



Intervention and Support with Adolescent and Adults with ASD: Challenges, Risks and Quality of Life

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The EPIC School



Educational Partnership
for Instructing Children

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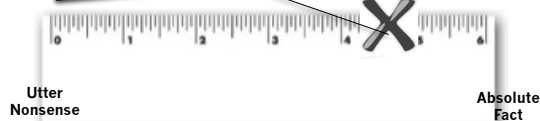
Sometimes I think I am an autism professional who works in field of applied behavior analysis. At other times I think I am a behavior analyst who works in autism. The truth is that I am both.

The need to be a generalist

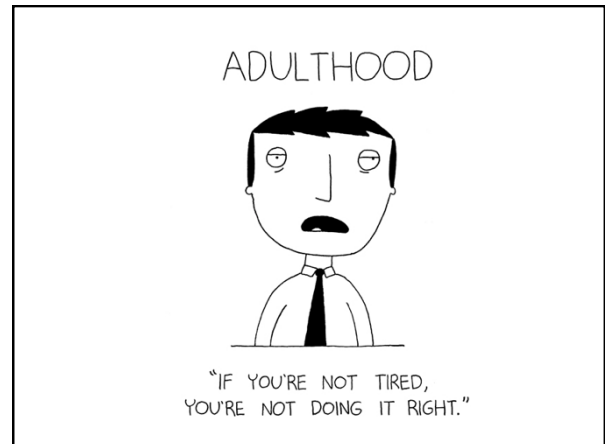
If you work with young kids you get to be a specialist. Whether you're a special educator, speech pathologist, occupational therapist, or board certified behavior analyst, you get to be a specialist. When working with adolescents and young adults you don't get to be a specialist and, instead, need to be something of a 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.

Fact-O-Meter

This presentation is based upon research, talks about research, but also logically extrapolates beyond the research. I will point out the difference as I go along. Thought you should know.



By the way, this is just a quick example of how researching on the internet can easily lead parents and well intentioned professionals in the wrong direction(s). This morning I was on Google images trying to find a graphic for "BABAT Conference" to use later in this talk. What follows is one of the images I was provided.



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

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

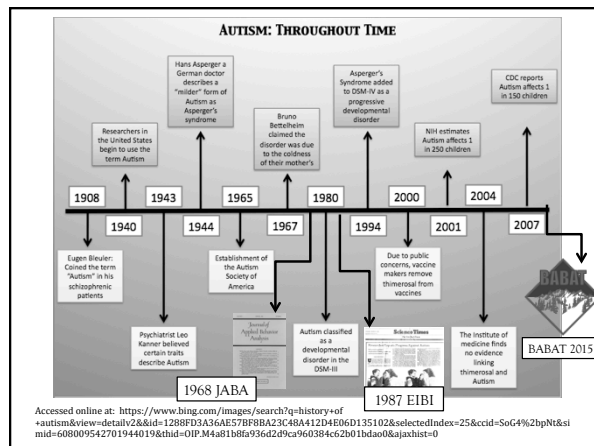
So maybe we need to consider generality, (voluntary participation) with adolescents/adults with ASD if we are to teach skills & skill sets that are initiated independently, generalizable, and maintained across time & environments.

There is another problem...

- 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.

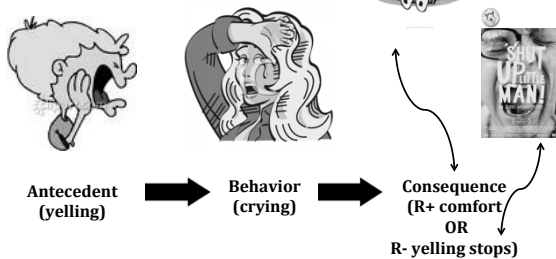
Before we go any further, I have a few thoughts on the short history of autism intervention and the relevance ABA to the lives of adolescents and adults with ASD



While our knowledge base in the application of Behavior Analytic principles in the complex areas of adulthood and ASD has slowly grown since 1968, there continues to be a troublesome perception that the application of this knowledge is, well, pretty simplistic.

