Autism 207:

Transition to Adulthood: Behavioral Support for Adults

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My hope for you today is to feel empowered and instilled with optimism for the future.

- Stay engaged in the disability community, you can’t do this alone
- Life after the entitled school years is often scattered with challenges and set backs, be persistent and hopeful.
- We cannot rely on the social service system to meet the needs of our sons and daughters, there isn’t enough money and there never will be!
- Dream, innovate, activate!
- Build your own tribe of support!
Adult Autism: Positive Behavior Supports

• The use of Positive Behavior Supports is more than just a politically correct approach to behavior management.
• Research shows that it is effective.
• While punishment might work immediately, it has been shown to be ineffective in the long run and can increase aggressive behavior, provide a model for additional undesirable behaviors, and strain the relationship with the caregiver (you).
• It is worth noting that to continue to be effective and maintain improvements, positive supports and feedback need to be ongoing.

Autism Speaks
http://www.autismspeaks.org/sites/default/files/section_5.pdf
DDA Policy 5.14: Positive Behavior Support

1. Positive behavior support is an approach to addressing challenging behavior that focuses on changing a physical and interpersonal environment and supporting a person’s skill development so their needs are met without resorting to challenging behavior.

2. Positive behavior support must be emphasized in all services funded by DDA for persons with developmental disabilities.

3. Positive behavior support is based on respect, dignity, and personal choice. It helps develop effective ways of meeting a client’s needs to reduce challenging behaviors. Different people will require different positive supports. Common types of support are:
Components of Positive Behavior Support

1. A supportive environment helps a person meet their needs through positive expression instead of resorting to challenging behaviors to get their needs met. In a supportive environment, caregivers proactively plan to meet a person’s needs. Many things contribute to a supportive environment, including:
   a. Promoting positive relationships;
   b. Increasing a person’s opportunity to make daily choices;
   c. Reducing factors and forms of treatment that may make a person feel anxious, afraid, angry, or devalued;
   d. Arranging environmental factors, such as location of residence, access to transportation, and user-friendly kitchens;
   e. Providing consistent, positive responses to appropriate behavior on the part of the person;
   f. Providing a consistent, predictable environment;
   g. Calmly interrupting and redirecting inappropriate behavior; and
   h. Assisting the person to understand, to the best of their ability, how and why behavior change is helpful.
Skill Development and Status

2. Skill development and personal improvement help increase a person’s status and confidence. It is dependent upon age, capabilities, interests, and personal motivation. Types of skill development support include:
   a. Teaching a person new skills or maintaining or enhancing existing skills;
   b. Assisting to increase a person’s communication skills, including but not limited to sign language and use of communication devices;
   c. Increasing participation in typical community activities such as work, socialization, shopping, recreation, leisure, etc.;
   d. Fostering skills and behaviors that promote mental and physical wellness;
   e. Encouraging a person to take more responsibility; and
   f. Helping a person to find ways to make contributions to others.

3. Healthcare

4. Treatment of Mental Illness

5. Protection from Harm
"It is never too late to expand the mind of a person on the autism spectrum."

-Dr. Temple Grandin
### Physical Being

- **My body and health:**
  - Looking after physical health
  - Eating a balanced diet
  - Hygiene and body care

- **The people around me:**
  - Having a spouse or special person
  - Family
  - Friends

### Psychological Being

- **My thoughts and feelings:**
  - Self-control
  - Self-concept
  - Freedom from anxiety

### Spiritual Being

- **My beliefs and values:**
  - Understanding right and wrong
  - Attaching meaning to life
  - Celebrating life

### Physical Belonging

- **Where I live:**
  - Place of residence
  - Space for privacy
  - Living in a neighborhood

### Social Belonging

- **The people around me:**
  - Having a spouse or special person
  - Family
  - Friends

### Community Belonging

- **My connectedness to the resources in my community:**
  - Access to meaningful work
  - Access to community places
  - Access to education

### Practical Becoming

- **My practical daily activities:**
  - Work, school or program
  - Work around the home
  - Looking after people/pets

### Leisure Becoming

- **What I do for fun and enjoyment:**
  - Visiting and socializing
  - Casual leisure activities
  - Hobbies

### Growth Becoming

- **What I do to change, grow and adapt:**
  - Learning about new things
  - Attaining new independent living skills
  - Adjusting to changes in life

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1. Lifelong Learning
2. Structured Opportunities
3. Acceptance
4. Access
5. Respect

[http://foundationforautismsupportandtraining.org/qualityProfile.html](http://foundationforautismsupportandtraining.org/qualityProfile.html)
Thoughts that go through the Minds of Moms and Dads in the Wee Morning Hours!

