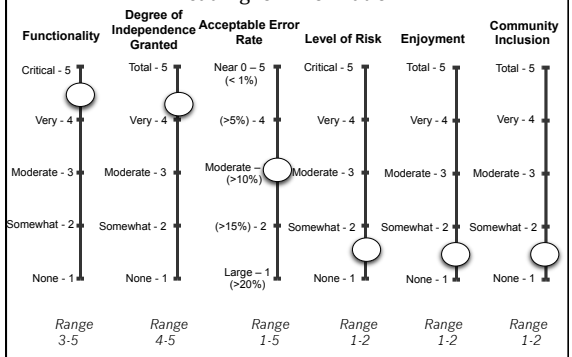
- ❑ Tooth brushing
- ❑ Sight words
- ❑ Street Crossing
- ❑ Reading for information
- ❑ Math facts – Addition & Subtraction
- ❑ Using a Credit/Debit Card
- ❑ Playing a video game
- ❑ Sorting by categories



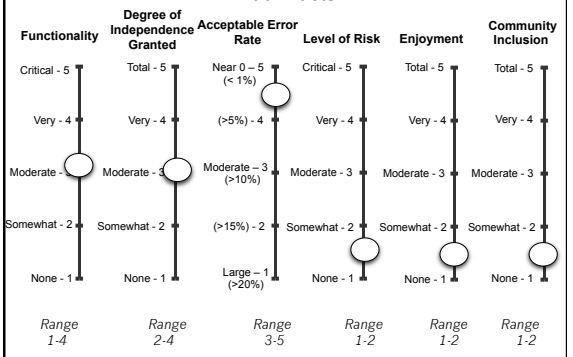




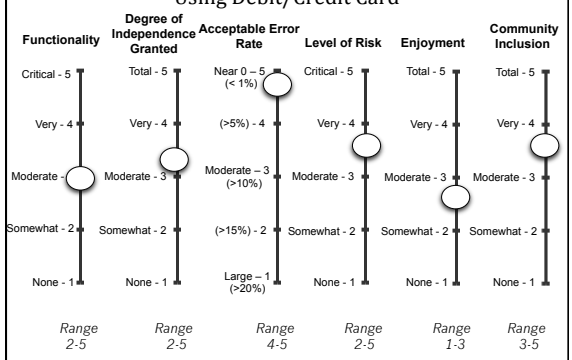
Reading for Information



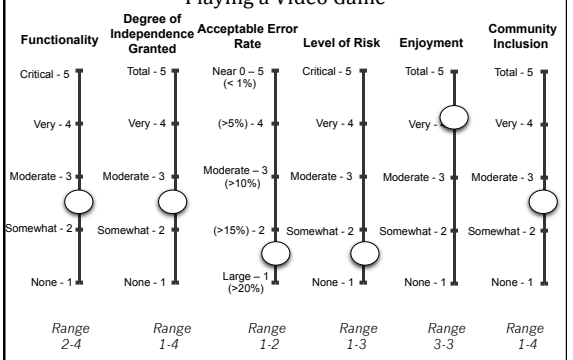
Math Facts



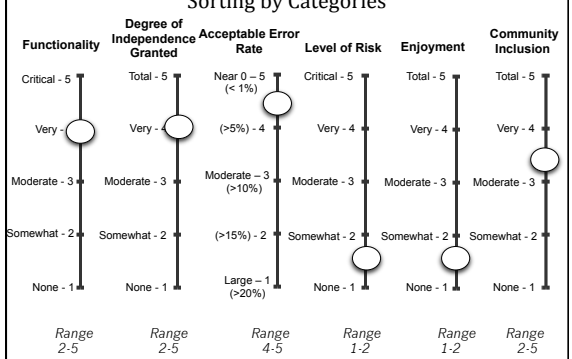
Using Debit/Credit Card



Playing a Video Game



Sorting by Categories



Functionality Index Combined Scores

	Functionality Ranking	Risk
Street Crossing	12	Very High 4.9
Credit Card	14	Moderately High 3.6
Category Sort	17	Very Low 1.5
Tooth	18	Moderately Low 2.6
Sight Words	18	Very Low 1.6
Reading 4 Info	18	Very Low 1.2
Math Facts	25	Very Low 1.4
Video Game	25	Low 1.5

Discussion

Of particular interest was that the two skills rated highest overall in functionality (i.e., street crossing and using a credit card) were also rated highest in potential risk. This would indicate that skills or skill sets with the greatest potential to directly impact the lives of adolescents with autism may also be those where fewer of the associated variables are controllable or, for that matter, even known. These are, however, the conditions under which the field of ABA may have its greatest potential impact with reference to QOL. Unfortunately, this has not been an active focus of research or practice and, as such, our knowledge-base is lacking.

