



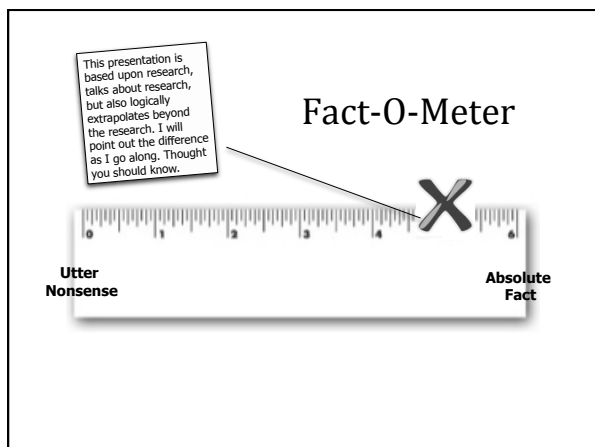
Transition, Adaptive Behavior, and Community Living for Individuals on the Autism Spectrum

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Today's Rules

RULE #1:

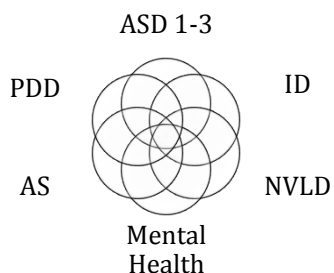
Everyone is capable of
living and working in
the community with the
proper supports.

RULE #2:

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

Rule #3

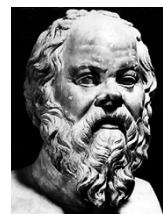
There is always some overlap



Let's start with a discussion of Quality of Life

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

Socrates (469 BC - 399 BC)



Although 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 autism spectrum disorder 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.

Supports are more important the degree of cognitive involvement

Renty (2006) investigated disability and support characteristics associated with variations in the level of quality of life among adults with ASD via self-report measures. Fifty-eight high-functioning adults with ASD participated in the study. The results indicated that support characteristics are related to quality of life in adults with ASD, whereas disability characteristics are not. The results reinforce the significance of an available supportive social network, the importance of a substantial needs assessment and effective professional support as central to a positive quality of life.

Quality of Life 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.

Physical Well Being: Life Expectancy in ASD

Shavelle and Strauss's (1998) conducted a population-based study to determine comparative mortality of persons with autism (but without severe physical disabilities or who were non-ambulatory) and found that *life expectancy was reduced somewhat when compared to the general population and the older the individual gets, the less significant the difference becomes. There was, however, an association between increasing level of intellectual disability and increased mortality risk.*

Shavelle, R. M., & Strauss, D. J. (1998). Comparative mortality of persons with autism in California, 1980–1996. *Journal of Insurance Medicine*, 30, 220–225.

Physical Well Being

- ❑ Children with autism are noted to have significantly increased frequency of visits to physicians for preventive, nonemergency, and emergency care compared to children without ASD (Gurney, McPheeters, & Davis, 2006).
- ❑ Conditions such as food selectivity, gastrointestinal distress, and sleep disorders are generally recognized as more prevalent in children ASD than in their typical peers but there is little research as to their prevalence, or the prevalence of other conditions, in adulthood (Perkins & Berkman, 2012)

Gurney, J. G., McPheeters, M. L., & Davis, M. W. (2006). Parental report of health conditions and health care use among children with or without autism. *Archives of Pediatric and Adolescent Medicine*, 160, 825–830.

Perkins, E.A. & Berkman, K.A. (2012). Into the unknown: Aging and Autism Spectrum Disorders. *American Journal on Intellectual and Developmental Disabilities*. 117, 478-496

Physical Well Being: Access to Adequate Medical Care

About 51.2 million, individuals with disabilities reside in the United States. [] Yet they must struggle to find health care providers who are sensitive to their needs. Many individuals with disabilities, particularly those who grew up with a disability or with severe impairments, may encounter patronizing attitudes and ignorance by health care practitioners [thereby] reducing the quality of care they receive. (World Institute on Disability, 2013)

Access to Medical Care: Training Tools for Health Care Providers, Disabled Patients and Advocates on Culturally Competent Care and Compliance with Disability Law. (2013). World Institute on Disability. Available at: <http://wid.org/publications/downloads/Access%20to%20Medical%20Care%20Curriculum%20%28PDF%20format%29.pdf>