- What happens if I die?
- Where will she go?
- Will he not have a choice and end up in some other part of the state where we’ll have to choose between moving to be closer to her or seeing her infrequently due to our need to work until we’re 82?
- Will he understand why he isn’t living with us anymore?
- Will she think we’ve abandoned her?
- Who will care for her?
- Will they be good to her?
- Will they “get her”?
- How long will it take for them to know that when she takes the milk and butter out of the fridge, she’s asking for Annie’s mac and cheese?

- Will they try and get her to sleep with her head at the head of the bed rather than the foot of the bed where she has comfortably slept for years now?
- Will people understand that he needs visual supports to communicate his wants and needs?
- Will her support staff understand that when she puts on her heavy coat that it doesn’t mean she is hot.
- Will his brother help with his support needs when I am gone?
- She will live with us! (until when?)
- What happens if his favorite DVD breaks?!
Parents: Our Role as a Lifelong Case Manager

• Definition of a Case manager:
  ▪ Helps people who are in difficult situations with advice,
  ▪ Figure out what kind of help they need,
  ▪ Help them find the services they need, create plans for treatment or recovery, work with other health and human service providers, and keep tabs on client's progress with treatment plans.

*Sound familiar? Don’t go it alone, have a plan and strengthen your sea legs!*
Person Centered Planning

• Person-centered planning is a way of helping someone to plan their life and support, focusing on what's important to the person. Person-centered planning has five key features:

1. The person with Autism and other Developmental Disabilities is at the center of the planning process
2. Family and friends are partners in planning
3. The plan shows what is important to a person now and in the future and what support they need
4. The plan helps the person to be part of a community of their choosing and identifies a way for the community to welcome them
5. The plan puts into action what a person wants for their life and keeps on listening - the plan remains 'live'
Life Does Not Happen in a Vacuum!

1. Capture history, if you don’t it always has a way of repeating itself!
2. Reminder of who a person is.
3. Keep the end in mind and work backwards.
4. Celebrate each movement on your path, however small or big.
5. A picture is worth a thousand words.
6. Use your plan as your calling card!
Key Words to Remember!

- Positive Behavior Supports
- Person Centered
- Self-Directed
- Supported Decision Making
- Whole-life
- Quality of Life Indicators
- Involvement/Inclusion
- Participation
- Autism and other Developmental Disabilities Research and Evidence Based Supports
- ADA Civil Rights
Inclusion versus Involvement

Inclusion

Involvement
Respect
Respect: Is Your Communication Strategy “Person Centered” and “Self-Directed”

- Often the practice of contracted agency, employment specialist or residential service provider sets the tone for how communication and teaching is delivered to the customer they serve with autism;
- Many times these differ entirely from what an individual with autism knows, has learned and practiced the majority of their educational career.
- If an individual with autism has had the opportunity to attend public school, their style of learning has already been identified.
Respect: Is Your Communication Strategy “Person Centered” and “Self-Directed”?

• Consider the barriers that impact accessibility for a person with autism
  • The basis for an autism diagnosis is Social-Communication and Repetitive Patterns of Behavior
• Understanding patterns of thinking and communication strengths and why it is important
  • Majority of people are visual learners
  • Use visual cues to communicate wants and needs
• Rediscover and/or develop innovative practice through the increased understanding of how autism impacts the learning and quality of life
Respect: Is Your Communication Strategy “Person Centered” and “Self-Directed”

• If communication solely depend on another person’s interpretation of their likes, dislikes and interests is that “Person Centered”?