Risk

Risks threatens things that we value. What we do about them depends on the options we have, the outcomes we value, and our beliefs about the outcomes we value that might follow contingent on each option we may choose. The outcomes can be certain or uncertain and our choices simple or complex. (Fischhoff & Kadvany, 2011) Risk, it seems, is unavoidable. However ignoring risk, under the guise of safety, would only seem to invite greater risk for the individual in question.

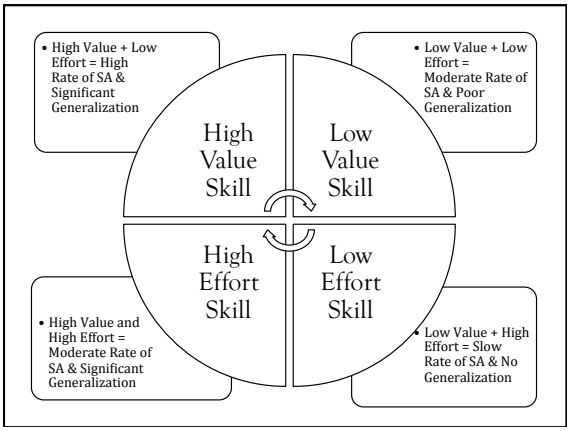
(Fischhoff, B., & Kadvany, J. (2011). *Risk: A Very Short Introduction.* New York: Oxford University Press

Discussion

- Among the respondents there seemed to be a tendency to rate skills according to their understanding of "functional" rather than by the definition(s) provided. Going forward this is a potential challenge if this tool is to be of use in determining instructional priorities.
- In addition, with the exception of playing a video game and reading for information, acceptable error rates associated with skill acquisition were at near "0" levels. This too presents a challenge in that we may be holding individuals to higher standards than does the community outside of the classroom.

A future implication?

- It is generally accepted that individuals with ASD demonstrate challenges in the generalization of mastered skills from one environment to another (e.g., Handleman & Delmolino, 2005)
- Yet there are those children who generalize the operation of the DVD/ Blue Ray player from unit to unit, from house to house, and from home to school without any additional intervention.
- The question then becomes to what extent a failure to generalize a particular skill is due to:
  - A neurological challenge associated with a Dx of autism.
  - Our failure to attend to context as a critical variable?
  - Our failure to provide sufficient opportunities to respond that may be necessary for true mastery?
  - Our failure to consider the relationship between skill value the effort needed to complete the skill?
  - Our failure to transfer control from the classroom environs to the world outside?



What other adaptive behaviors are critical intervention targets?

What is a critical instructional target?

- 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*.

FREQUENCY OF USE

	Objective	≥ 1X/day	1X/day	2-3X/Wk	1X/Wk	1-2X/Mnt	Less Frequent	Importance* 0-2
1	*"When is your birthday?"*						X	0
2	*"Where do you live?"*						X	2
3	*Wiping after BM*	X						2
4	*Make a meal with recipe*				X			1
5	*Make meal with Microwave*			X				2

0 = Not Important; 1= Maybe important but not essential; 2 = Important

So this whole transitioning thing is very complex. Are there any simpler ways we might be able to obtain similar, if not the same, outcomes?

Curb Cuts

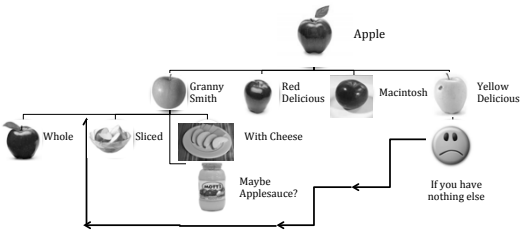
"Curb Cut (n) - A small ramp built into the curb of a sidewalk to ease passage to the street, especially for bicyclists, pedestrians with baby carriages, and physically disabled people. [sic]"

So what would constitute a curb cut for someone with ASD?

