

# Autism: Strategies for Families

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# Background

- B.A. Psychology: Western New England College, Springfield, MA
- M.S. Educational Psychology, concentration in Applied Behavior Analysis
- Psy.D. School Psychology: University of Southern Maine, Portland/Gorham, ME
- Pre-doctoral internship in Behavioral Psychology: Center for Autism Spectrum Disorder, Munroe-Meyer Institute, University of Nebraska Medical Center, Omaha, NE
- Post-doctoral internship: The Family Behavior Analysis Program, Syracuse, NY

# FBA Program

- Intensive Outpatient Clinic
  - Severe Behavior Disorders sub-clinic
  - Pediatric Feeding Disorders sub-clinic
  - Behavioral consultation
  - Autism Diagnostic Evaluations\*

# Overview

- Autism: Symptoms, Causes, Diagnosis, Treatment
- Tips for Success:
  - General Information
  - Increasing Appropriate Behavior
  - Decreasing Inappropriate Behavior
  - Feeding Difficulties
  - Toileting
  - Sleep Difficulties
  - Social Skills
- Wrap up

# Autism

- Biologically based, neurodevelopmental disorder
- Deficits in communication, socialization, and presence of restrictive/repetitive behaviors
- Symptoms typically recognized during early developmental stages

# Communication Deficits



- Absence of babbling in infants or start then stop
- Fail/slow to respond to name or develop gestures
- Difficulty with back & forth conversation
- Problem behavior (nonverbal)
- Repeat certain words or phrases (i.e., echolalia)
- Unusual tone of voice
- Use of odd/out of place words

# Social Deficits

- Lack eye contact/poor eye contact
- Do not respond to or acknowledge others in environment
- Do not engage in back-and-forth play
- Do not seek to share enjoyment
- Unusual response to others' emotions



- Difficulty understanding that others think, feel, act differently
- Likely do not notice subtle emotional/facial cues

# Restricted/Repetitive Behaviors

- Overly focused on certain objects or parts of objects
- Hand/arm flapping, jumping, spinning
- Subtle finger movements
- Preoccupation with specific topics (i.e., trains)
- Lining toys/objects up
- Routine-based behavior
- Get stuck on something





# Associated Symptoms

- Sensory difficulties (over/underreact)
  - High pain tolerance
- Sleep difficulties
- Adaptive living skills deficits
  - i.e., Toileting
- Gastro-intestinal problems
- Feeding difficulties
- Challenging behavior
- Seizures
  - 1 in 4 with ASD ([www.nih.nimh.gov](http://www.nih.nimh.gov))

# Causes of Autism

- Combination of genetic and environmental factors
  - Many forms/many causes
- Genetic
  - Known syndromes or medical conditions associated with risk (e.g., Fragile-X Syndrome, Rett Syndrome, etc.)
  - Various gene mutations, deletions, and interactions (Idiopathic autism)
  - Brain differences (observations, not causes)
- Environmental
  - Maternal infection during pregnancy
  - Extreme prematurity
  - Parental age at birth
  - \*Increase risk of autism, not a cause

# Screening & Diagnosis

- Well-child evaluation by Pediatrician
  - “The AAP stands behind its recommendation that all children be screened for ASD at ages 18 and 24 months, along with regular developmental surveillance. “ (American Academy of Pediatrics)
- Screenings for autism
  - Modified Checklist for Autism in Toddlers-Revised (M-CHAT-R)
- Comprehensive diagnostic evaluation
  - Observation, detailed history, physical examination, record review, developmental assessment (motor, adaptive, cognitive skills), hearing test, language evaluation, genetic tests (American Academy of Pediatrics, 2012)
  - Autism Diagnostic Observation Scale – Second Edition (ADOS-2)
- Earlier diagnosis = better prognosis

# Prognosis

- Long-term outcomes are improving
  - Early, intensive intervention
- Factors that may slow progress:
  - Intelligence/Cognitive abilities
  - Severity of Autism symptoms
  - Associated medical conditions (i.e., seizures) or behavioral disorders

(American Academy of Pediatrics)