Emotional Well Being: Prevalence of Mental Health Challenges

Children & adults with a developmental disability and a co-existing psychiatric disorder are one of the most underserved cohorts in the US. Beginning in adolescence, individuals with a developmental disability *are two to four times more likely to have a psychiatric disorder than their neurotypical peers.* (Fletcher, et al., 2007)

Emotional Well Being: Anxiety Disorders

Vasa, et al (2013) examined age-related differences in the prevalence and anxiety in 1316 children and adolescents with autism spectrum disorder (ASD) The prevalence of clinical and subclinical anxiety were examined in three age groups of children: preschool, school age and adolescents. *Findings showed that the prevalence of anxiety in each age group exceeded the prevalence of anxiety in the general population. Adolescents and school age children had the highest prevalence of clinical (40%) and subclinical anxiety (26%), respectively.*

Vasa, R. A., et al. (2013). Age-related differences in the prevalence and correlates of anxiety in youth with autism spectrum disorders. *Research in Autism Spectrum Disorders*, 7(11), 1358-1369.

Emotional Well Being: Psychotropic Medication Use

Spencer, et al., (2013) examined rates and predictors of psychotropic use among insured children with (ASD). The authors used administrative medical and pharmacy claims data linked with health plan enrollment[] and from 2001 to 2009. *The results indicated that among children with ASD, 64% had a filled prescription for at least 1 psychotropic medication, 35% had evidence of psychotropic polypharmacy (≥2 classes), and 15% used medications from ≥3 classes concurrently. Median length of polypharmacy was 346 days.*

Spencer, D., Marshall, J., Post, B., Kulakodlu, M., Newschaffer, C. Dennen, T., Azocar, F., & Jain, A. (2013). Psychotropic medication use and polypharmacy in children with autism spectrum disorders. *Pediatrics*. Nov;132(5):833-40.

Quality of Life is also, to some extent, a familial construct

Families, as a social unit, generally have their own QOL indicators which are subject to both internal (e.g., health concerns) and external (e.g., financial) stressors and are, in part, tied to the indicators of other family members. In addition, in ASD accessing appropriate and effective services can be both a significant source of stress or a source of support.

Family Functioning

Childhood autism is associated with a substantial loss of annual household income. This likely places a significant burden on families in the face of additional out-of-pocket expenditures. The average loss of annual income associated with having a child with autism spectrum disorder was \$6,200 or 14% of their reported income. (Montes & Halterman, 2008)

Montes, G., & Halterman, J.S. (2008). Association of Childhood Autism Spectrum Disorders and Loss of Family Income. *Pediatrics*, 121, pp. 821-826.

Family Functioning

- In the *Living with Autism Study* (Easter Seals, 2008) the overall experience of parenting a child included:
 - 61% of families of children with ASD reported incurring debt to meet family needs as opposed to only 46% for typical families.
 - When compared to typical families, families of children with autism report being significantly more afraid that:
 - Their child will not have sufficient financial support after the parent dies,
 - The cost of caring for the child will drain the family's current and future financial resources, and
 - The cost of raising their child with autism will have a financial impact on other siblings.

Easter Seals' (2008). Easter Seals' Living with Autism Study. Accessed on-line on December 18, 2008 at http://www.easterseals.com/site/PageServer?pagenam=ntlc&living_with_autism_study_home

Family Functioning

Karst & Van Hecke (2012), note that raising a child with ASD can be an overwhelming experience for parents and families. The pervasive and severe deficits often present in children with ASD are associated with a plethora of difficulties in caregivers, including decreased parenting efficacy, increased parenting stress, and an increase in mental and physical health problems compared with parents of both typically developing children and children with other developmental disorders. In addition to significant financial strain and time pressures, high rates of divorce and lower overall family well-being highlight the burden that having a child with an ASD can place on families. These parent and family effects reciprocally and negatively impact the diagnosed child and can even serve to diminish the positive effects of intervention.

Family Functioning

Using population data Seltzer, (2011) studied parents of individuals with intellectual and developmental disabilities ($n = 220$) and parents of individuals without disabilities ($n = 1,042$). Parents of individuals with ID and DD were further divided into those who lived with their adult child and those whose adult child lived elsewhere, and the 3 groups were compared regarding parental patterns of attainment, social participation, psychological functioning, and health in midlife and early old age. *In midlife, parents of individuals with intellectual and developmental disabilities were similar in general to comparison parents. However, by early old age, these parents had poorer health and mental health. Co-residence between the adult with intellectual and developmental disabilities and the parent was prevalent during midlife (51.4%) and in the early years of old age (38.6%), and there were different patterns of parental outcomes, depending on the residential status of the adult with intellectual and developmental disabilities*

Marsha Mailick Seltzer, Frank Floyd, Jeon Song, Jan Greenberg, and Jisuk Hong (2011) Midlife and Aging Parents of Adults With Intellectual and Developmental Disabilities: Impacts of Lifelong Parenting. *American Journal on Intellectual and Developmental Disabilities*. November 2011, Vol. 116, No. 6, pp. 479-499.