#1
Decent Choice Making Instruction

Effective choice making is central to many of the competencies of adulthood. However, most of us master simple either/or choices pretty early in life.

For Example:
I think I might like an apple



#2

Resilience/Problem Solving

(or, as a behavior analyst, resistance to extinction)

Resilience is an individual's ability to properly adapt to stress and adversity. Resilient behavior develops over time and is is composed of a variety factors which prescribe the manner in which we respond to challenges. Behavioral competencies associated with resilience include:

- Perseverance, or the ability to continue with the behavior in question in the absence of high rates of positive reinforcement.
- Flexibility, or the ability to generate new strategies to solve a particular problem.
- A learning history that has included error identification and correction as a specific instructional goal.
- The ability to manage impulsive behavior and/or ignore environmental distractors

In behavior analysis

We have long acknowledged the phenomena of learned helplessness (Seligman, 1975). Learned helplessness arises from repeated experience with unpredictable and uncontrollable events (often traumatic events) and results in a reduced ability to cope with life challenges across multiple domains.

Seligman, M. E. P. (1975). *Helplessness: On Depression, Development, and Death*. San Francisco: W. H. Freeman.

In behavior analysis

Yet we have not provided the same level of interest or understanding to phenomena of learned optimism (Seligman, 1990). Learned helplessness arises from repeated experience with unpredictable and uncontrollable events (often traumatic events) and results in a reduced ability to cope with life challenges across multiple domains.

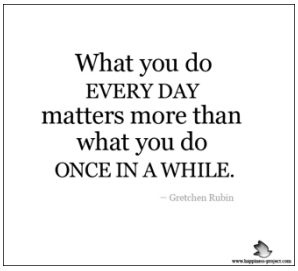
#3
Train the Typicals

"If you neurotypicals have all the skills, why don't you adapt for a while dammit! Why is it always me fault?

Donna Vickers

#4

Teach the right skills in the right context (i.e., where the behavior is most likely to be displayed.



What you do every day might include

1. Wake to alarm clock
2. Morning routine
    1. Shower, dress, hygiene, etc.
3. Coffee/Breakfast
4. Remember keys & lock door
5. Get to work somehow
6. Follow verbal/written prompts
7. Use restroom
8. Take a break
9. Purchase and eat lunch
10. Fix mistakes
11. Ask for help
12. Use computer/smart phone
13. Get home somehow
14. Get the mail
15. Unlock the door.
16. Change out of work clothes
17. Get something to eat
18. ADLs
19. Prepare dinner and eat
20. Clean up. Use dishwasher
21. Go on-line
22. Home/Office work
23. Shower
24. Prep for bed inc. meds
25. Review next day schedule
26. Set alarm clock
27. Sleep

#5

The ability to self monitor ones schedule, behavior, work output goes a long way to supporting independent functioning across multiple environments and skill domains in adulthood.

#6
Accept that life is not perfect

- For example, a recent study found that 15% of men and 7% of women didn't wash their hands at a public restroom. When they did wash their hands, only 50% of men used soap, compared with 78% of women. Further, only 5% of people who washed their hands scrubbed long enough to kill germs that can cause infections.
- In a recent study on casual sex during spring break, researchers found that 15% of men and 13% of women had sex with someone they just met. Further 77% of college-age women and 83% of men reported having had casual sex at least once.
- Errors and mistakes happen all the time. The trick is minimize big mistakes while accepting a certain, "non-dangerous" error level. So is competence to be average? Better than average? What? Accept some variability from time to time.

Employment Development and Support

Employment is about more than the actual job task. In fact, the job task is usually the easiest part of employment for individuals on the Autism Spectrum.

