Successfully Engaging and Treating Individuals on the Autism Spectrum

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Financial Disclosures

I have no financial relationships to disclose.

Objectives

- Provide practical guidance for healthcare providers (HCPs) to successfully engage people with ASD and their families.
- Encourage maximal inclusion of people with ASD in healthcare encounters across the lifespan.
- Promote awareness of the challenges and unmet healthcare needs of this vulnerable population.
- Explore multi-disciplinary community action.

A Memorable Experience

Recall a memorable experience/encounter you've had with a person on the autism spectrum...

Autism Spectrum Disorder (ASD)

- A group of neurodevelopmental disorders coalescing impairments in communicative abilities, social functioning, and rigid/repetitive behaviors.
- 1 in 68 school-aged children - IDENTIFIED.
- Causes significant communication
  - social and
  - behavioral challenges
- Learning, cognitive, and problem-solving abilities of people with ASD comprise broad continuum.

ASD Information

- ASD diagnosis now comprises:
  - Autistic disorder,
  - Pervasive Developmental Disorder not otherwise specified (PDD-NOS), and
  - Asperger syndrome.
- Lack of self-perceived HCP competency reported.
- Improvements needed to effectively identify and care for people with ASD.
First Signs

- Changes in emerging behaviors, and structural brain changes have been documented in infants by 6 months of age.
- The ASD “diagnostic odyssey” from initial concern to diagnosis is complicated for children and families.
- Long waitlists increase anxiety and valuable intervention time is lost.

ASD Signs and Symptoms

- Lack interest in others and difficulty relating to them (absence of joint attention).
- Avoidance of eye contact.
- Failure to point at objects to convey interest or to look at objects when others point at them.
- Preference for solitude.
- Inability to empathize.
- Difficulty conveying personal needs and desires.
- Exhibition of unusual reactions to sights, smells, tastes, textures, or sounds.
- Inability to engage in pretend play.
- Preference not to be touched or only on one’s own terms.
- Appear unaware when others speak to them and/or hyper attentive to other sounds.
- Have difficulty initiating play/interactions.
- Repeat or echo words or phrases, or repeat words or phrases in place of normal language (scripting).
- Display restricted, repetitive actions.
- Difficulty navigating routine changes.
- Loss of skills previously attained (regression).

Early Intervention Developments

- The vast majority (87 percent) prior to age 3 had developmental concerns noted in their educational or medical records.
- Less than half the children identified with ASD (43 percent) received comprehensive developmental evaluations by age 3.

Early Intervention is Key

- ASD can be reliably diagnosed by age 2.
  - Greater opportunities for intervention to support improvements in function and quality of life.
- Effective interventions at earliest possible age
  - Modifies early experiences when brain is most pliable.
  - Alters cognitive organization to enhance learning.

Autism Ambassador

- https://www.youtube.com/watch?v=1qMAMp8iE
Thinking Upstream

Common Community Resources

- Options and resources available at 3 years old (vary by State)
  - Speech Therapy
  - Play Therapy
  - Occupational Therapy
  - Nutritional Services
  - Applied Behavior Analysis
  - SCI non-profits
  - HeadStart
  - Special Education (ARDs, 504s)
  - Classroom accommodations
  - Peer-based extracurricular activities

Best Practice Next Steps

- Approach concerns rather than avoid!
- ASD is evolving from a lifelong condition with a very poor prognosis to one in which significant neuroplasticity gains may be realized.
- Decades of research reveal early intervention services may greatly improve a child’s development. To ensure a child reaches his/her full potential, it is critical to secure help immediately.
- Advances in genetics and neuro-imaging offer detection vehicles prior to the syndrome becoming fully manifest.

Universal Autism Screening

American Academy of Pediatrics (AAP) recommended developmental screening using a validated screening tool at 9-, 18-, and 24- or 30-month well child visits, with special attention to subtle red flags in infants who have sibling(s) with ASD.

ASD specific screening using a validated tool at the 18- and 24-month visits.

Scheduling a targeted clinic visit when PCP or parent concerns remain after a negative screen and acting quickly on a positive screen or in the presence of two or more ASD risk factors with referral for formal ASD evaluation and/or early intervention.