Siblings

Green (2013) conducted a review of the literature (14 articles) regarding the psychosocial impact of growing up with a sibling with autism and to identify gaps in the related literature. Although the majority of studies involved both children and adolescents (leading to confounding results) autism appears to contribute to unique environmental stressors for the typically developing sibling. *So despite some vulnerability to behavioral and emotional dysfunction in at-risk children, siblings have the potential to not only adjust but to thrive in the face of disability adversity. In other words, growing up with a sibling with autism appears to manifest in both positive and negative outcomes for siblings, depending upon important demographical, family, and individual variables.*

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



Part II

How come no one ever taught you this?

Having worked with a large number of adolescents and adults who could identify 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

I have come to understand that for a school, having an educational mission focused on “allowing all students to reach their highest potential” has become an excuse for pretty minimal outcomes.

So perhaps a better mission statement would be:

The mission of autism education is that graduates will exit the program:

- ☐ **Not just employable but employed a minimum of 20 hrs/wk;**
- ☐ **Not just with social skills but with a social support network centered around where they live, work, and recreate;**
- ☐ **Not just with the ability to follow directions but with the ability to initiate actions on their own, and;**
- ☐ **Not just under our stimulus control but under the stimulus control of the environment and their ability to manage their own behavior.**

Which, to me, is pretty congruent with “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)]

Part IV 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 any 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, (i.e., voluntary participation)
with adolescents/adults with ASD if we
are to teach skills & skill sets that are
initiated independently, generalize
across environments, and maintained
over time.

This is of
particular
concern given:

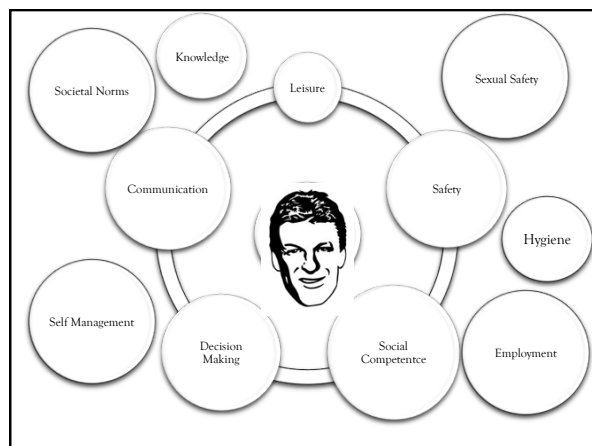
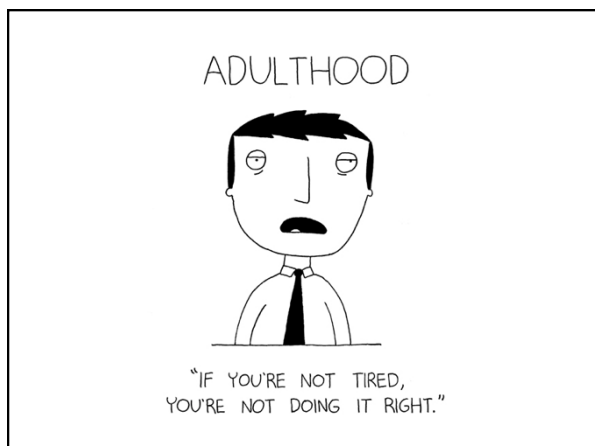
- ❑ “The next decade or so is Hurricane Katrina for adults with developmental disabilities. Every state has cut Medicaid services in response to the economic crisis and, historically, when states cut Medicaid services they are cut for a long time.” (Ellen Blackwell, CMS, 2010).
- ❑ Roux, et al (2013) reported that only half of young adults with **ASD have ever worked for pay** [emphasis added] since leaving high school. When they do work they earn significantly lower wages than do age-referenced peers. Odds of ever having a paid employment were higher for those with more financial resources, greater language skills and higher levels adaptive behavior.

