Behaviors of Concern: Is it Autism? Does it Matter?

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Despite dramatic evidence as to the power and long-term benefits of early intervention services in children with developmental and behavioral challenges, the rate of screening for these conditions in early childhood remains meaningfully low.

This is especially true for Autism Spectrum Disorder (ASD)

The earliest symptoms, while subtle, are often present in the second year of life.

As such, formal screening with an ASD-specific instrument is recommended by the American Academy of Pediatrics (AAP) for ALL children at 18 and 24 months of age.

Yet recent (2016) studies confirm trends revealed by the 2011 National Survey of Children’s Health that only 20% of eligible toddlers are screened for ASD as per guidelines

What is Autism?

• *Autism* is just one of many words used to describe a wide range – or “spectrum” – of certain atypical behaviors and patterns of social interaction, communication and behavior.

• While these have had many different names over the years, children and adults who demonstrate these in some form or combination are now referred to as having Autism Spectrum Disorder (ASD).
How Common Is ASD?

• The rate of autism diagnoses among American children more than doubled throughout the 2000s.

• However, a 2016 analysis from the US Centers for Disease Control and Prevention may indicate the rise in diagnoses may finally be leveling off.
What’s the Reason For this Increase?

• It is very clear that one of the major drivers of the increase in ASD diagnosis is better awareness of the characteristics of the condition and more specific and sensitive screening and diagnostic tools
  – In the past many children with autism were undiagnosed or seriously misdiagnosed.
  – ASD includes more of the spectrum than ‘autism’ alone
ASD is a Complex Condition

• However, better identification is only one piece of the puzzle for the increase in autism diagnoses
  – Many researchers are actively looking into genetic, biological and environmental factors that could affect both risk for and incidence of autistic spectrum disorders.

• For today, we are going to focus on the issue of identifying and helping those children who have the condition.
What does ASD look like?

• People with ASD have difficulties with...
  – Communication
    • Using and understanding language, non-verbal behavior and interpreting cues and symbols in their environment
  – Social interaction
    • Making connections, relationships, understanding intents, desires, shared experience
  – Behavior
    • Emotions management, frustration tolerance, repetitive actions, sensory problems
If You’ve Seen One Case of ASD...

• The way these problems show themselves in any individual is affected by their developmental stage and personal temperament.
  – People who have ASD can have symptoms which can range from mild to severe.

• In some children, ASD may also be linked to other medical problems, developmental, behavioral and educational disabilities.
How Can We Tell If A Child Has ASD?

• Looking back, some parents of children with autism say they saw signs as early as 6 months, but most of the time experts can’t make a definite diagnosis until around age 2.
  – That’s because their needs be a certain amount of brain development before we can see if anything is truly a pattern in the child’s life

• The American Academy of Pediatrics recommends routine screening all children at 18 months and again at 24 months of age
“Child Find” Delays Are Common in ASD

• However, a 2016 Centers for Disease Control report reveals that on average children are not being identified until after age 3
  – Median age at first comprehensive evaluation 3 years, 4 months
• Further lags between assessment and diagnosis adds an additional 10 months delay
  – Median age at diagnosis 4 years, 2 months
– Delays are longer for children with milder symptoms
  • Median age 6 years for “Aspergers Syndrome

Diagnostic Delay = “Treatment Opportunity Loss”

- “Child Find” delays create an average of 2+ years of treatment opportunity loss for children with ASD
  - Additional delays driven by “wait and see” attitudes
- Unnecessary delays reduce the opportunities for children and families to stabilize and improve long-term function and success for the child and the family

Why Worry About Treatment Opportunity Loss?
Because Early Intervention Works

• Studies on children with ASD are very clear:
  – Starting as early as 18 months of age with **intensive behavioral therapy** decreases core symptoms and improves cognition, language and adaptive skills
  – Early intervention can have powerfully positive effects on a child’s behavior, capacity for communication, relationships with family and friends, their performance at school and their interactions with other children.

• Children who received early intensive behavioral intervention better integrate into school and maintaining gains in adaptive behavior over long periods of time.