Employment is not a pipe dream

Wehman, et al., (2014) presented the results of a randomized clinical trial comparing a modified Project SEARCH model of intervention with a control group on employment outcomes with young adults (ages 18-21 years) with ASD. Project SEARCH is a highly specialized school-to-work program that takes place entirely in the workplace and focuses on hands-on, or experiential, instruction on a rotating number of actual jobs. As Project SEARCH is not autism specific modifications were made to better meet the needs of young adults on the spectrum. Modifications included systematic instruction utilizing the principles of Applied Behavior Analysis (ABA), on-site support from a behavior specialist, and intensive staff training in ASD and the Project SEARCH model. Members of the control group, on the other hand, attended their assigned high school and received transition services as outlined in their Individualized Education Plan (IEP). Following intervention 87.5% of those in the treatment group were employed while only 6.25% of the control group were employed. Further, the young adults in the treatment group achieved higher levels of independence (as measured by the Support Intensity Scale Employment Activities Subscale) than did those in the control group.

Important considerations toward successful employment for learners with ASD

- There is a need to redefine work readiness

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- Job sampling needs to provided with sufficient instructional intensity to develop competencies is critical

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- A service economy requires one to be proficient at job carving or customized employment.

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- Promote competence over disability
- Attend to the social and navigation components of job training and support
- Job match!

What is Job Match?

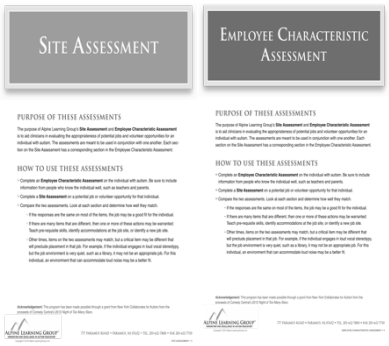
Job Match is the extent to which a particular job meets the individual's needs in terms of challenge, interest, comfort, camaraderie, status, hours, pay & benefits. Ideally, as we move through the job market, we get closer and closer to our ideal job match.

We can't get no job satisfaction.

- (AP) Even Americans who are lucky enough to have work in this economy are becoming more unhappy with their jobs, according to a new survey that found only 45 percent of Americans are satisfied with their work. That was the lowest level ever recorded by the Conference Board research group in more than 22 years of studying the issue. [ ] worker dissatisfaction has been on the rise for more than two decades." It says something troubling about work in America. It is not about the business cycle or one grumpy generation," says Linda Barrington, managing director of human capital at the Conference Board, who helped write the report, which was released Tuesday. Workers have grown steadily more unhappy for a variety of reasons:
  - Fewer workers consider their jobs to be interesting.
  - Incomes have not kept up with inflation.
  - The soaring cost of health insurance has eaten into workers' take-home pay.

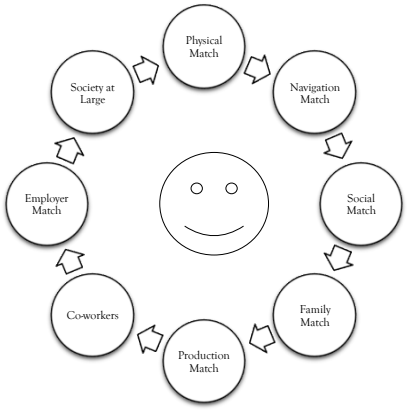
SOURCE: http://www.cbsnews.com/stories/2010/01/05/national/main6056611.shtml

Alpine Learning Group Job Match Assessments



In the end, effective employment development and support requires a re-conceptualization of who our constituents are to include:

- *Individual on the spectrum*
- *Their family*
- *Their employer and coworkers*
- *The community-at-large who benefits from their work.*



The Individual

- Was there adequate and intensive transition programming provided prior to graduation?
- What are the individual's interests?
- What are the individual's areas of strength? Of deficit?
- What are their current communicative competencies?
- What level of support will the individual need in the areas of life, social, and navigation skills?
- What safety skills do they possess?
- What job experience (if any) does the individual possess?
- What was the experience of the employer and the individual prior to graduation.

The Physical Match

- Is the space accessible and other individuals willing to accommodate
- Challenging work that is, in effect, doable.
- Physical location that will not make the individual anxious such as loud noises, smell, lights etc.
- Does the job require the individual to stand or to sit? Walk or remain in one place? Start early or start late?
- Is the job environment too hot, cold, loud, dark, etc.?
- Are the physical demands of the job compatible with the abilities/preferences of the individual (i.e. heavy lifting, etc.)?

The Social Match

- What social skills need to be assessed prior to employment (based upon on-site observation)?
- Will there be ample time for social interactions with other employees?
- Does the job require too much social interaction with co-workers? Customers?
- Does the employer offer after hours social activities such as softball, bowling, etc.
- What type of dress code does the job require?
- How might the physical environment affect the social demands of the job and can they be modified?