According to the NY Times, (Goehner, 2011) there are going to be half a million children with autism in the next 10 years who will become adults. Services for adults with autism exist, but unlike school services, they are not mandated, and there are fewer of them. Combined with shrinking government budgets, the challenges are daunting. Further, “We are facing a crisis of money and work force,” said Nancy Thaler, executive director of the National Association of State Directors of Developmental Disabilities Services. “The cohort of people who will need services — including aging baby boomers — is growing much faster than the cohort of working-age adults that provide care.”

Goehner, A.L. (2011) A generation of autism, coming of age. New York Times. April 13, 2011.
Available on line at :<http://www.nytimes.com/ref/health/healthguide/esn-autism-reporters.html>

- ❑ While data are limited, some estimates put the percentage of individuals with developmental disabilities who will be victims of sexual abuse at between around 40%.
- ❑ The 1:1 “Behavior Tech” in the adult world is generally not a BCBA but rather a retired bouncer... when the position even exists.
- ❑ Classrooms are both artificial, and artificially simple, environments that are never again to be replicated in the individual’s life.

Why then focus on
adaptive behavior?



In truth, the most desirable outcomes are in Adaptive Behavior

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

Further...

- ❑ While all ADL skills are adaptive behavior not all adaptive behavior skills are ADLs.
- ❑ Adaptive behavior competencies are more complicated than inferential calculus.
- ❑ Adaptive behavior competencies involve both simple and complex decision making skills
- ❑ Adaptive behavior skills are not always highly preferred skills (e.g. tooth brushing) but, then again, some are (leisure skills).

In other words...

Adaptive behavior is everything you do that is not directly tied to academic responding. Yet adaptive behavior is not separate or distinct from academic responding. For example:

- ❑ Reciting a chemistry equation is academic but using that equation to pull a McGyver is adaptive behavior.
- ❑ Being able to identify the "EXIT" sign is academic responding but using that skill to actually leave a building is adaptive behavior.

Adult outcomes can, at least in part, be seen as a function of adaptive behavior competencies (Mazefsky, Williams, & Minshew, 2008). It is not an overstatement to say that adaptive behavior competencies will get you through times of no academic skills better than academic skills will get you through times of no adaptive behavior competencies

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 [].**

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 skills should be targets of intervention early on in the intervention process because...

Adaptive Skills (chores) 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 chores 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.

Two generally ignored areas of adaptive functioning in adults

Sexuality

In two (somewhat) recent studies, (McCabe & Cummins, 1996; Szollos & McCabe, 1995) researchers concluded that individuals who have an intellectual disability have lower levels of sexual knowledge and experience in all areas except menstruation and body part identification when compared to a typical student population.

Sexuality

Stokes, Newton, & Kaur (2007) examined the nature of social and romantic functioning in adolescents and adults with ASD. What they found was that individuals with ASD were more likely than their NT peers to engage in inappropriate courting behaviors; to focus their attention on celebrities, strangers, colleagues, and exes; and to pursue their target for longer lengths of time (i.e. stalking).

Adaptive Behavior and Incarceration

Professionals have been aware of high rates of learning and behavior disorders among incarcerated youth for some time (Moffitt, 1990) leading some professionals to characterize the juvenile justice system as a default system for special needs learners with more complex emotional and behavioral challenges (Quinn, et al, 2005)

Adaptive Behavior and Incarceration

Paterson, (2008) looked at two adults with Asperger Syndrome incarcerated in the U.K. Both individuals faced challenges understanding the complex formal and informal social hierarchies of prison life and accepting unfamiliar or non-preferred rituals and routines. Both were ultimately placed in a modified form of secure custody for their own safety.

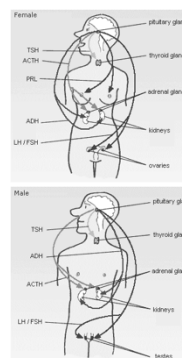
And where the two meet

Walters, et al (2013) examined the self-reported presence and severity of abuse, neglect, and depressive symptoms **for 43 adolescents adjudicated delinquent due to a sexual offense. Twenty-seven of the adolescent sexual offenders were also diagnosed with an autism spectrum disorder**, and 16 did not carry an autism spectrum disorder diagnosis. Both groups reported moderate to high levels of abuse and neglect. Adolescent sexual offenders with an autism spectrum disorder reported significantly higher depressive symptoms than those without an autism spectrum disorder. **Results suggest a need to tailor treatment programs to match the unique needs of sexual offenders.**

A Few Reasons Why We Should Teach Human Sexuality Education To Individuals With Autism Spectrum Disorders

Number 4

They Have The Same Hormones & Urges & Need To Make The Same Choices As Their Peers



Number 3

The Internet and other readily accessible media



Internet Rule #34

If you can imagine it, then it exists as internet porn.