• Some have even progressed to optimal outcomes, where they no longer require any special services or supports.
Two Ways To Improve Access to Treatment

• Routine screening
  – The American Academy of Pediatrics recommends screening all children at 18 months and again at 24 months of age

• “Raise a red flag” around behaviors of concern!
  – Watch and assess developmental skills progress in the first two years of life
What are Behaviors of Concern?

• Lack of acknowledgement of others
• Impaired communication and speech
• Dysfunctional object play
• Lack of joint attention
• Poor imitative skills
• Poor behavior regulation
Most often, diagnosis is driven by parental concerns over their child’s behavior, language or skills.

- In interviews with parents of ASD-diagnosed children ages 6-11
  - Half were referred to a specialist when they expressed concerns about their child’s behavior or learning
  - HOWEVER, the other half were told by their providers that:
    - Their child “might grow out of it”
    - It was “too early to tell” if there was a developmental concern,
    - The behavior was normal or suggested they talk with the school.

- Parents, who desperately want to hope for the best for their child, will internalize these informal reassurances, which may be to their child’s long term detriment
Even experts can’t tell if a child has autism simply by looking at them

• In one study, expert raters missed 39% of known cases during brief (10 minute) informal observations meant to model a typical office visit
• The authors concluded that brief clinical observations may not provide enough information about atypical behaviors to reliably detect autism risk and support appropriate referral patterns
What does this mean?

FORMAL SCREENING IS IMPORTANT
Screening is Not The Same As Diagnosis

• Screening is a brief, but formal, standardized evaluation which helps determine whether -- or not -- more intensive assessment needs to be undertaken.
  – Screening looks at the child’s social and emotional communication, receptive and expressive speech, and symbolic
• Screening can be performed at any age when parents or teachers identify behaviors of concern.
• Screening is OBJECTIVE....it’s not just your opinion.
• The American Academy of Pediatrics recommends screening for all children for autism at age 18 months, and again at 2 years of age.
Routine Screening

• The most common validated screening tool is the M-CHAT-R™ – Modified Checklist for Autism in Toddlers, Revised
Please answer these questions about your child. Keep in mind how your child usually behaves. Circle “YES” or “NO” for every question. There are no right or wrong answers. If you have seen your child do the behavior sometimes but he or she does not usually do it, then please answer “NO”.

