Turn Autism Around with Dr. Mary Lynch Barbera

Kaden Page, B.A., David Puder, M.D.

On this week's episode, Dr. Puder interviews Mary Lynch Barbera, Ph.D., RN, BCBA-D, creator of the approach and book titled *Turn Autism Around*. Dr. Barbera began her journey in the autism world over 20 years ago, when her first son, Lucas, was diagnosed with autism. Dr. Barbera made the incredible transformation from a confused parent to a doctoral-level behavioral analyst, best-selling author, and a tremendous resource for health professionals and parents of children with autism all over the world.

Kaden Page and David Puder have no conflicts of interest.
Dr. Mary Lynch Barbera conflicts includes a course and books for parents of autism.

During the interview, we strive to focus on the following material:

- Why is it important to catch autism early? What is the data supporting it?
- How can we diagnose autism early? What do we look for?
- How do we turn autism around?
- What areas do we focus on improving? How?

What exactly is autism?

Autism spectrum disorder (ASD) is a neurodevelopmental disorder characterized by "persistent impairment in reciprocal social communication and social interaction, and restricted, repetitive patterns of behavior, interests, or activities" (American Psychiatric Association, 2013). ASD is most commonly diagnosed in children, as the symptoms usually begin to show themselves during early childhood and early school years. However, many features of ASD are sustained throughout childhood development and on into adulthood. Classic early symptoms of autism are poor interpersonal communication, behavioral dysregulation, and ritualistic behaviors. In summary, there are five criterion established to reach a diagnosis of autism spectrum disorder including deficits in social communication, restricted/repetitive patterns of behavior/activities/interests, presence of symptoms in early developmental period, significant impairment in person's social/occupational functioning, and symptoms not better explained by another disorder, respectively.

Catching Autism Early

Chapter one of Dr. Barbera's book is titled "Early Signs of Autism Are an Emergency—So Why Are We Waiting?". A look at some of the data exemplifies just how crucial this is.

1) Lovaas (1987), published data that indicated if autism is caught early enough and treated intensively, some children are able to improve to a level of cognitive functioning similar to that of their peers.
    a) Experimental group subjects were, on average, 6 months younger (34.6 months old) than the control group (40.9 months old) and received 40 hours per week of behavioral therapy as opposed to 10 hours a week of behavioral therapy for the control group.

b) Over the course of approximately 3 years of treatment, the experimental group subjects gained an average of 30 IQ points more than the control group.

2) Additionally, Dr. Ami Klin and colleagues (2020) conducted a meta-analysis of several quantitative studies and formulated a proposition that encouraged a redefinition of the importance of early brain development and its relationship to ASD.
   a) According to Klin et. al., there is a "tremendous" window of opportunity in the early years of development, specifically the first two years, due to the neuroplasticity of the growing brain.

How do we diagnose early? What do we look for?

In chapter two, Dr. Barbera lists out ten signs that parents and clinicians should be aware of if they observe the child falling behind in the first few years of life:

1) Pointing
   a) After about 18 months, children should be pointing on a regular basis.
2) Speech/Language Delay
   a) It is important to determine if the child has a receptive/expressive language delay, as these are frequently present in children on the spectrum.
3) Excessive Tantrums
   a) Dr. Barbera makes the point that most children have tantrums, whether or not they are on the spectrum. She goes on to state that aggression, self-injurious behavior, and crying/screaming are three behaviors to look out for.
4) Not Responding to His/Her Name
   a) After ruling out hearing loss (which is an important first step), Dr. Barbera observes that many children with autism are "in their own world" or have "selective hearing."
5) Playing Behaviors
   a) Dr. Barbera points out that by around three years of age, most children will be sharing toys, playing games, and engaging in pretend play.
6) Repetitive Behaviors
   a) Assessing for repetitive behavior can be challenging, as it can show itself in many different ways. Close observation of the child is necessary for catching this.
7) Sameness
   a) Children on the spectrum tend to respond negatively to change in their daily activities, which can cause tantrums due to increased stress on the child.
8) Sensory Issues
   a) Overreactive and underreactive responses to stimuli are commonly seen in children with autism, which can lead to tantrums or other expressive behaviors.
9) Motor Delays and Toe Walking

a) Dr. Barbera makes the point that, statistically, children with autism are more likely to take their first steps later in life, and may walk with impairments like "toe walking."

10) Imitation
    a) It is not unusual for a large delay in imitation or imitative behavior to be present in children with autism, according to Dr. Barbera.

How has COVID-19 impacted the rate of ASD?