# Treatment

- No cure
- Evidence-based Early Intervention
  - Toddler – Preschool years (birth-36 months)
- Behavioral Interventions (i.e., Applied-Behavior Analysis)
- Medication
  - Do not target symptoms of autism
- Sensory Integration Therapy
- Complimentary and Alternative Medicine (CAM)
  - Dietary changes; facilitated communication
- When new “treatments” are in the media – DETAILS!
  - B12 injections

# When to think twice....

- Treatments are based on overly simplified scientific theories
- Therapies are claimed to be effective for multiple different, unrelated conditions or symptoms
- Claims that children will respond dramatically and some will be cured
- Use of case reports or anecdotal data rather than carefully designed studies to support claims for treatment
- Lack of peer-reviewed references or denial of the need for controlled studies
- Treatments that are said to have no potential or reported adverse effects

(American Academy of Pediatrics, 2007)

# Goals of Treatment

- Minimize primary symptoms
- Ensure optimal level of success and quality of life
- Increase communication and socialization
- Decrease challenging behaviors and other associated symptoms
- Educate families and other caregivers regarding evidence-base treatments

(American Academy of Pediatrics, 2007)

# Applied Behavior Analysis

- Apply principles of learning to systematically change behavior and *ensure the procedures implemented are in fact responsible for behavior change*
  - “Understanding & modifying behavior in the context of environment.” (Autism Speaks)
- Increase appropriate behavior & decrease challenging behavior
- Increase functional skills
- Generalize behaviors to new environments and situations
- Objective evaluation (data-based versus anecdotal based) within home, school, and community settings
- Evidence suggests gains in IQ, language and social skills, academic performance, and adaptive behavior
- Evidence-based, best practice treatment (U.S. Surgeon General and American Psychological Association)

(American Academy of Pediatrics, 2007)



# ABA Therapies

- Are structured
- Collect data for target skills or behaviors
- Include positive strategies for changing behavior
  
- Positive reinforcement: “When a behavior is followed by something that is valued, that behavior is more likely to be repeated.”
- What does ABA “look” like? It varies!

(Autism Speaks)

# Learning May be Different

- Individuals with autism may see and interpret the world differently than you and me
- Traditional teaching strategies may not be effective
  - Trial and error vs. errorless learning
- What others may learn by observing, individuals with autism may only learn through direct practice and assistance
- What others may learn in whole, individuals with autism may need to learn in steps

“The child with autism is like a Mac in PC world. He’s hard wired differently. Not incorrectly – just differently. Teach him in a manner meaningful to *him*.”

~ Ellen Notbohm

# Keys to Success

- Patience....



Change takes time and often there are bumps in the road

- Consistency

“I’ve tried that before and it didn’t work.”



# First things first...

- Identify preferences
  - Preferences vary and shift
  - Not just what the child will engage with, but what will motivate the child
- Assess the situation (skill deficits or behavioral excesses)
  - Develop goals and strategies that directly link to assessment outcomes – don't waste time!
  - Individualize goals and strategies
    - Not all individuals with autism respond to the same strategies in the same way

# And don't forget....

## SET THE CHILD UP FOR SUCCESS!



- Start out with small expectations/goals
  - What skills does this child *need* to learn to succeed at this point in time?
- Start where the child is at, not where you want them to be
- Increase expectations gradually
- Follow through and provide assistance – learning is difficult.

# Appropriate Behavior

- Reinforce it! Providing a desired consequence after a behavior increases the likelihood that the behavior will occur again.
- Difference between a bribe and a reinforcer
  - Bribe: reinforcer is provided before the desired behavior occurs (i.e., “I’ll give you a cookie now if you promise you’ll do your homework.”).
  - Reinforcement: reinforcer is provided after the desired behavior occurs (i.e., “When you finish 5 math problems you’ll get 1 cookie.”).
- Limit access to powerful reinforcers to maintain value