• Communication for a person with autism is often left unheard or unnoticed when left to support staff “interpretation”
Scenario

• Aaron loves anything with Peanut Butter.
• Aaron’s staff realized that if they stopped by the store bakery first and get a Peanut Butter Cookie he would have a better grocery shopping experience.
• This has been their routine for a couple of months.
Scenario

- **Support staff**: Aaron! Would you like a Peanut Butter cookie?
- **Aaron**: NO!
- **Support Staff**: Here, let’s get one anyway.
- **Aaron**: Runs towards the check out stand and started to grab as much candy as he can.
- **Support Staff**: Chases after Aaron and tries to pull the candy out of his hands.
- **Store Clerk**: Starts yelling at Aaron; “Dude, let go of the candy!”
- **Aaron**: Runs towards the door, pushing a small child out of the way and onto the floor.
- **Support Staff**: Runs after Aaron, does a run-by apology to the Mother of the child who had been knocked to the floor
- **Store Clerk**: Followed Aaron and staff out to the car and told them to please not come back to their store again.
Difference Between a Question and Choice: *The rest of the story!*

- Aaron was with his family last week.
- He was offered a bakery Peanut Butter Cookie OR a *Reese’s™* Peanut Butter Cup.
- Aaron opted for the Reese’s Peanut Butter cup.
- The shopping experience went well.
Respect: What Functional Communication and Support Should Have Looked Like

1. Aaron needs to participate in his shopping experience, not distracted with cookies or candy. This scenario only enhances the staff’s experience, it does not provide Aaron with any skill development opportunity, other than reducing the occurrence of a behavior.

2. Teaching decision making skills with favorable activities is important.

3. Generalization of skills using the same format is crucial.

4. What might a visual look like to increase participation and choice? Start small and end on a positive!
Respect: What Functional Communication and Support Should Have Looked Like

- Provide Aaron with information
  - What we will be doing?
    - Grocery shopping with only a few (or maybe only one) favored items
  - Where we will be doing it?
    - Safeway
  - How long will we be there?
    - Until the grocery List is Complete
  - How do I know when we will be done?
    - When Aaron makes his choice
  - What is next?
    - Go home and eat his choice (cookie or candy bar)
Likes and interests are not set in stone, visual choice and opportunity often yield surprising results. Use options for choice.

• Support Staff:
  • What would you like to eat for lunch?

• Tom:
  • Mac and Cheese

• Staff makes Mac and Cheese but Tom doesn’t eat it.

• Support Staff:
  • You have these choices for lunch!

• Support Staff:
  • Wow, I didn’t know Tom liked turkey sandwiches!
Executive Function, Communication and Decisions

• Executive function (EF) has long been of interest given its proposed role in contributing to specific impairments in ASD in the areas of *theory of mind and social cognition, social impairment, restricted and repetitive behavior patterns* as well as broader impacts on quality of life.

• EF encompasses a broad range of purposeful higher-order neuropsychological domains, including goal-directed behavior, abstract reasoning, decision making and social regulation.

• It’s even more important for us to take time for people with autism to visually understand high-order, goal-directed, decision making and social judgement.
Executive Function, Communication and Decisions – Autism EBP

1. Know how the person learns
2. Involve the use of visual supports
3. Provide outcomes of decisions
Beth is non-verbal and works bussing tables at Ribs R Us

• Job Coach takes Beth to a closet that has stacks of T-Shirts that employees wear for work, they are also sold to customers.
• Job Coach: Ok Beth, here is where you get you work uniform.
• Beth: Takes the T-shirts
• Job Coach: Starts to train Beth on her job duties.
• Beth has a great memory for details. Follows a routine flawlessly.

• Job Coach: Fades supports to monthly check-in with the restaurant owner
• 4 months later, Beth is fired from her job for being a thief!
The Rest of the Story!

- The employer delighted with Beth’s work performance and ethics.
- The employer starts Beth on a new task of spraying BBQ trays to load in the commercial dishwasher.
- The employer did not know the support needs of Beth, rather he verbally training Beth leaving “critical thinking and problem solving” to Beth’s who is a concrete and literal thinker.
- Part of the problem was that the employer did not know he needed to tell Beth to wear a rubber apron while doing this task.
- Beth would become totally soaking wet.
- When Beth got wet, she went to the closet where she would pull out a clean dry shirt to put on.
- Beth collect 17 shirts over 4 months.
- The employer did not provide Beth with a task and tools list.
- Beth showed great skill and mastery with her job, she was fired because the job coach did not visually show Beth that each employee was given two shirts, but after that the employee would need to purchase.
Who is Responsible?