The Navigation Match

- Physically manageable environment
- Close proximity to home or accessible by reasonable transportation options.
- Can the individual navigate all components of the environment (elevators, stairs, cafeteria, restrooms etc.)?
- Safety protocols and requirements matched to individual skill sets

The Family

- Families are full partners in the process
- What is the family's overall vision of employment for the individual?
- Maintain high (yet reasonable) expectations for their son or daughter in terms of employment
- Support and encourage the individual to remain employed
- Keep channels of communication open
- Is there someone in the family who has an "in" at a potential place of employment (ex. Family business)?

The Employer

- Willing to commit to time & sensitive to accommodations
- Does the employer have experience of employing individuals with disabilities?
- Is willing to be part of the team on a regular, but limited, basis
- Is able to define clear expectations and duties for employee.
- Able to promote equality and fairness to all employees.
- Does not look at this job as a "token" or favor (i.e., Realistic and needed job, not one made up for the individual)
- Is willing to allow training for co-workers?
- Can identify areas of need for the employer/business?

Co-workers

- Willing to participate in training
- Are there co-workers who can be counted on for support if needed (i.e. "natural supports)?
- Willing to treat all coworkers the same
- Willing to be honest and candid
- Sensitive to, and accepting of, any special accommodations.

Society-at-Large

- Needs to accept the individual as a contributing member of the community
- Needs to stop feeling sorry for the individual as a "victim" of their disability
- Needs to acknowledge the strengths the person has to offer and accept their (minor) behavioral idiosyncrasies.
- Needs to respect the person as any employed adult in a job that is job socially significant, of value to the community, and personally fulfilling/ significant for the individual

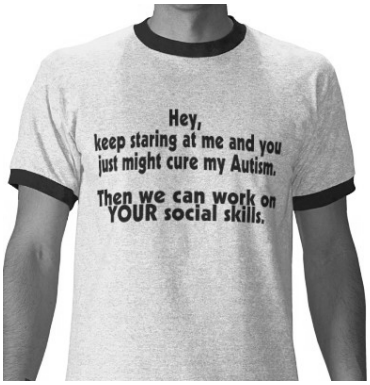
According to an survey of actual employers, the most important job skills are:

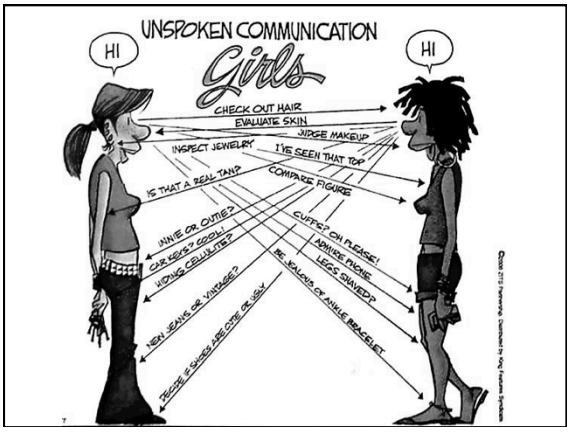
- **Endurance/time on task** – e.g., Working more than 15 minutes at a clip - PRODUCTION
- **Quality control** – e.g., Completing their specific job correctly - PRODUCTION
- **Rate or production (Fluency)** – i.e., The rate relative to that of other employees for that specific job -PRODUCTION
- **Knowing when to seek assistance** – e.g., The ability to self correct – SOCIAL
- **Break skills** – i.e., what to do during scheduled work breaks or when waiting for help – SOCIAL/NAVIGATION
- **Self control/self management** – i.e., Minimal external stimulus control - SOCIAL

According to an employer survey, the most important job skills are:

- **Accepts and responds to feedback** – i.e., Follows directions from supervisor – SOCIAL/ NAVIGATION
- **Age appropriate dress and hygiene** – i.e., Relative to culture of the business – SOCIAL
- **Timeliness** – The ability to arrive on time and adhere to a schedule of assignments or appointments – SOCIAL/ NAVIGATION/PRODUCTION
- **Eats neatly with co-workers (yes, they said that)** – This goes hand and hand with appropriate toileting. – SOCIAL/ NAVIGATION

The Social World





What do we mean by the term "SOCIAL SKILLS"?