Examples of Rule #34 can be found almost everywhere



Examples of Rule #34 can be found almost everywhere



From a new **facebook** friend

"Hey, I added you since you look familiar, but once I looked at your page I knew I was mistaken.. but hey, you seem like a good guy so i'll just introduce myself :) Im quirky, funny, and never afraid to have a good time.. I recently moved here about six months ago from a small town in Idaho for work and like it so far! Check out my profile.. if you want to I would love to meet sometime for lunch. Any way.. I wanted to attach more photos of me but its giving me some stupid error! If you give me your email addy I can send the pics to you that way. Hope to hear from you soon!"



From another new **facebook** friend

How are you doing today?? you are a really cool and enchanting dude that's why i did opt for a message to you ok winks...Just want to know more about you with due respect that's if you don't mind. do take care and have a wonderful day feel free to reply ok.....with regards Fiona



Number 2

Sexual Abuse

Self-Protection

- ❑ Teach that refusing to be touched is a right
- ❑ Teach self-protection skills
 - ❑ Who can/can't touch the individual and where on his/her body
 - ❑ How and when to say "No"
 - ❑ How to ask for assistance
 - ❑ How to recall remote events and convey where an individual touched him/her

(American Academy of Pediatrics, 1996; Nehring, 2005; Roth & Morse, 1994; Volkmar & Wiesner, 2004)

Number 1

Because They Are People & Like All People
Individuals with Autism Have The Right To
Learn All They Can To Enable Them To
Become Sexually Healthy Persons

Healthy Sexuality



Why ABA-based interventions to teach sexuality?

First

Sex is just behavior. Whatever
body parts are involved it is all just
behavior.

-J. Bering, (2012)

Second

Despite much discussion about decision making skills in the self-determination literature (e.g., Clark, et al., 2004), there continues to be "lack of evidence [supporting the] effectiveness of sex education and training for persons with developmental disabilities" (Duval, 2002, p. 453) which Behavior Analysis is able to provide.

and Third

- ❑ Many of the basic instructional goals in sexuality education boil down to complex discrimination skills. For example:
 - ❑ Boy or Girl
 - ❑ Men's room or Lady's room (or Blokes v. Shielas; Senors v. Senoritas; M v. W; and so on...)
 - ❑ Where or with who you can/cannot:
 - ❑ Be naked
 - ❑ Masturbate
 - ❑ Curse
 - ❑ Help with toileting or menstrual care
 - ❑ Touch certain parts of your body

What 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 community-referenced living skills AND
- ❑ Any skill that is used with sufficient frequency to remain in the individual's repertoire. The exception here are safety skills which, ideally, are low response frequency skills AND
- ❑ Any skill that can be acquired within a reasonable time frame*.

*Time Is Not On Our Side When it Comes to School-Based Intervention

❑ School Days/Year (NYS)	211.0
❑ Hours/day engaged time	4.5
❑ Total hours/year engaged	949.5
❑ Total hrs 17to 21-years	4,747.5
❑ Est. goals in typical IEP	30.0
❑ Total goals across 5 years	150.0
❑ Hours/goal available	31.65

But that's 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...

But we don't have best case scenario so let's include an error rate of .3. This means we have

Somewhere around 22 hours (3.6 days) of instruction time available for a student to acquire a skill as defined in his or her IEP. Time, it seems, is not on our side.

Adaptive Behavior Intervention and The Functionality Index

A brief note here

- ❑ The research that follows would not be considered typical behavior analytic research and, as such, is unusual for an ABAI symposium and very preliminary.
- ❑ However, if found to be both valid and reliable, the Functionality Index should prove to be a useful tool for behavior analysts working in autism, particularly adolescents and adults with autism.
- ❑ For an excellent discussion on expanding the parameters of behavior analytic research I would refer you to Vyse (2013) and its subsequent commentaries.