<table>
<thead>
<tr>
<th>QUESTIONS</th>
<th>CIRCLE ONE</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. If you point at something across the room, does your child look at it? (FOR EXAMPLE, if you point at a toy or an animal, does your child look at the toy or animal?)</td>
<td>YES</td>
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<tr>
<td>2. Have you ever wondered if your child might be deaf?</td>
<td>YES</td>
</tr>
<tr>
<td>3. Does your child play pretend or make-believe? (FOR EXAMPLE, pretend to drink from an empty cup, pretend to talk on a phone, or pretend to feed a doll or stuffed animal?)</td>
<td>YES</td>
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<tr>
<td>4. Does your child like climbing on things? (FOR EXAMPLE, furniture, playground equipment, or stairs)</td>
<td>YES</td>
</tr>
<tr>
<td>5. Does your child make unusual finger movements near his or her eyes? (FOR EXAMPLE, does your child wiggle his or her fingers close to his or her eyes?)</td>
<td>YES</td>
</tr>
<tr>
<td>6. Does your child point with one finger to ask for something or to get help? (FOR EXAMPLE, pointing to a snack or toy that is out of reach)</td>
<td>YES</td>
</tr>
<tr>
<td>7. Does your child point with one finger to show you something interesting? (FOR EXAMPLE, pointing to an airplane in the sky or a big truck in the road. This is different from your child pointing to ask for something [Question #6])</td>
<td>YES</td>
</tr>
<tr>
<td>8. Is your child interested in other children? (FOR EXAMPLE, does your child watch other children, smile at them, or go to them?)</td>
<td>YES</td>
</tr>
<tr>
<td>9. Does your child show you things by bringing them to you or holding them up for you to see - not to get help, but just to share? (FOR EXAMPLE, showing you a flower, a stuffed animal, or a toy truck)</td>
<td>YES</td>
</tr>
<tr>
<td>10. Does your child respond when you call his or her name? (FOR EXAMPLE, does he or she look up, talk or babble, or stop what he or she is doing when you call his or her name?)</td>
<td>YES</td>
</tr>
<tr>
<td>11. When you smile at your child, does he or she smile back at you?</td>
<td>YES</td>
</tr>
<tr>
<td>12. Does your child get upset by everyday noises? (FOR EXAMPLE, does your child scream or cry to noise such as a vacuum cleaner or loud music?)</td>
<td>YES</td>
</tr>
<tr>
<td>13. Does your child walk?</td>
<td>YES</td>
</tr>
<tr>
<td>14. Does your child look you in the eye when you are talking to him or her, playing with him or her, or dressing him or her?</td>
<td>YES</td>
</tr>
<tr>
<td>15. Does your child try to copy what you do? (FOR EXAMPLE, wave bye-bye, clap, or make a funny noise when you do)</td>
<td>YES</td>
</tr>
<tr>
<td>16. If you turn your head to look at something, does your child look around to see what you are looking at?</td>
<td>YES</td>
</tr>
<tr>
<td>17. Does your child try to get you to watch him or her? (FOR EXAMPLE, does your child look at you for praise, or say “look” or “watch me”?)</td>
<td>YES</td>
</tr>
<tr>
<td>18. Does your child understand when you tell him or her to do something? (FOR EXAMPLE, if you don’t point, can your child understand “put the book on the chair” or “bring me the blanket”?)</td>
<td>YES</td>
</tr>
<tr>
<td>19. If something new happens, does your child look at your face to see how you feel about it? (FOR EXAMPLE, if he or she hears a strange or funny noise, or sees a new toy, will he or she look at your face?)</td>
<td>YES</td>
</tr>
<tr>
<td>20. Does your child like movement activities? (FOR EXAMPLE, being swung or bounced on your knee)</td>
<td>YES</td>
</tr>
</tbody>
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A Positive Screening Needs More Investigation

• Once a child is identified for further evaluation, a more detailed process of testing their social and emotional communication, receptive and expressive speech, and symbolic behavior will be required to confirm the diagnosis of Autism Spectrum Disorder.
Diagnostic Process

• Diagnosing autism spectrum disorder (ASD) can be difficult, since there is no medical test, like a blood test, to diagnose the disorders.
• Diagnosis is accomplished through a comprehensive evaluation.
  – Doctors take a detailed look at the child’s behavior and development to make a diagnosis as well as search for complicating factors.
Not All Symptoms = Autism

• There are significant overlaps in symptoms and behaviors
  – Genetic disorders
  – Anxiety
  – Depression
  – Attachment disorders
  – ADHD
  – Epilepsy
  – Tics

• The diagnostic process considers, differentiates and eliminates possible reasons
Diagnostic Evaluation

- Structured testing of a child’s behavior and development
  - ADOS, Vineland, ADI-R
- Interviewing the parents
- Input from teachers
- It may also include a hearing and vision screening, genetic testing, neurological testing, and other medical testing.
With a confirmed diagnosis of ASD.....

“Early Intensive Behavioral Intervention” (EIBI) is the best approach to therapy
What do we mean by EIBI?

Therapy based in Applied Behavioral Analysis (ABA)
What is ABA?

Evidence-Based Treatment

• ABA is a scientific discipline, not just a single therapy.
  – The science of ABA can be used to achieve client-specific goals for communication, social interaction and behavior change.
• When applied in a child-centered and individualized manner, the principles of ABA have been proven to
  – Powerfully enhance the growth and development of children with autistic spectrum disorder and help them become the best they can be and
  – Significantly improve the opportunities for success and quality of life both for the children with autism and their families
The Evidence is Clear

• While the academic community still continues to study and gather evidence on ABA-based therapies, from a practical perspective ABA-based therapies are the most successful method of treatment for children with Autism Spectrum Disorder (ASD).

• The comparative effectiveness literature is clear that non-ABA approaches to autism intervention just don’t work as well, or have as sustained positive effects, as ABA-based therapies.
  – Extensively researched for more than 30 years, ABA is one of the most successful methods of treatment for children with Autism Spectrum Disorder (ASD).