Social skills might best be understood as access and navigation skills… they are how we acquire desirables and avoid negatives by successfully navigating (and manipulating) the world around us. They are complex, multilayered skills that are bound by both content and context.

Walton & Ingersoll (2013) note that most work on social skill interventions has been conducted with young children, and that a number of potentially effective interventions have been developed. While social skills intervention needs be begin soon after diagnosis, social skill intervention remains important across the lifespan. This is of particular importance given that the social deficits associated with ASD do not resolve with development and may, in fact, be more pronounced given the normative social repertoire of typical peers.

Watson, K.M. & Ingersoll, B.R., (2013) Improving social skills in adolescents and adults with autism and severe to profound intellectual disabilities: A review of the literature. *Journal of Autism and Developmental Disorders.* 43, 594-615

The Increasing Demands of the Social World

- Your social demands are often lowest within your home. Why? Because you set the rules of acceptable behavior.

- Your social demands at work are higher. However, work is a somewhat scripted social environment and one with a secondary measure of competence (i.e., production).

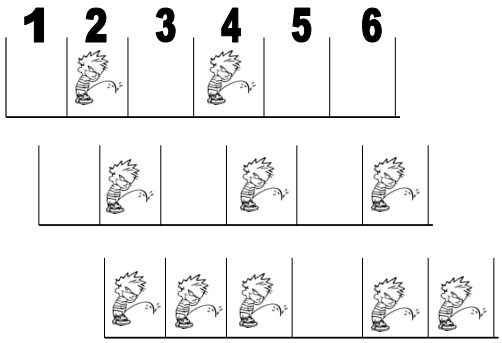
The Increasing Demands of the Social World

- Next comes the community at large. Why? Because in the community you have less control over events and actions that impact you.

- Lastly comes the world beyond your community. Whether a different social circle or different country, chances are you social skill repertoire may be less than adequate.

The social context of urinals

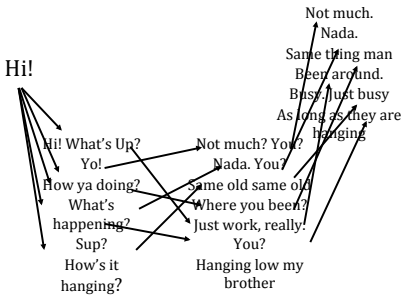
The Urinal Game



What this means then…

Social Skills are NOT Linear

But rather logrithmic in nature



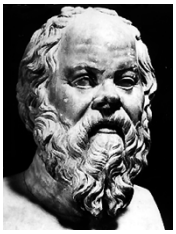
So remember

"A greeting...is a social skill that is thought to be simple. However, further analysis shows this skill, which most take for granted, to be extremely complex. How a child greets a friend in the classroom differs from the type of greeting that would be used if the two met at the local mall. The greeting used the first time the child sees a friend differs from the greeting exchanged when they see each other 30 minutes later. Further, words and actions for greetings differ, depending on whether the child is greeting a teacher or a peer.... [G]reetings are complex, as are most social skills."

Myles & Simpson (2001)

Quality of Life

Quality of Life is Not a New Concept



Not life but good life, is to be chiefly valued.

Socrates (469 BC - 399 BC)

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)

But in ASD, while the concept of quality of life has been used for over 30 years in the field of intellectual disabilities, the factors contributing to quality of life of persons with ASD have received relatively little attention (Renty & Roeyers, 2006) in the literature and in practice.

Renty, J.O., & Roeyers, H. (2006). Quality of life in high-functioning adults with autism spectrum disorder: The predictive value of disability and support characteristics. *Autism,* 10, 511-524.

The WHO has defined QOL as…

The individual's perception of his or her position in life ***in the context of the culture and value system, and in relation to one's goals, expectations, standards and concerns***. It incorporates the individual's physical health, psychological state, level of independence, social relationships, personal beliefs and his or her relationship to salient features of the environment in a complex way. (*The World Health Organization*, 1995)

World Health Organization (WHO) (1995) *World Health Organization Quality of Life Assessment (WHOQOL): position paper from the World Health Organization.* Social Science & Medicine 41: 1403–1409.