*Vyse, S., (2013). Changing course. *The Behavior Analyst*. 36, 123-135. (And subsequent commentaries)

Adaptive Behavior Intervention

The parameters of effective intervention in adaptive behavior would appear to include:

1. **Context** – Where instruction takes place
2. **Intensity** – How often instruction takes place
3. **Efficiency** – What is the response effort/ equivalence associated with instruction
4. **Transfer of control** – Where does stimulus control lie
5. **Value** – Why might this skill be important to the student

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

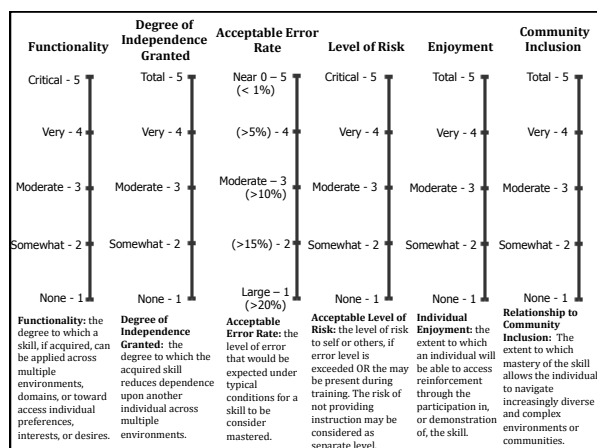
- ❑ A general goal of many ABA-based programs is for teachers to demonstrate stimulus control over their students and classroom.
- ❑ However, the ultimate goal of any transition program is to transfer such control from the teacher to both the environment (e.g., stop at the red light) and the individual 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, have significant functional utility or provide access to R+) 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. [Now "Frequency of Use"]
- ❑ **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.



Method

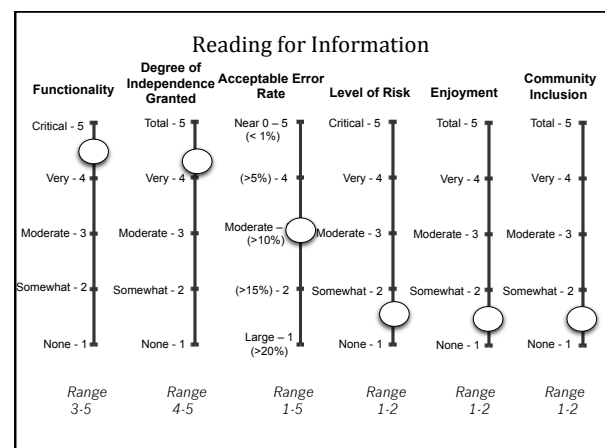
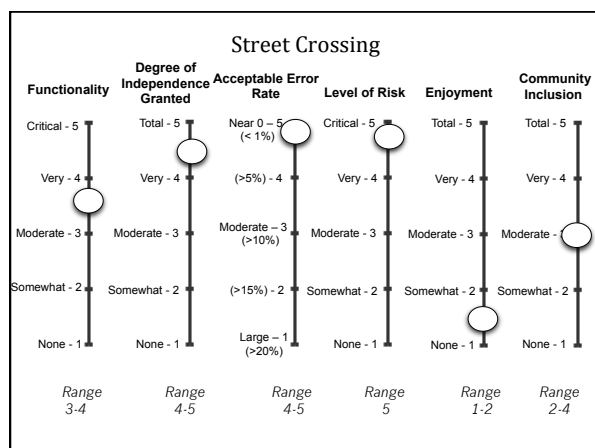
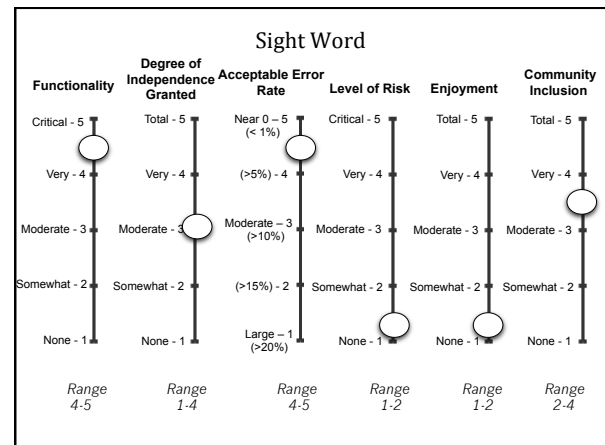
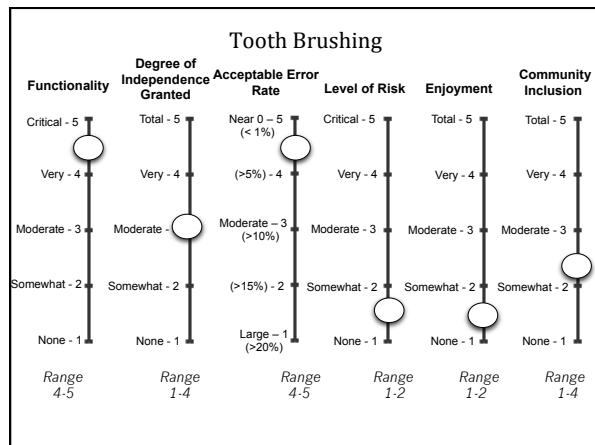
- ❑ An on-line survey was distributed via Survey Monkey to 60 educators and behavior analysts working at a behaviorally based school in NYC.
- ❑ Respondents were asked to use the Functionality Index (FI) to score 8 instructional goals randomly selected from an existing IEP developed for a 17 year old man with autism with an intellectual disability