# Increasing Appropriate Behavior

- Catch them being good; look for the behavior
  - Identify teachable opportunities and praise/reinforcer appropriate responding
- Make appropriate/reasonable requests in a way the child can understand
  - Things he/she can do independently
  - Break tasks down into smaller steps
  - Only ask to complete part of an activity independently, then provide assistance for completion
  - What is the reinforcement contingency? Be specific.
  - Increase expectations gradually and always follow through (if you don't have time to wait, don't make the request)
- Plan ahead to ensure success (Autism Treatment Network, Autism Speaks)



# Challenging Behavior - General

- Always focus on increasing appropriate behavior first, but when challenging behavior does occur:
  - Limit attention (i.e., comments about the behavior, warnings, soothing statements, etc.)
  - Remind your child of what he can do (i.e., instead of “stop biting” you can say, “If you need help, say “help please”).
  - Keep the child, yourself, and those around you safe
    - Be aware of your positioning, don’t put yourself in harms way

# Challenging Behavior - Specific

- Assess environmental factors – be a “social detective”
- What purpose does the behavior serve? What is the child attempting to get out of using the behavior?

<b>Escapes or avoids tasks or requests</b>	<b>Gains Attention from others</b>
<b>Gets Access to an item, etc.</b>	<b>The behavior feels good to the child</b>

- What is an alternative response that I can help the child engage in to get access to the consequence the child is seeking?
- This is not a simple task...

# ABC's

- Antecedent: what happened before the behavior?
- Behavior: problem behavior we want to change
- Consequence: what happens following the behavior?
  
- Knowing this information can help us create a plan for modifying the environment or situation to help prevent the behavior from occurring (antecedent strategies), as well as introduce the desired consequence contingent on alternative, appropriate behaviors (consequent strategies).

# ABC Example

“A boy with ASD is walking with his babysitter in the park when a dog begins barking loudly. The boy begins to yell. The babysitter remembers that the boy likes gum and gives him a piece. He calms down.

In this example, the **behavior is the boy screaming. The dog began barking before the boy began yelling, this is the antecedent. The babysitter gave the boy gum after he began yelling, this is the consequence.**

The next time the boy is at the park with the babysitter, he yells until given a piece of gum. The gum is a reinforcer or something that the little boy likes that increases the frequency of the yelling behavior. If the babysitter wants to stop or extinguish the yelling behavior she must stop providing the gum reinforcer following yelling behavior.

(from Autism Treatment Network, Autism Speaks)

# Remember...

- Changing behavior takes time – it is a learning process
- Things may get worse before they get better
- Work with a qualified professional, trained in the treatment of challenging behavior disorders
- Applying inappropriate strategies, or appropriate strategies incorrectly could worsen the behavior or become dangerous

# Communication Tips

- Determine the target communication system (i.e., vocalizations, sign language, voice-output device [i.e., Ipad], etc.).
- Work with providers (i.e., speech language pathologist) to help determine what may work best for the child
- Be consistent with communication expectations
- *Practice!*
- *Ensure access to communication is available at all times*



# Feeding Difficulties

- *Rule out medical issues (Gastroenterologist)*
- Feeding Assessment – to establish the child’s current abilities and provide a starting point for treatment
- Food preference assessment – choice and/or consumption
  - Novel and known foods
- Behavioral hierarchy
  - Increase the expectation across steps to a terminal step of food consumption (i.e., pick up, smell, touch to tongue, put in mouth, chew 1 time, etc.)
- What about idiosyncratic preferences (i.e., certain colors, drinking containers, fun food shapes, etc.)?

# Addressing Feeding Concerns

Autism MEAL Plan – multi-component, behaviorally-based parent training curriculum to address feeding problems associated with autism (Sharp et al., 2013)

1. Introduction
2. *Structuring the meal and Monitoring behaviors (data collection)*
3. Ways to increase appropriate behavior
4. Effective communication
5. Ways to decrease inappropriate behavior during meals
6. Methods of introducing foods
7. Teaching self-feeding skills
8. Monitoring and maintaining progress



# Meal Structuring

- Clear, predictable expectations
- Identify what foods or liquids will be available based on child's current diet and keep them consistent
  - How many foods? What texture?
- How much food?
  - Remember set them up for success!
- What utensils and/or type of cup will be available?
- Meal duration
- Consumption expectation (i.e., how many bites?)
- Is reinforcement available and if so:
  - What type and for what behaviors?
- Providing attention