Like the rest of the world, COVID-19 has affected the mental health of millions of people over the past few years. Every two years, the Centers for Disease Control reports on the prevalence of autism in 8-year-old children across the United States. In December 2021, the CDC released 2018 *pre-covid* data stating that 1 in 44 children are diagnosed with autism, which is an increase from the 1 in 54 number just two years prior. Data at this point for how COVID-19 is affecting the rates of autism is largely speculative, with studies currently being conducted. For further discussion on COVID-19 and autism, check out Dr. Barbera's podcast episode with distinguished autism researcher, Dr. Catherine Lord.

Here is a quick synopsis of what Dr. Lord and Dr. Barbera addressed in the episode:

- Initial pairing and testing sessions between therapist and client were heavily disrupted by the facemask protocol necessary for COVID-19. By covering part of the face, children were unable to recognize verbal cues and facial expressions from the therapist, and vice versa; which is a crucial part of ABA.
- Diagnosis shifted from in-person testing sessions to parents recording their children and sending the video in to clinicians who would conduct an assessment virtually (Programs like *NODA* and *TELE-ASD-PEDS*).
- Perri Class, M.D., published an article in the *New York Times* that addressed the difficulties pediatric clinicians have been faced with regarding the care of their patients. Dr. Class states that "because families are isolated or may not have good access to medical care, neurodevelopmental problems may be being missed in these critical early years…".
- Dr. Lord's current work is longitudinal assessment of children with autism and other developmental delays. Dr. Lord and colleagues followed their first group of subjects from 15 months old to 30 years of age, with follow-up assessments done approximately every 4 years (Lord, 2012).

How do we turn autism around?

Turn Autism Around provides strategies for both parents and medical professionals to become equipped to catch the early signs of autism and turn it around. Dr. Barbera's approach incorporates the best of

behavioral psychology and applied behavioral analysis into a condensed, easy-to-understand formula that focuses on four steps:

1) Assess
2) Plan
3) Teach
4) Evaluate

Throughout her book, Dr. Barbera covers these four steps and provides helpful tools, like the One Word x3 approach, which caters towards nonverbal children.

In her first book, *The Verbal Behavior Approach*, Dr. Barbera discusses the basics of the ABC model of ABA and the four functions of behavior; these two topics play a large part in the foundation of the Turn Autism Around approach.

TAA General Tips

Simple, practical steps to implementing positive behavior using TAA program:

- Create a safety plan for the home and frequently visited places
- Utilize techniques found throughout *Turn Autism Around*, including;
    - "Sh, label, and give" procedure: Dr. Barbera suggests telling your child to quiet down by putting your index finger over your lips, indicating the "sh" sign. After they are able to calm down, label different items that they may be interested in, give at least three seconds of quiet, and then deliver the item. Dr. Barbera stresses the importance of withholding the item during problem behaviors. Providing positive reinforcement for problem behaviors will only lead to an increase in said behavior (chapter 6).
    - Avoid time-outs/punishment: Dr. Barbera states that punishments and time-outs are reactive strategies that may lead to an increase in problem behaviors (chapter 6).
- 5 interventions to ease transitions:
    - A notifiable marker of ASD is the insistence on sameness and the difficulty with change. Dr. Barbera offers several tips on how to ease the process of change (chapter 6):
        i. Dangle the reinforcement before the problem behavior occurs
        ii. Avoid physically moving a child from one place to another
        iii. Offer choices as much as possible
        iv. Place less desirable activities between two preferred activities, and utilize schedules or timers
        v. Pair the learning table with reinforcement and avoid the word "work"
- Assessing and planning in order to desensitize difficult social situations
    - Dr. Barbera emphasizes the importance of desensitizing, or "repairing" the child in order to prepare for doctor appointments, dentist visits, haircuts, etc (chapter 13).

An In-depth Look into the Seven Areas of Focus

Dr. Barbera covers seven areas of focus that, when improved, greatly increase the quality of life for families faced with the challenges that often accompany an autism diagnosis. Rather than continue ineffective, or even counterproductive cycles, she has developed effective, gentle techniques that provide relief and progression towards more age-appropriate and neurotypical behaviors, such as sleeping through the night in his/her own bed and transitioning out of diapers. Improvement in these areas can profoundly alleviate stress associated with the social and physical ramifications of autism and create healthier family dynamics and processes.

Each of these topics requires a baseline assessment to determine the best starting point for the child and the creation of an appropriate plan.