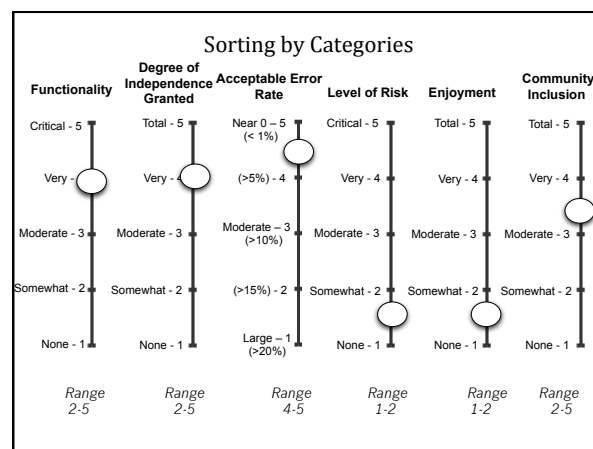
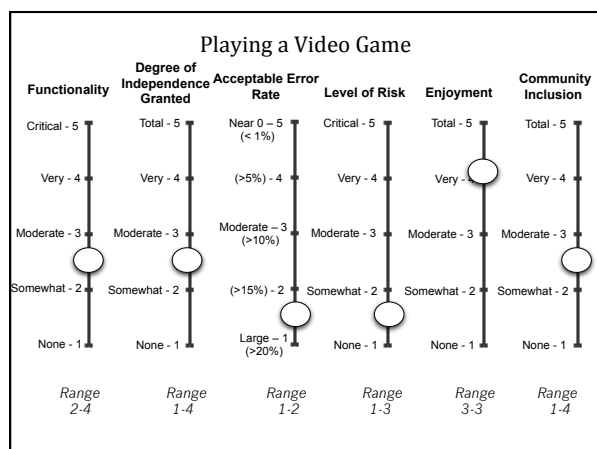
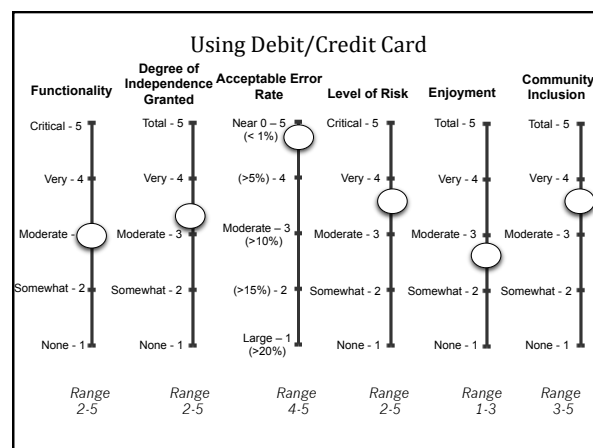
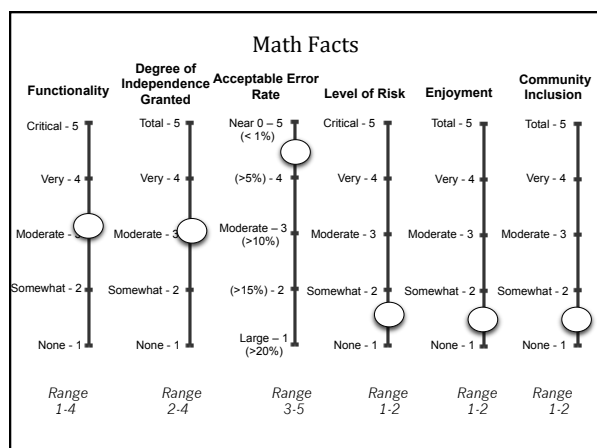
Rated IEP Goals

- ☐ 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

Results

- ☐ Of the 60 surveys, 33 were returned. Of these, four were considered unusable as they were incomplete leaving 29 usable responses.
- ☐ Rankings were totaled for each IEP goal and the averages were plotted on the FI. Results are presented in the following slides.