But a more useful definition is…

Quality of life (QOL) 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. (Wehmeyer & Schalock, 2001)

Wehmeyer, M.L. & Schalock, R.L. (2001). Self determination and quality of life: Implications for special education services and supports. *Focus on Exceptional Children*, **33**, 1-16.

Components of QOL

1. **Physical well-being** – Personal health status
2. **Emotional well-being** – Personal mental health status
3. **Interpersonal relations** – Valued & reciprocal friendships
4. **Social inclusion** – Valued society role
5. **Personal growth** - Continued opportunities to learn and acquire new skills/knowledge
6. **Material well being** – Financial literacy
7. **Self-determination** – Decision-making role in ones own life
8. **Individual rights** – Life, liberty, happiness, etc.

Much of the research on QOL and ASD has focused on a limited number of aspects of adult life (e.g., employment) and primarily on quantitative aspects of these few domains (e.g., employed v. employment satisfaction). QOL, however, is much more complex state of being (Van Heijst & Geurts, 2015).

Van Heijst, B.FC., & Geurts, H.M ((2015). *Quality of life in autism across the lifespan: A meta-analysis.* Autism: The International Journal of Research and Practice, **19**, 158-167.

Van Heijst & Guerts, (2015) recently completed a meta-analysis on the topic of QOL and adults with ASD. An extensive literature review ***identified a total of 10 peer reviewed studies published on 2004-2012***. The results indicated that the quality of life is significantly lower for people with autism when compared to their typical peers. Age, IQ and symptom severity did not predict quality of life in this sample. Across the lifespan, people with autism experience a much lower quality of life compared to people without autism.

Van Heijst, B.FC., & Geurts, H.M ((2015). *Quality of life in autism across the lifespan: A meta-analysis.* Autism: The International Journal of Research and Practice, **19**, 158-167.

However…

Parsons (2015) conducted an online survey designed to solicit the views of adults with ASD about current life satisfaction. Fifty-five respondents, most of whom attended mainstream schools and were diagnosed later in life, completed the survey. Respondents were least satisfied with their current employment situation and most satisfied with personal relationships. There was substantial individual variation in responses demonstrating the importance of respecting personal views, circumstances and aspirations. This is significant as little is known about the actual views of adults with ASD on QOL and that, in general, "good outcomes" in adult life are often judged according to normative assumptions of quality.

Parsons, S., (2015). *"Why Are We an Ignored Group?" Mainstream Educational Experiences and Current Life Satisfaction of Adults on the Autism Spectrum from an Online Survey.* International Journal of Inclusive Education. **19,** 397-421

Choice, control and competence in Quality of Life

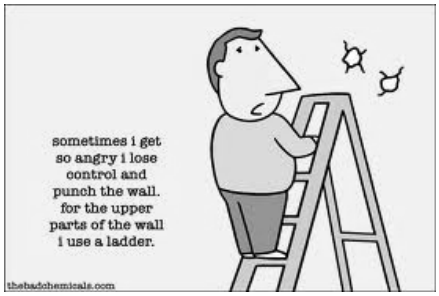
CHOICE

The ability to make un-coerced choices and have those choices honored is integral to one's perception of QOL. From the moment we wake up each day we are presented with choice making opportunities that may impact our lives. Should I hit the snooze? Should I have breakfast? What should I wear today? And so on … How well we make these choices, and how frequently our choices are, if not granted, at least acknowledged, greatly contributes to our personal sense of well being: our Quality of Life

CONTROL

We all desire some degree of control over our fates. Much of this sense of control we get by making or, at least, participating in decisions that directly impact us. The more control we exhibit over decisions relevant to our lives, the more satisfied we feel as a person and the greater our sense of well being: our Quality of Life.

Everyone strives for more control over their lives



COMPETENCE

The interplay between choice and control is an area called competence. We generally chose to engage in tasks where we have some demonstrated or emerging level of proficiency. We may control the situation along such parameters as how long we work on a task, whether we work in public or in private, or whether we give up on a task all together. The better we are at some personal and public assortment of tasks, the better our sense of well being: our Quality of Life.

The community understands autism but they still wont accept incompetence.