• Assumptions were made by Job Coach and Employer
• Support strategies were made Beth’s responsibility...Ummm, who has the disability?
• Beth was fired because;
  • No functional communication
  • Executive Function Disorder was not accommodated for.
  • No Job Coach training on Autism
**Respect:**
What Functional Communication and Support Should Have Looked Like?

Job Coach takes Beth to a closet that has stacks of T-Shirts that employees wear for work, they are also sold to customers.

**Rules**
- Employees needs to wear their Ribs-R-Us T-shirt when they are at work.
- Each employee gets “2” shirts
- Each employee is responsible for keeping their shirts clean.
**Respect:**

What Functional Communication and Support Should Have Looked Like?

Job Coach takes Beth to a closet that has stacks of T-Shirts that employees wear for work, they are also sold to customers.

**Social Story**

• Each employee wears a Ribs-R-Us T-Shirts when they are at work.
• Each employee gets only “2” T-shirts from this closet.
• Beth is an employee and has her “2” shirts.
• Beth will wash her shirts after work to make sure she is ready for work.
• Beth is happy to follow the rules at work.
Respect: Beth’s “Work-Ready” List

The night before work:
Wash and dry work shirts

The morning of work:
Put on one work shirt
1 shirt in backpack
1 pair of pants in backpack
1 Name Badge in backpack
Bus pass
Lunch

Work Supports for People with Autism don’t start and end at the employer:
1. What do I need to be work ready?
2. Identify the “what if’s?”
3. Prepare the employer for “next-steps”;
   • New tasks
   • New co-workers
   • New boss
4. Work collaboratively with family and/or residential provider and share “work-ready” supports.
5. Share with worker and family and/or residential provider weekly work schedule.
Respect: Are Your Communication Strategies “Person Centered?”

• RECAP: If communication solely depend on another person’s interpretation of their likes, dislikes and interests is that “Person Centered”?

• Communication for a person with autism is often left unheard, unnoticed when left to support staff “interpretation” who may or may not have the whole picture

• The person with autism may start to engages in “aggressive behaviors” to communicate their wants and needs

• It is important to use Evidence based - Autism Specific support strategies for the consumer/client/customer you support
Autism Evidence-Based Practices (EBPs)

• Scientific research has found only some interventions to be effective.
• The interventions that researchers have shown to be effective are called Autism evidence-based practices (EBPs).
• One reason for using EBPs is because, by law (IDEA), teaching practices must be based on evidence of effectiveness.

  • http://autismpdc.fpg.unc.edu/evidence-based-practices
Autism Evidence-Based Practices (EBPs)

- Antecedent-based Intervention (ABI)*
  Cognitive Behavioral Intervention (CBI)**
  Differential Reinforcement of Alternative, Incompatible, or Other Behavior (DRA/I/O)
- Discrete Trial Teaching (DTT)*
- Exercise (ECE)*
- Extinction (EXT)

- Functional Behavior Assessment (FBA)*
  Functional Communication Training (FCT)
- Modeling (MD)*

- Naturalistic Intervention (NI)
- Parent-implemented Intervention (PII)
- Peer-mediated Instruction and Intervention (PMII)*

The National Professional Development Center on Autism Spectrum Disorder
http://autismpdc.fpg.unc.edu/evidence-based-practices
Autism Evidence-Based Practices (EBPs)

- Picture Exchange Communication System (PECS)*
- Pivotal Response Training (PRT)
- Prompting (PP)*
- Reinforcement (R+)*
- Response Interruption/Redirection (RIR)
- Scripting (SC)**

- Self-management (SM)
- Social Narratives (SN)*
- Social Skills Training (SST)*
- Task Analysis (TA)*
- Technology-aided Instruction and Intervention (TAII)
- Time Delay (TD)*
- Video Modeling (VM)
- Visual Support (VS)*

http://autismpdc.fpg.unc.edu/evidence-based-practices
While the student is in school, communication supports should follow them when the student exits school.
Distressing?