For example:

**The three term contingency
Young Child**



3-Term Contingency with Adolescents & Adults



So the challenge is

$$\begin{aligned}
 x &= \frac{-b \pm \sqrt{b^2 - 4ac}}{2a} \\
 &= \frac{-3 \pm \sqrt{9 + 40}}{4} \\
 &= \frac{-3 - \sqrt{49}}{4} \text{ or } \frac{-3 + \sqrt{49}}{4} \\
 &= -2.5 \text{ or } 1
 \end{aligned}$$

Not look for simple solutions to complex problems...



While not forgetting that sometimes simple solutions work best. Easy, right?

Applied Behavior Analysis is NOT:

- ❑ Synonymous with DTI (or FBA) and is, in fact, a very large field with a variety of possible interventions
- ❑ 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.
- ❑ Unaware of the individual as a person. In fact, "when done correctly, there is not a field of intervention that is more person centered than applied behavior analysis"-
Gina Green, Personal Communication

Prompts

In ABA-based intervention the use of verbal prompts is often regarded as, well, heresy. They are hard to fade (theoretically) and have a low response effort on behalf of the prompter so they tend to be repeated with increased volume and tone. Having said that I want to point out that the world outside your classroom functions on verbal prompts. Besides, apparently we all rely on some level of prompting for skills we should have already mastered.



In the final analysis, adult skills are difficult to teach and difficult to acquire. So is there an easier way that we can achieve this goal?

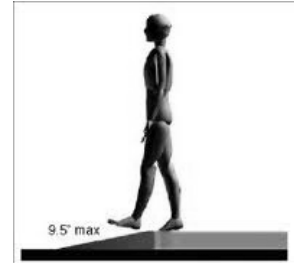
So what's a behavior analyst to do?



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

Resilience

(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 composed of a variety of 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.

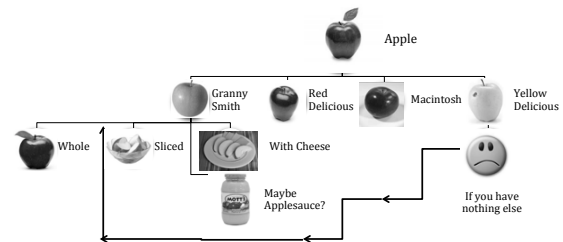
#2

Decent Choice Making Instruction



For Example:

I think I might like an apple



#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

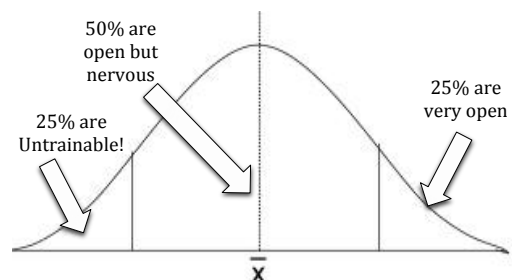
Knowledge can be Powerful!

"... under appropriate conditions interpersonal contact is one of the most effective ways to reduce prejudice between majority and minority group members." (Alpert, 1954)

Information that can be shared to great benefit

- Let's start with their name.
- How other people can best communicate with him/her.
- What his/her preferences, likes, and interests are so to better be able to engage them.
- What makes him/her smile? What makes him/her unhappy?
- What his/her relevant challenges might be.
- What autism means in his or her life.

How open is the community to this level of training?



#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
matters more than
what you do
ONCE IN A WHILE.

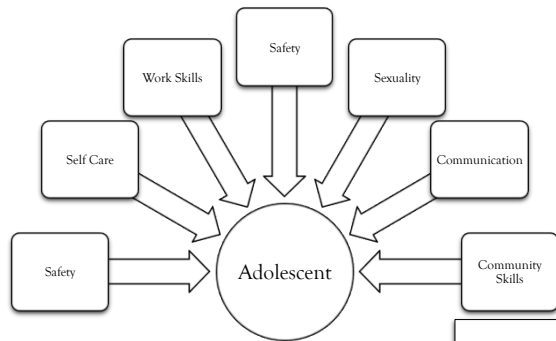
— Gretchen Rubin



What you do every day might include

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

Complementary Curriculum



For example

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

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).