Absolute Indications for ASD Diagnostic Referral

<table>
<thead>
<tr>
<th>Behavior Indicator</th>
<th>Referral Time Frame</th>
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<tbody>
<tr>
<td>No gesturing (waving bye-bye and pointing)</td>
<td>By 12 months</td>
</tr>
<tr>
<td>No babbling</td>
<td>By 12 months</td>
</tr>
<tr>
<td>No single words</td>
<td>By 16 months</td>
</tr>
<tr>
<td>No spontaneous (excluding echolalia) two word phrases</td>
<td>By 20 months</td>
</tr>
<tr>
<td>Any loss of language or social skills (regression)</td>
<td>Any age</td>
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Appropriate Action

The CDC directs concerned parents to their child’s HCP first. If the HCP is concerned, or if the parent is still concerned, a referral to a specialist who can complete an in-depth evaluation and make a diagnosis should be placed. These credentialed professionals include:
- Developmental Pediatricians
- Child Neurologists
- Child Psychologists or Psychiatrists

Getting Help for Children

Simultaneously, parents should be directed to the State’s public early childhood system to request a free evaluation. This call does not require a HCP referral or a medical diagnosis.
- For children under 3 years of age, contact the local early intervention system.
- For children 3 years or older, contact the local public school system.

Unsure who to contact? Call the Early Childhood Technical Assistance Center (ECTA) at 919-962-2001 or visit: http://ectacenter.org/contact/619coord.asp

Early Action for Suspected Autism

Impact on Healthcare Provision

- Gaining Attention:
  - Influence of healthcare contexts and practices engendering manifestations of behavior and socio-communicative challenges.
  - Further research is needed to discern effects of socio-communicative and sensory impairments evident in ASD on healthcare delivery.

A Different World

"It is too easy to get frustrated and be dismissive of some of the difficult autistic children, because they are running around the office more, they may be more destructive. It’s hard, very hard to do an exam, you don’t know how far you are getting through.” …

A Different World

"They have a logic going on in their own brain, interpreting the world in a different way, speaking a different language. So the burden is upon me to understand them as much as it is for them to understand our world. It is not about decreased intelligence, it’s a different world.” – Dr. Taketa
Enacting Competence

- HCPs interactions with typically developing children with a chronic illness have been linked to parent adherence to prescribed treatments and care satisfaction.
- Families of those with ASD highly value rapport build with HCPs, with emphasis on visit greetings.

Practical Tips

- Call the person by name
- Position yourself to their eye-level
- Engage the person whether you perceive they are unable or able to participate
- Foster opportunities for the person with ASD to safely practice navigation of societal demands

Make Appointments Meaningful

- Arrange an informal trip prior to an actual trip (graduated exposure).
- Take pictures of key facility areas, equipment, and healthcare staff.
- Allow the person with ASD to watch a family member undergoing a similar exam.
- Inform staff of patient condition and encourage patience.

Appointment Tips

- The first or last appointment of the day is ideal.
- Ask about health care history and prior health care exposures.
- Allow caregivers to stay in the room if possible.
- Allow extra time to accommodate any additional patient needs when possible.

Interaction

- Explain what you will be doing prior in initiation of any exam/procedure.
- Show the person the equipment and let them touch it.
- Provide a picture illustrating what will happen.
- Avoid extra language – Less words is better!
- Enlist caregiver/supporter help when possible as needed.

Communication

- Speak in short sentences with clear, simple language.
- Use concrete, literal language.
- Provide a choice if possible.
- Set up a contingency (First, then ___)
- Ask for specific information.
- Use an intraverbal fill-in if appropriate.
- Give direct requests.
- Avoid figures of speech, metaphors, idioms, words with double meaning or irony.
- Gestures, body language and facial expressions may not be understood.
Modes of Communication

- Some patients may understand spoken language, but not be able to speak.
- Others may speak fluently but not be able to accurately process auditory information, or may simply repeat words he/she has heard.
- Use of supporting or alternative communication:
  - Picture-based systems, text-based systems, sign language, or other signs or behaviors.
  - These devices may be stand-alone or exist as programs on tablets, smartphones, or paper notes.