# Other Considerations

- Feeding is a complex behavior
- Various events can affect compliance with feeding
  - Development, medical issues, oral-motor abilities, smells, tastes, textures
- You are asking the child to do something they do not like or want to do – seek out help
  - Weight loss, eating fewer foods, increase in challenging behavior, concerns with nutrition
- Be consistent and patient

# Toileting

- Appropriate toileting often happens at a later age with individuals with autism (Tsai, Stewart, & August, 1981)
- Children with autism require 1.6 yrs of toilet training for day time dryness & more than 2 yrs for bowel control (Dalrymple & Ruble, 1992)
- Rule out medical concerns
- Consider developmental issues: language deficits, adaptive living skills, biological readiness
- Restrictive behavior: changing the way they toilet or using new toilets



# Toileting, cont.

- Start with small expectations or behaviors that are working toward the terminal goal of independence
  - Entering the bathroom, standing near the toilet, opening the toilet seat lid, sitting on the toilet for 10 s, then 30 s, etc.
- Schedule toilet trips
  - Monitor urination and bowel movements
- Use the same language and other cues
  - Timers, visual schedule
- Select reasonable reinforcers specific for toileting behaviors – set clear expectations
- Commit, persevere, and expect accidents

# Toileting: Visual Schedule



Sit on toilet



Wipe until clean



Flush toilet



Wash hands

# Sleep Difficulties

- Rule out medical cause – trouble falling or staying asleep and early morning waking can be typical in all children
  - Snoring, gasping, bedwetting
- Keep in mind:
  - Select strategies that fit with your family style
  - This is a time commitment –start when you have the energy
  - Start small, gradually add new strategies
  - Change will take time

(Autism Treatment Network, Autism Speaks)

# Sleep Tips

- Provide a comfortable environment
- Develop a bedtime routine that everyone follows
- Use of visual schedule and calming activities
- Maintain a regular sleep and wake schedule
  - Adjust bedtime if needed
- Non-sleep habits
  - Exercise and diet
- If problems persist or new ones arise seek out medical advice



(Autism Treatment Network, Autism Speaks)

# Sleep: Visual Schedule



Knowing changes everything.™



# Social Skills

- Traditional and naturalistic behavioral strategies – direct teaching of skills
- Pairing procedures
- Reasonable expectations
- Recognize opportunities
- Social skills groups, social stories, scripts, etc. require continued evaluation



# Some Closing Thoughts

- Autism is truly a spectrum disorder
  - Individuals can present with a variety of symptoms and range of behavioral concerns
- Individuals with autism have many strengths and skills to highlight and build upon to ensure success
- Seek out help from professionals with specialized training and avoid fad treatments – do your research!
- Patience, consistency, and finding support are key!
- The family is the most important part of this process....

# Family as Change Agents

- Parents/Caregivers play a key role in effective treatment
- Stress & depression are higher in parents & siblings of individuals with autism
- Provide education, training, and support
  - Natural supports: spouses/significant others, extended family, neighbors, friends, community groups
  - Informal supports: other families, community agencies, respite care, social events, recreational activities
  - Formal supports: state-funded early intervention, Medicaid, in-home & community-based waiver services (i.e., OPWDD), special education, vocational services, residential/living services

*"Learning your child has autism can certainly change your perception of what you thought your life might be. You may have to restructure your priorities and develop new coping skills. And you may have to change some of your plans for the future. But in their place will be new dreams, new goals, and new priorities. The key is finding ways to adapt and adjust that suit your family, your needs, and your circumstances. It likely won't be easy. But people often find strength from within and from those around them to succeed. By loving your child dearly, you will be inspired to do what you can to learn as much as possible about ASD so that you too will be rewarded as you discover what works for your family."*

— [Autism Spectrum Disorders: What Every Parent Needs to Know](#); Alan I. Rosenblatt, MD, FAAP, and Paul S. Carbone, MD, FAAP, editors

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