	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	Where to work, live, eat, vote, etc. Risk/ Benefit Analysis	Moderate across settings & routines	Job w/ career path, access to tangibles x settings, self sched., desired social life
Adult	Where to work, live, worship, eat, vote, sleep with, etc.	Significant	A life

"Improving the quality of people's lives has been one of the implicit goals of service provision in recent decades, and remains so today. [ ]Moving from quality of life as an implicit or explicit goal to quality of life as a helpful concept and set of practical strategies to improve policy, practice, and life for individuals or groups of people has been a strong theme within the rich panoply of quality of life work in the field of intellectual disabilities. This work has been considerably more challenging than might be expected." (p. 316)

Brown, I., Hatton, C., & Erickson, E. (2013), Quality of life indicators for individuals with Intellectual Disabilities: Extending current practice. *Intellectual and Developmental Disabilities,* **51**, 316-332.

Some closing thoughts…

But what is happiness except the simple harmony between a man and the life he leads.

Albert Camus (1913 - 1960)

That's the difference between me and the rest of the world! Happiness isn't good enough for me! I demand euphoria!

Calvin, speaking to Hobbs

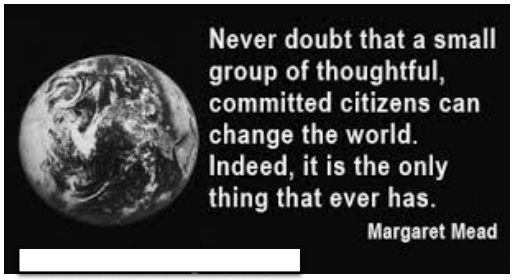
If I had to live my life again, I'd make the same mistakes, only sooner.

Tallulah Bankhead (1903 - 1968)

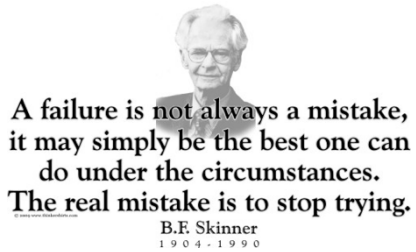
"Oscar, you know that's not good for you!"

"Felix, when I look back on the best times on my life, none of them were good for me!"

Felix Unger and Oscar Madison
The Odd Couple



Don't dream it. Be it!



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**Stolen, without permission, from the University of Houston, Clear Lake ABA Program Website.*

Summary Points:

- Interventions based on the principles of ABA are applicable across skill domains and across the lifespan.
- It is easy to be successful when you set the bar low so think big and have high expectations.
- Start planning early and, certainly, no later than age 16 years.
- To the maximum extent possible, work cooperatively with all involved in the process to the benefit of the teen/young adult with ASD.
- Remember that transition planning is a process and first drafts of ITPs are rarely the final draft.

- Keep your eyes on the prize of your long term transition goals for employment, living or postsecondary education. Frame all your discussions with reference to those desired outcomes. Involve extended family and friends in the process, particularly in the area of employment as they may have contacts and resources you do not.
- Remember, you are a critical part of this process no matter what title your have (parent, speech pathologist, transition specialist, etc.).
- With reference to community skills, remember to teach where the skills are most likely to be used. It is more effective to teach grocery shopping at an actually supermarket than it is to teach it in the classroom

- Identify the level of "risk" with which you are comfortable and then work to maximize independence within that framework. (For example, while you may be uncomfortable with him or her crossing the parking lot of supermarket without close supervision, he or she may not need the same intensity of supervision in the supermarket) As the teen/young adult gains greater independence across tasks and environments, reassess you acceptable level of risk.
- Good, effective transition planning is effortful and time consuming. There are, sadly, no known shortcuts but when it is done well, the outcomes are well worth the effort.

Recommended Follow-up Activities

1. The principles of applied behavior analysis work to shape our behavior every day. Over the next 24 hours try to notice, and document, a minimum of 25 instances where your behavior, or the behavior of others, was modified via positive reinforcement.
2. Spend 30 minutes observing a specific, yet commonplace, community skill (e.g. grocery shopping, dining out, purchasing gas. Write a task analysis for the teaching the skill incorporating production, social, and navigation skills.
3. Identify, for one of your students, a minimum of 3 job carving opportunities at places you might frequent across the course of a week. What would then be your first step toward getting him or her hired?

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