Sensory Guidance

- See the person in a quiet room if possible.
- Use natural light or dim fluorescent lighting if appropriate.
- Encourage only one person to talk at a time.

Autism Sensory Simulation

- https://www.youtube.com/watch?v=l4_dOaroG

Autism Sensory Kit (ASK)

- Awareness tool to help calm situations and give first responders confidence when interacting with a person exhibiting signs of ASD

ASK Contents

Each bag includes:
- 10 inch tablet
- Noise canceling headphones
- Ear buds
- Sun glasses
- Ball cap
- Communication cards
- White board
- Large plush towel
- Chewy tube
- Variety of fidget toys
Patient Response

- Eye contact may be lacking, especially in distressing situations.
- Extra time to process information may be required.
- Never assume a non/minimally verbal person does not understand what is being said.

Patient Response

- Expect YOU to understand what they are thinking.
- Stimming (pacing, hand flapping, fidgeting or rocking)
  - Do not assume the patient is inattentive or distracted
  - Often used to cope with distress
- May invade personal space or require increased personal space.

Getting Help for Adults

- Under the Americans with Disabilities Act, HCPs must accommodate the specific needs of patients with ASD.
- Use individualized strategies to address limitations of patients with ASD that may contribute to healthcare barriers.
- Persons with ASD may find it difficult to request special accommodations. The Autism Healthcare Accommodations Tool (available at http://www.autismandhealth.org) may help patients with ASD create personalized reports for HCPs.
- Proactive responses to accommodation requests save time and resources, improve therapeutic relationships, facilitate effective healthcare and help improve health outcomes.

The Power of Pairing

- Pairing before demands are placed.
- A process of building or maintaining professional rapport. Often begins with intentional interest in what the patient enjoys and making that available to them on a non-contingent basis (for FREE). Should start off with low demand and high reward.
- Specify reinforcer in the medical record.
- Note anything the person with ASD finds aversive.

Remember the A-B-C's

A. Antecedent: Preceding event
B. Behavior: Response to situation/stimulus
C. Consequence: Result/effect of action/condition

A-B-C's of Behavior

- Every behavior has an antecedent and a consequence. These particular variables maintain behaviors.
- Think of behavior in terms of “why” it’s occurring as opposed to “what” the behavior is.
- All behavior serves a function.
Four Functions of Behavior

1. Access to tangibles, activities, attention etc (from someone)
2. Escape (from someone or something someone is imposing)
3. Produce sensation (alone)
4. Remove sensation (alone)

Challenging Behavior

- Most medical exams and procedures are seen by patients as “demands” and are under conditions that are unusual or unfamiliar. This “tips the scale” in the direction of escape.
- Antecedent strategies increase the likelihood that patients will comply with the “demands” of the exam or procedure and refrain from problem behavior to attempt escape.
- Use behavior specific praise.

Challenging Behaviors

- Challenging behaviors are:
  - More difficult to overcome when allowed to persist
  - May eclipse more promising behaviors
  - Potential giftedness and strengths are less likely to be identified and refined with delayed or no behavioral interruption

Pharmacology

- Medications are often part of a comprehensive ASD treatment plan.
- Generally aimed at decreasing problem behaviors rather than treating core underlying ASD symptoms.
- Start low
- Collaborate with specialists
- Watch out for polypharmacy

Family/Caregiver Support

- “Tell me a little bit about your _____...”
- “What are your biggest concerns?”
- Awareness of the emotional impact
- Importance of caregiver training
- Focus on opportunities during prognosis discussions.
- Explore appropriate action and avoid negative predictions.
Looking Ahead

“The art of nursing, perhaps more than the science, offers vulnerable groups something they need most: HOPE. The use of our presence with all its holistic emotional intelligence, caring, compassion and competence tells people that they are valuable and valued, unique, and worthy fellow human beings..."

Dr. Loretta Ford, co-founder of the Nurse Practitioner role (email communication, April 2017).

Looking Ahead

“Transformations can occur if vulnerable individuals are encouraged to find, focus and harness their strengths. As nurses, we can help them become invigorated, energized and emboldened to determine their future for themselves in health and in life.”

Reflection

1. What is the most interesting lesson you learned?
2. What is the most important lesson you learned?

References

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