• It has the broadest endorsement across the medical and educational communities, including the American Academy of Pediatrics, the US Surgeons Generals Office, the Centers for Disease Control and The American Association on Intellectual and Developmental Disabilities.
  – Judicial review as ‘medically necessary”
  – State-mandated insurance waivers
What Can ABA Do?

• Depending on their needs, ABA can help children increase and maintain communication and language, intellectual function, and socially important behaviors, including attention, situational awareness, adaptive skills, interaction and relationship management and academic performance.

• At the same time, ABA-based therapy can help reduce or eliminate disruptive, destructive, aggressive, or significantly repetitive behaviors, as well as family stress and conflicts.
The Goals of ABA

• Optimal outcomes, meaning the child reaching the highest level of function possible for them
• Support for a child’s ongoing developmental and educational progress
• Sustaining positive and productive behaviors, communication skills and patterns of social interaction once ABA therapy is stopped
• Developing skills that are generalizable to new situations outside those in which they were taught
How Does ABA Work?

• An ABA treatment plan is developed based on two components designed to provide a baseline and benchmark to shape the treatment plan and track process

  1. A formal assessment using a validated autism tool such as the Verbal Behavior Milestones Assessment and Placement Program (VBMAPP) or the Assessment of Basic Language and Learning Skills (ABLLS)

  2. A comprehensive functional assessment, which is designed to identify child-specific needs and challenges and individualized goals for a child’s developmental needs and capacity to function and interact in their world.

• From the information gathered from these components, a set of goals and treatment plan is developed and the work begins between the child and their treatment team, which usually consists of a Board Certified Behavior Analyst (BCBA) and a behavior technician.
Functional Assessment

For me....Deadlines = Doughnuts

Using Functional Behavior Assessment as a Foundation for Positive Behavior Support Plans for Individuals with Autism

Richard J. Cowan, Ph.D., NCSP
Kent State University
Ongoing Planning

• Children are regularly re-assessed and their treatment plans updated to take advantage of their new skills to further enhance their skills and behavior.
• Formal assessment track progress at least every 6 month
Parents Have a Critical Role

• A major component of ABA is a high level of parental involvement, both in terms of identifying treatment goals and being engaged in the process of therapy.
Success Factors in ABA

• Studies have been very clear that continuity and intensity of services are important factors in achieving optimal outcomes for children and their families.
  – It is well established that the gains achieved are directly related to the intensity of therapy.
• Many studies have revealed that children who receive less than 20 hours a week -- or who do not keep to a regular schedule -- do not progress as well as children who regularly receive 25-40 hours of ABA therapy per week.
• Children with severe conditions or families that have ambitious goals for improvement of function and relationships should consider high intensity (40 hours per week) therapy.
Outcomes of ABA-based Therapy

• The goals of ABA go far beyond simply acquiring skills or eliminating disruptive or disturbing behavior, they are about shaping the person who will emerge from childhood.

• ABA Treatment Plans are designed on a “continuous improvement” model, in which each achievement or gain is then factored into a next set of goals designed to take the child to the next level and the next and the next.
Optimal Outcomes

• In some cases, intensive ABA-based therapy has resulted in children “testing out” of the autism diagnosis, achieving function in the average range on diagnostic and other assessments!
• Many children who receive early and intensive ABA do not require special support services from the educational system later in life.
Sometimes “More” is Not “Better”

- Studies compared ABA-exclusive intensive behavioral intervention with a number of “mixed” (sometimes called ‘eclectic’) approaches, including:
  - *Autism-specific educational programming* in special education settings by credentialed special education teachers and paraprofessionals, which included, among other things, elements of ABA
  - *Generic ‘special needs’ educational programming* by credentialed special education teachers and certified speech and language pathologists
- In all the initial studies -- and follow-up studies with the same children 2 and 3 years later -- the children receiving ABA-exclusive behavioral interventions had significantly more improvement in cognitive, language and adaptive skills than either of the ‘mixed’ approaches
  - There were also twice as likely to score in the normal range on measures of cognitive, language and adaptive functioning as children who received with form of the “mixed” forms. of intervention.
The Type of Therapy Matters

• In addition, these studies also showed that the type of therapy is as important as intensity of therapy.
  – “Mixed” treatments, even when provided more than 30 hours per week did not prove very effective.
• The idea that virtually any intervention can produce meaningful benefits for children with autism if it is provided intensively is just not supported by the research.