1) Develop social and play skills

Children with autism do not always naturally develop the typical interactive skills as their neurotypical peers. They may appear to be in their own world, not play with their classmates, or not be on par with milestones such as being able to stand in a line or drink out of an open cup. Teachers may pick up on these behaviors. At times, these behaviors, as well as possible aggressive tendencies, can lead to a child needing a specific type of environment rather than the typical daycare or school. It is a good idea to assess programs to see if they best fit the child's needs.

a) Teaching eye contact:
   Lack of eye contact is common in autistic children. This skill isn't best taught directly, but can be encouraged and developed by cursory actions such as positioning yourself at eye level with the child and using visual reinforcers to encourage the child to look at or towards your face. Eye contact should not be forced, but will accompany the development of other skills.
b) Teaching pointing:
   Typically developing children should be regularly pointing by 18 months. Children with autism may instead present with "hand leading", where they attempt to get your attention by grabbing your hand instead of pointing.

   When teaching pointing, determine the child's dominant hand by testing for preference when reaching for objects. Next, introduce "touch pointing" where you hold and name the item and guide the child's (dominant) finger or hand to touch the item. Ask the child to touch the item independently, and repeat this process until they begin to understand the concept. Then you can move on to items that are farther away, with the same

process as he works towards mastery. Verbal reinforcement is very encouraging. Continue to look for opportunities to point during the day or during your time together.

c) Teaching simple greetings
Children with delays usually need to be taught this skill directly. As this concept is introduced, choose a greeting to teach. If a child is not yet verbal and repeating back your words, waving "hi" is a perfect starting point. You can gently help him wave his hand. Prepare the child to say (or wave) the greeting (She uses the example, "Let's go say hi to daddy!"). Encourage parents and siblings to return in kind at the eye level of the child. Once "hi" is mastered, "bye" can be taught with this same process.

d) Teaching pretend play and other advanced social skills
Before attempting to teach advanced skills such as pretend play, manners, sharing/taking turns, or understanding the concept of "sorry", an assessment for readiness should be considered, such as prerequisites like developed expressive and receptive language and maintaining focus on a toy for a moderate amount of time.

2) Teach talking and following directions

Babies begin to experiment with language as young as just a few months old. They babble and imitate actions as a means of learning to play. Children with autism don't make many sounds or echo words or seek the attention of adults as much through these behaviors. However, even if a child is considered nonverbal, he or she is still communicating via whatever method gets their needs met such as gestures and tantrums. What is important is for your child to be both verbal and *vocal*. Alongside the goals of teaching expressive and receptive language skills, following directions, imitating, and matching tasks work as excellent tools and are also skills that need developing. Speech instruction is found to be a very beneficial task to take place at a designated table with designated toys and learning material.

a) Pairing and reinforcement
Pairing is the concept of associating something that your child likes within the process of a goal you are trying to achieve. If the goal is for the child to learn to sit at a table for learning time, offering a preferred toy or a favorite snack or drink at the table, without requiring anything of the child or forcing the child to come or sit, would be an act of pairing. It is a very useful form of positive reinforcement to promote child engagement.

b) Sign language
Teaching sign language is an excellent precursor to vocalized language, especially if the child is having difficulty getting started with speaking. Because it increases the child's ability to communicate their needs, it can also lead to a decrease in behavioral problems or tantrums.

c) Teaching at the table
Once the child is comfortable at a table for 3 to 5 minutes, teaching items can be introduced for "table time." The child's favorite items can continue to be offered as reinforcement during instruction time. Over time, table time may actually become a reinforcer in its own right. Utilizing visual aids such as flashcards, photos, Mr. Potato

Head, toys, and books are excellent table time activities to demonstrate cause-and-effect, build imitation and echoic skills, and learn to follow directions.

d) Teaching matching
Matching can be taught with the introduction of puzzles, beginning with simple inset puzzles, or two identical sets of "first word" flashcards. Begin with only two or three and, if using pictures, use a variety of pictures from different categories. (She gives the example of a car, mommy, and a bed) Hold the item up and name it up to three times, and pair it with its matching item. Be sure to use immediate praise after correct responses.

e) Teaching imitation skills
Children typically learn language and play through imitation, but this is a missing skill for children with autism. To teach imitation, use visual prompts and coinciding verbal commands (Touch your head and also say, "Touch your head."). This can be done using simple movements of your body or everyday items like cups and spoons or small toys. Immediate reinforcement is also important here to increase the desired behavior.

f) Getting them to respond to their name
Not overusing your child's name is actually helpful when teaching them to respond to their name, as with overuse they tend to tune it out. Avoid using his name in conjunction with the word "no" or "stop." Use the child's name during activities they enjoy or with positive reinforcement. The child will begin to make positive associations with his name, increasing responsiveness.