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

What defines 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

Discussion

- ❑ In general, 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. In other word, they are risky skills. These are, however, the skills and 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

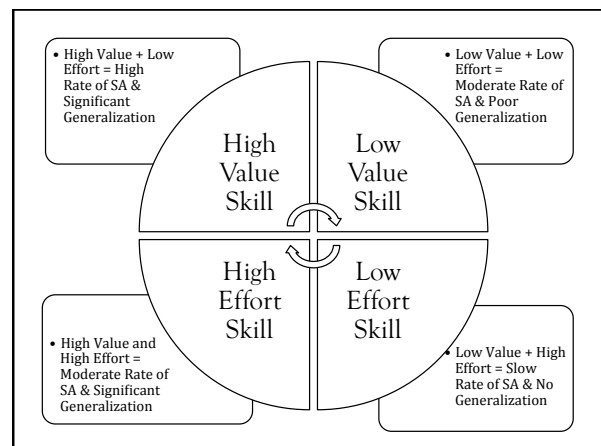
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#5

We need to pay more attention to matching law and response effort

Matching theory, in its simplest form, states that behavior is distributed in direct proportion to the positive reinforcement inherent on the display of the behavior. And as a general rule the lower the response effort, the lower the sR+ necessary to maintain (and generalize) the response in one's repertoire. Taking both of these into consideration when picking instructional targets may result in behavior change that is more resistant to extinction.



#6

When we have interventions that are evidence-based, they need to be used.

Video Modeling: An EBP

- ❑ Video modeling interventions involve having an individual with ASD watch a video of an adult, peer, or him/herself perform a behavior correctly, in hopes that the individual with ASD will begin to spontaneously perform the observed behavior after viewing it on video.
- ❑ Video modeling has been used to teach a variety of social, educational, adaptive, and vocational tasks to individuals with autism (Bellini and Akullian 2007) although only one study (Nikopoulos and Keenan, 2003) has targeted social skills in older individuals

Bellini, S., & Akullian, J. (2007). A meta-analysis of video modeling and video self-modeling interventions for children and adolescents with autism spectrum disorders. *Exceptional Children*, 73, 264-287.

Nikopoulos, C., & Keenan, M. (2003). Promoting social imitation in children with autism using video modeling. *Behavioral Interventions*, 18, 87-108.

Social Stories or Scripts:
Not so much

Social Stories, popularized by Carol Gray, consist of brief stories or scripts describing a particular social, behavioral, or problem solving skill. Though popular, the research into the effectiveness of Social Stories is, at best, mixed. One possible explanation is that there may be two different groups of individuals (i.e., responders v. non-responders) but, beyond a certain level of language comprehension, the characteristics of each group are undefined.

Peer Mediated Social Interventions: Possibly EBP

A small number of studies have found that peer-mediated interventions, can be effective at increasing social interactions of individuals with ASD (Chan et al, 2009). Peer mediated interventions are those in which typically developing peers are taught strategies for interacting with individuals with ASD. Peer-mediated strategies are meant to capitalize on the existing social skills of typical peers and to serve as models of appropriate social behavior. (Chan et al. 2009).

Chan, J., Lang, R., Rispoli, M., O'Reilly, M., Sigafoos, J., & Cole, H. (2009). Use of peer-mediated interventions in the treatment of autism spectrum disorders: A systematic review. *Research in Autism Spectrum Disorders*, 3, 876-889.

Social Skill Groups:
Not so much

- ❑ Social Skill Groups, while commonly used with high verbal individuals, lack an adequate research based. Among the myriad questions are what constitutes a social skills group, what curriculum is used, what social behaviors are targeted, how frequently should sessions be run and, how many sessions are needed to produce behavior change.