Role Of Early Childhood Educators

• Educators and other educational program staff are in a unique position to experience a child’s behavior, demeanor and temperament independent of the characteristics, customs and conventions of their family life.
  – As such, they are often able to identify patterns of conduct, communication or interaction which indicate potential risks to development and learning.

• These can be hard conversations to hold: Every parent or caregiver has an “imagined future” for their children, and it can be incredibly stressful to be confronted with information that conflicts with their idea of who their child is or may become.

• These conversations come in two types:
  – Worried Parent Expressing Concern to Teacher
  – Worried Teacher Expressing Concern to Parent
What Your Center Can Do?

• Make your policy --and commitment to children --clear
• Manage parental expectations upfront
• Share your knowledge
• Build bridges and add value to the pediatric community
Supporting An Imagined Future

• Every parent or caregiver has an “imagined future” for their children, and it can be incredibly stressful to be confronted with information about a child that conflicts with your sense of who they are or what their future might bring.

• The key here is to be brave and realistic so that your own fears don’t interfere with your child getting the proper evaluation and, if appropriate, services that will allow them to becoming everything that had been imagined for them.
a free resource sponsored by Centria Healthcare, a national provider of Autism Services to children and families.
ASDAccess: Parent Handouts

- **Frequently Asked Questions About Autism and ABA-based Therapy**
  - *Simple answers to 10 common questions parents should ask when their child has behaviors of concern or has been diagnosed with ASD*

- **Child Development Milestone Charts (9/12/18/24 months)**
  - *Four separate charts describing neurotypical behavior in four common categories (social/emotional; language communication; cognitive development; motor skills) and an list of behaviors of concern at each age*

- **Should You Be Worried About Autism? Probably Not.**
  - *A reassuring handout for parents of newborns or infants up to 12 months of age; serves as anticipatory guidance for autism screening at 18 and 24 months of age*

- **My Child Seems Normal, Why Are You Testing?**
  - *A brief explanation of why developmental screening is important*

- **Child Screening Checklist For Communication And Social Interaction**
  - *A non-threatening presentation of the M-CHAT-R™ (Modified Checklist for Autism in Toddlers-Revised), a validated autism screening tool*

- **Why ABA? Should We Do More?**
  - *A review of the medical literature on ABA-based interventions*
ASDAccess: Professional Resources

• **A Pediatric Practice Guide to Managing Screening and Referrals for Autism**
  – A brief outline of a simple and non-disruptive system and steps for pediatric practices to increase their capacity to meet AAP guidelines for autism screening in toddlers

• **Early Identification: How Pediatricians, Early Childhood Educators and School Nurses Can Work Together Successfully**
  – A short essay on the power of collaboration between pediatricians, early childhood educators and school nurses in the process of early identification, screening and referral of children with behaviors of concern

• **Referral Form: Early Childhood Educator to Pediatrician**
  – A simple form for early childhood educators to use with parents and pediatricians to refer a child with behaviors of concern

• **Talking to Parents About Behaviors of Concern: A Guide for Educators and School Nurses**
  – A brief review of how to work with parents when you have concerns about their child’s behavior

• **Center/School Policy on Identifying Behaviors of Concern**
  – A draft statement to share with parents

• **Scoring the Child Screening Checklist For Communication And Social Interaction**
  – The instructions for scoring the M-CHAT-R™ validated autism screening tool
ASD Access: Services

• Autism Care Coordination Services
  – A no-cost/ no-obligation program providing care coordination and navigation services to families to help manage the process of ASD screening, assessment, diagnosis and, if appropriate referral for early intensive behavioral intervention services for their patients.
Thank You

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OR CALL CENTRIA AUTISM SERVICES
1-855-77-AUTISM