Why and what could be distressing?

Don’t reinvent the wheel!

• Michael Callahan, author of *Discovery* writes:
  • “The presumption that a collection of individuals who know the person all know the same thing”
  • and
  • “If we do not take the time to document the complexity, the nuance, in the lives of people with significant disabilities, our efforts to pursue outcomes such as employment are vulnerable to that which is overlooked.”
Respect, Dignity and Supported Decision Making

1. Research Evidence Based Practices utilized while in school, with other practitioners and families that provided the person with autism functional communication
2. Take the time to document the complexity and nuances
3. Training is needed to ensure fidelity of communication strategy
4. Implementation of supports with fidelity
5. Build capacity
6. Sustainability
What if there is not a record of functional communication supports?

1. Refer to Autism Evidence Based Practices
2. Assessment, Implementation and Outcomes
3. Life Long Learning
Seriously Monica, this seems impossible!

1. We have a significant turn over of staff
2. We have other required training that needs to be completed first
3. Relationship development is foundation to communication and learning; it takes more than a few hours spent with the person with autism

Albert Einstein said the definition of insanity is doing something over and over again and expecting a different result...when we should be referring to is Marc Gold: Pioneer of “Try Another Way”

Rather than forcing “compliance” from the person with autism, offer another support (i.e. visual support) for learning through the implementation of an Evidence Based Practice.

It’s easy to pass the inevitable buck to the person with autism, write up incident report after incident report and not “trying another way.”
Communication

- Consistent process for a person to follow
Respect, Dignity and Supported Decision Making

1. All behavior is communication
2. Seek functional communication supports
3. Meet the communication and learning style of the person with autism - visual
4. Teach concepts rather than following your verbal prompting and expect compliance
5. Let the person you support, know what to do rather than telling them what NOT to do
6. Facilitate communication
7. Seek help if support strategies don’t work
   • Length of time, type of support, fidelity in implementation
Functional Communication...is *Respect*

Everyone has thoughts, opinions, the desire to be "heard" and essentially respected. People who experience autism are no different...no matter their age or intellect.

Talk with me, NOT about me! Unless you have the ability to read my mind with 100% accuracy do not patronize me by speaking for me.

Help ME develop a functional way (for me) to communicate MY wants, MY needs, MY likes, MY dislikes, MY thoughts, My dreams...and then listen...let ME make choices...”

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Ronda Schelvan, MS.Ed.
K-2 Social Communication Inclusion Program (SCIP)
The Hidden Curriculum: Co-Author

The least restrictive environment (LRE) is Learning with Respect and Expectations.
DIGNITY OF RISK
Dignity of Risk

• The dignity of risk is a very powerful concept. We cannot allow our fear of harm or wish to protect a person with a disability from harm to effectively mean we are making choices for others.

• People with disabilities, like everyone else, must be free and empowered to make their own choices and live with the consequences.

• That is how we all develop our character and personality. That is the real meaning of choice and control.
Dignity of Risk

- Has implications we all need to consider
- It’s not throwing caution to the wind

<table>
<thead>
<tr>
<th>Dignity of Risk</th>
<th>Duty of Care</th>
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<tbody>
<tr>
<td>A person’s right to take a calculated risk</td>
<td>The need for safety and freedom from distress</td>
</tr>
<tr>
<td>The person’s right to freedom and independence</td>
<td>The ability to restore function</td>
</tr>
<tr>
<td>The person’s right to choice</td>
<td>Effect the person’s lack of insight</td>
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Permission, Acceptance and One Giant Jump – Mollie’s Voice

• One of the most amazing days of my life was witnessing the bravery and joy of my brother. In 2003, on a warm, sunny summer day, we headed to our favorite destination: Sunset Falls. We always passed the favorite hot spot of many local visitors, and continued miles up a windy road where few bothered to explore. It was usually just us. A perfect little water hole coming from a mountain run off, just putting your foot in is rather terrifying, the water is literally freezing. But it didn't matter, it was the thrill of the jump, the excitement of the challenge, and a whole lot of family fun.
Permission, Acceptance and One Giant Jump – Mollie’s Voice

• My mom told Michael, who was already well equipped in his swim suit and life jacket, to jump in... or at least put his toes in. He put his toes in, but wasn't real enthusiastic about going any further.