Self Monitoring/Management: An EBP

Self-management strategies are intended to teach individuals with ASD to independently regulate their own behaviors and act appropriately in a variety of home, school, and community-based situations. Considered an evidence-based practice, the critical elements of self-management include goal setting, monitoring behavior, evaluating progress and self reinforcement.

#7

Prioritize attempts and changing challenging behavior

Prioritize according to the answers

- ❑ Why is it important to address this particular behavior?
- ❑ If this behavior is reduced or eliminated, how does the individual's quality of life change?
- ❑ To what extent is the behavior in question really just a personal idiosyncrasy?
- ❑ Are staff sufficiently trained and are other resources available to effectively intervene and maintain behavior change over the long term?
- ❑ Who is responsible and capable of giving consent to this attempt to change behavior?
- ❑ Is the alternative behavior functionally equivalent and similarly efficient to the behavior in question?
- ❑ Is the the hill I want to die on today?

#7

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.
- ❑ A recent study found that less than 20% of Americans actually balance their checkbooks... ever. Yet balancing a checkbook continues to be an integral part of our transition curriculum.
- ❑ 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.

Closing Thoughts

Quality of Life as a strong socially important effect



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.

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.

Moving forward

"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.

Happiness

G. Satriale, A. Glickman, & P. Gerhardt, 2009

Technology: Electronics

MP4 player/ iPod™

- ❑ Purpose: To reduce stigma associated with one-on-one instruction (close proximity and physical prompts) by providing auditory /visual cues via watch during the workout routines at the local fitness center



Technology: Electronics

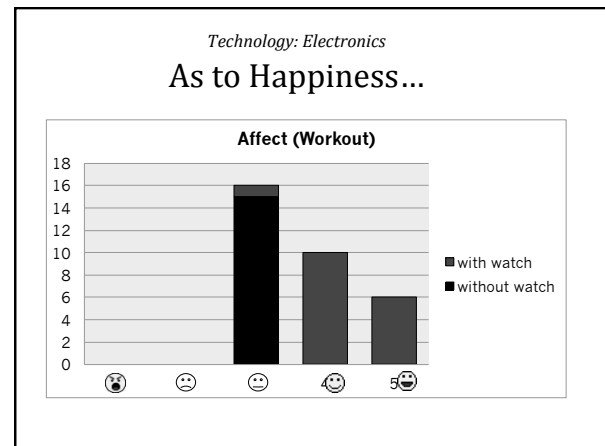
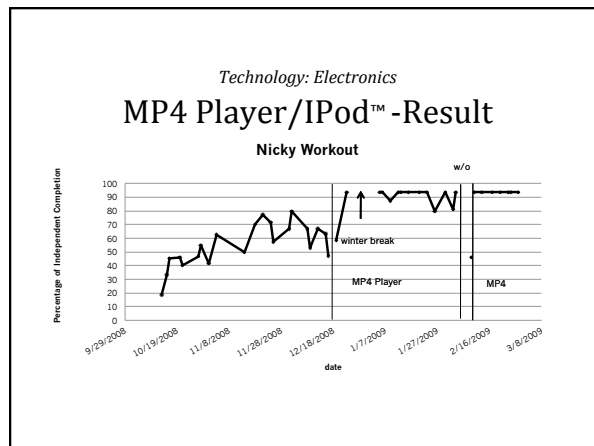
MP4 player/ iPod™

- ❑ Baseline:
 - ❑ Participants wore the MP4 player watch or iPod and earphones/headphones connected to the device
 - ❑ Use written schedule and a portable timer to follow the workout schedule (checking schedule, setting a timer,
 - ❑ Partial and/full physical prompts were provided as needed

Technology: Electronics

MP4 player/ iPod™

- ❑ Intervention:
 - ❑ Participants wore the MP4 player watch or iPod with earphones or headphones connected to the device
 - ❑ Verbal directions combined with highly preferred music were given via MP4 player or iPod
 - ❑ Partial/full physical prompts were provided as needed



So...