3) Expanding language development

a) The importance of picking the right goals
Speech builds on itself, so it is crucial to not skip steps to achieve the end goal. Goals like yes/no, using pronouns, and an understanding of prepositions, are advanced and should be predicated by achieving echoic control through play and positive reinforcement.

b) Developing echoic control
Echoic control is the ability to "echo" back verbal prompts ("Say ball." and the child says "ball".). This is the most basic approach to gaining echoic control, but the TAA approach is multifaceted, intertwining mands, tacts, and echoics, or "multiple control" strategies. Learning echoic control is extremely important since so much learning is based on this method. Even if it takes time, usually children do develop echoic control skills.

c) Common mistakes in teaching conversation skills
   i) Mistake 1: Focusing on length of phrases and sentences:
   Often, "carrier phrases" are taught with sentence development to encourage longer phrasing, but this can lead to lack of spontaneous talking because the child becomes dependent on the prompts of an adult to use a full sentence instead of using the one word they can say independently.
   ii) Mistake 2: Not knowing how to deal with scripting
   Scripting is an echoic response without the child understanding what they are saying. It may make you think that their language is more advanced than it really

is. Instead of using this as proof of language development, revising the plan and setting new goals is needed.

iii) Mistake 3: Not knowing how to prevent or correct language errors
Words for items vs their functions can be confused during the language-learning process. Or perhaps similar items within the same category (pens and pencils). It can be hard to differentiate between form and function.

iv) Mistake 4: Hyperfocusing on colors and other pre-academic skills
A child with delays has less discriminatory skills, which mean it can be hard for them to distinguish more minor differences, such as the difference between the numbers six and nine, or the colors orange and red. Other skills are needed before moving on to this more advanced skill.

v) Mistake 5: Focusing too much on talking while neglecting other areas
While speaking is certainly an important function, so are other areas such as hygiene and self-care, listening, and leisure activities. Learning how to advance in these areas should not be overlooked because of the focus on verbal skills.

d) Preventing and fixing errors
   i) Step 1: Start with an assessment, plan, and a goal selection or revision
   ii) Step 2: Use your child's strengths to develop more advanced language
   iii) Step 3: Select activities and targets carefully, and use errorless teaching and transfer trials
   Errorless teaching refers to giving your child as much help as they need, meeting them at their level, instead of teaching them concepts that are too advanced. It is about error prevention to reduce confusion and frustration. This may mean guiding the child to the exact answer until they grasp the concept.
   Transfer trials is the act of transferring a concept from one mode to another, such as from visual to verbal. This method can be used to fade out the use of prompts and also to teach them the more advanced skills.

e) Video modeling
   Dr. Barbera has found video modeling to be extremely effective in the use of developing language skills. It is an evidence-based method in which you record yourself teaching a skill and having the patient watch the video.

4) Solve picky eating

According to Dr. Barbera, "feeding and talking are intricately related" (p. 149). She cites a study that showed that "children with autism remained highly selective to carbs, white foods, and crunchy food" (p. 149). Addressing picky eating as soon as possible is important, because this doesn't tend to get better with age and actually, may become more difficult to overcome. It is always a good idea to seek professional counsel when it comes to the diet and feeding of your child.

a) Food journals and food lists

Creating lists of foods that are easy, medium, and difficult to get your child to eat is helpful to establish a baseline and goals.

b) Drinking interventions
The ability to suck through a straw is a developmental milestone that is a part of other oral motor skills, including the ability to form and articulate words. Sippy cups should be transitioned out as soon as possible, replaced by cups with straws or open cups. Offer water throughout the day and consider places like the bathtub to practice these new skills to offset the mess of spills.

c) Weaning off bottles and pacifiers
Much like sippy cups, the extended use of bottles and pacifiers can be linked to delayed language development and significant dental repercussions. A gradual approach to weaning is suggested, first by determining when the greatest need for the item is (such as bedtime), then setting boundaries around these needs, gradually tapering off. Using positive reinforcement is often helpful. This is challenging, but creating boundaries for the child will ultimately lead to successful weaning.

d) Feeding interventions
It is helpful to designate meal times and snack times, limiting grazing so they will be hungry for their meals, which are where they will have the opportunities to be introduced to new foods. She offers some useful strategies such as removing foods from their packaging to avoid brand recognition, introducing as much nutritious food as possible (beginning with the ones already best tolerated), and then moving on to medium foods. Presenting them in different forms and shapes can also be helpful. Using negative language surrounding feeding should be avoided and patience should be the rule.

e) Using utensils
Working on feeding supersedes learning to use utensils, but when they are ready, teaching by guiding their hands, beginning with forks and spoons and then moving on to cutting skills.