• With my blue lips, and a quiver in my voice I told my brother to jump in, or at least slide his booty in and swim with me to the other side--where the cliff was.

• With a few loving voices coming from his favorite cousins all around him to JOIN the fun, he did. Almost just like that, it didn't take much. Michael carefully sat on the wet rocks, and slid in. Slowly.
Permission, Acceptance and One Giant Jump – Mollie’s Voice

• With a few loving voices coming from his favorite cousins all around him to JOIN the fun, he did. Almost just like that, it didn't take much. Michael carefully sat on the wet rocks, and slid in. Slowly.

• As he gasped and acclimated to the water, we paddled to the other side of this mini river, just for fun, certain we'd be making the loop back as soon as we hit the other side. But no. That's not how this story ends.

• Michael took the hand of his favorite cousin, Cameron, and I went behind him to spot his ascent.
Permission, Acceptance and One Giant Jump – Mollie’s Voice

• His cousin, Cameron, was about the climb the cliff to take another jump, and carelessly asked Michael if he wanted to go up. Second-guessing if this was an acceptable risk (I mean, you do have to JUMP once you're up there!), I glanced over at a beaming mom whose encouraging eyes didn't cause me to delay this endeavor.
Permission, Acceptance and One Giant Jump – Mollie’s Voice

• We reached the top. As I looked down the cliff, it looked different. It suddenly looked really tall, dangerous, and impossible. I had jumped this cliff a million times; I could jump off of it like I would a curb. It wasn't any big deal until that moment.

• Again, with a big eyes look to Mom, to make sure I wasn't taking it too far. I mean, was he ready? Was he going to enjoy it? Would he be scared? I was scared. This was new for me. My brother, up on a cliff. Doing what I did with my peers. His peers. This was new, and in unfamiliar territory I wasn't sure what to make of anything.
Then it all becomes a blur. The next thing I know I'm finger locked with Michael's right hand, and his left hand is in the care of his cousin. And on the count of three, we jumped. Just like that. With no time to think I saw my brother's feet take flight. My grip tightened fast onto his hand, I wasn't letting my brother go.

We jumped, on Michael's demand. He wanted to. He was ready. He had watched us time and time again, he was ready. Summer after summer he had watched his cousins, friends and sister jump. He knew what he was supposed to do. He wanted to. Most importantly, he had *permission* and felt *acceptance*. 
SUPPORTED DECISION MAKING
How Many of You Use Supported Decision Making Properties?
Supported Decision Making

• Supported decision-making (SDM) allows individuals with disabilities to make choices about their own lives with support from a team of people. Individuals with disabilities choose people they know and trust to be part of a support network to help with decision-making.

• Supported decision-making is an alternative to guardianship. Guardians make decisions *for* the person with a disability. However, supported decision-making allows the person with the disability to make his or her *own* decisions instead of having someone else make them for him or her.

• Supported decision-making promotes self-determination, control, and autonomy. It fosters independence.
Supported Decision Making

- Empowering People with Disabilities
- Make Choices
- With help from supporters/advisors
- Explore Options
- Understand the options
- Know the risks and benefits of the options
- Offer recommendations, without coercion
- Make the choice
- Have the help of supporters to carry out the choice
Responsibilities of Lay Guardianship

- Not a continuation of parenting
- Age of majority
- Supported Decision Making
Don’t Go It Alone!
Power and Choice

Not compliance, but relationship, comprehension and trust

Joint Attention Activities
Don’t reinvent the wheel, but know how to use the wheel!

“I thought I was on to something but I can’t figure out how to move it.”
Lest we forget!

1. Functional Communication
2. Concepts to teach
3. Executive Function
4. Visual Supports, Learning Modality
5. Social Stories, Social Thinking
Technology is at our finger tip!

- Visual
- iPhone
- iPad
- Picture Montague
- Apps

- Skill
- Capacity
- Sustainability
- Assessment
- Data Collection
- Responsibility, Answerability
- Train staff to where your customer is
- Do not omit the subtleties and nuances
Thank You!

• For more training information, check out my website at:
  • HTTP://MONICAMEYER.COM