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 & Kadvan, 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.

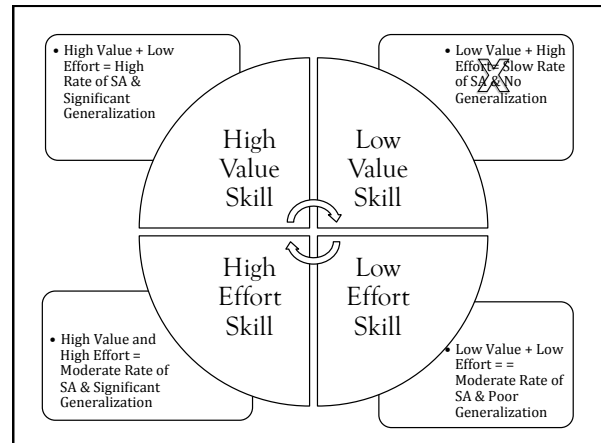
(Fischhoff, B., & Kadvan, J. (2011). *Risk: A Very Short Introduction*. New York: Oxford University Press

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.

Generalization and Adaptive Behavior

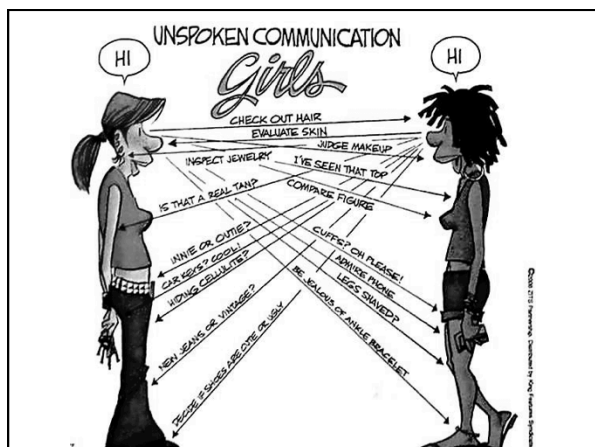
- ❑ It is generally accepted that individuals with ASD demonstrate challenges in the generalization of mastered skills from one environment to another (e.g., Handleman & Delmolino, 2005)
- ❑ Yet there are those children who generalize the operation of the DVD/ Blue Ray player from unit to unit, from 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?



Adaptive Behavior and Social Responding.

A quick opinion here:

I currently think that no other set of adaptive competencies relies so heavily on extremely subtle environmental cues for their correct display than do social competencies. So in this special case, the “Applied” is as critical as are the “Behavior” and the “Analysis”. Absent context, the vast majority of social competencies are meaningless. I would, therefore, point out that independent of how evidence-based your interventions may be, teaching social skills well but out of context is really no better than teaching these skills poorly, either in or out of context.



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

So how are we supposed to
figure out what to teach?

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 desired 1 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 desired 1 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 desired 1 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

- ❑ Solicit student and family input as to desired 1 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
- ❑ Attend to safety skills
 - ❑ Significantly overlooked but very important to consider.

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 desired 1 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
- ❑ Attend to safety skills
- ❑ Attend to skills that reduce dependence
 - ❑ Sometimes just being less dependent is an excellent goal.

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 desired 1 year, 5 year, 10 year outcomes.
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- ❑ 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

The Shortest Cut

In order to...

- ❑ John will be able to obtain his driver's license in order to get back and forth to work.
- ❑ Susan will be able send an email in order to make plans with others, ask for information, or make a request.
- ❑ Jaxon will be able safely cross streets in her neighborhood in order to not get killed.
- ❑ Mark will be able to identify the sizes of his clothes in order to purchase preferred clothes independently.
- ❑ Brian will be able to sort items by color or shape in order to...
- ❑ Maggie will be able to name all 50 states in order to...

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

There are times when not following the rules is actually the best thing you can do. Now try and teach that little truism.



Never doubt that a small group of thoughtful, committed citizens can change the world. Indeed, it is the only thing that ever has.

Margaret Mead

Don't dream it. Be it!



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

B.F. Skinner
1904 - 1990

It's just a green straw...



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

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