5) Solving sleep issues

Sleep-deprived parents will do whatever it takes to settle their children at night, even if it is ultimately to their detriment and not beneficial, in the long run, to the child. Teaching children to sleep through the night in their own bed is essential to proper rest for the entire family. This can be accomplished with some boundaries and consistency. First, assess the current sleep scenario and establish a sleep plan. This can involve many points of considerations such as home safety, getting rid of pacifiers or bottles, and appropriately responding to your child during night wakings.

a) Bedtime routine checklist
Begin by choosing a way to reinforce good sleep habits that fits your child best. Choose one person to lead bedtime every night during the course of the transition, so that everything can be done in exactly the same way each night. Write out a checklist of

everything to be done in the bedtime routine and follow it each night. Within a few nights, progress, if not complete mastery, is reported.

b) Assess what works
Keeping a chart of the progress of the bedtime routine is helpful to gather data and assess what is working and what needs to be adjusted.

6) Dispose of diapers

Children with autism are often not potty-trained by the age of 5, unlike what is typical for their developing peers. The continued use of diapers is stressful, difficult to navigate in life outside the home (including school), and expensive. Approaching potty-training from an angle that will keep it as low stress as possible is often most effective, as well.

a) Create a plan
Determine if your child is ready for potty-training. This may look like staying dry for 2 hours at a time, not being ok with staying in a dirty diaper, and having regular bowel movements. Dr. Barbera also includes a readiness checklist from Dr. Mark Sundberg on page 186. Assess for met milestones and set upcoming goals. Allow two weeks to implement your plan, which means you will need to be able to spend a lot of time at home during this period.

b) Pairing the potty and bathroom
Use positive reinforcement to create a positive connotation with the bathroom.

c) The right wording
Choose words for naming bathroom-related items (such as toilet vs. potty) and stay consistent with them.

d) Schedule
Take your child to the bathroom at regular intervals, every 30 to 60 minutes to start, for 5 minutes at a time. Using a timer can be a way to indicate to your child each time.

e) Materials and reinforcers
Depending on the size of your child, you may need a child-size potty, a stool, or other tools that will make the process easier for your child and less messy. Use positive reinforcement to encourage the desired behavior.

f) Encourage independence
Allow your child to perform as much of the process as he is capable of (pulling down pants, sitting, washing hands, etc.). As progress is made, reduce the amount of scheduled bathroom times and instead allow your child to prompt the timing.

g) Nighttime training and post-training accidents
Nighttime training may take longer than daytime. Continue the use of nighttime diapers for a little while. When he or she begins to wake up dry for about a week, attempt underwear overnight. Do expect accidents. To increase success, reduce liquids before bed and direct the child to the bathroom directly before bed and directly after waking.

7) Desensitize doctor, dentist and haircut visits

These visits can be distressing for autistic children, and in turn, for parents. Some preparation can help make these visits less stressful. We can desensitize the child to these visits (since it is often sensory and communication issues that cause the distress) by pairing or repairing the child to that environment. Pairing things they may experience during these visits (such as someone touching their hair) with a comfortable environment (such as home) first, will help tremendously.

a) Preparing for haircuts
Role play "haircut time" at home, detailing every step that will be taken in the real salon. Notice what steps cause discomfort to your child and work through these slowly, allowing more time for acclimatization. Keep a lighthearted and positive attitude. When your child is successfully sitting through haircut time at home, find a salon that is kid-friendly and try to book with the same stylist each time.

b) Teaching to take medication
Disguising medications in foods can be an option to facilitate medicine administration, but when that is unsuccessful, training to swallow pills is the next step. Beginning with a grain of rice or very small bean, model swallowing it with water and encourage them to imitate your behavior.

c) Dentist and doctors visits
These can be difficult to desensitize to, but using the same method of recreating the steps that will happen prior to the visit is helpful (such as an ear exam). If the child has been to these places before, try to remember what caused them distress in the past and how those experiences can be repaired.

Pairing and repairing is an integral, highly-successful strategy in Dr. Barbera's Turing Autism Around program. She offers some general tips for optimal success.

- Make the pairing or repairing process very gradual and slow
- Fill the process with positive words and reinforcers such as desired foods and toys
- Encourage, but do not force, compliance with next steps
- Keep exposing until acclimation is successful
- "Any person, place, object, procedure, or activity can be paired or repaired with time, practice, and patience" (p. 211).

To learn more about how to effectively turn autism around, visit Dr. Barbera's website, https://marybarbera.com/, where she has books, workshops, podcasts, and more.

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