Caring for patients with autism

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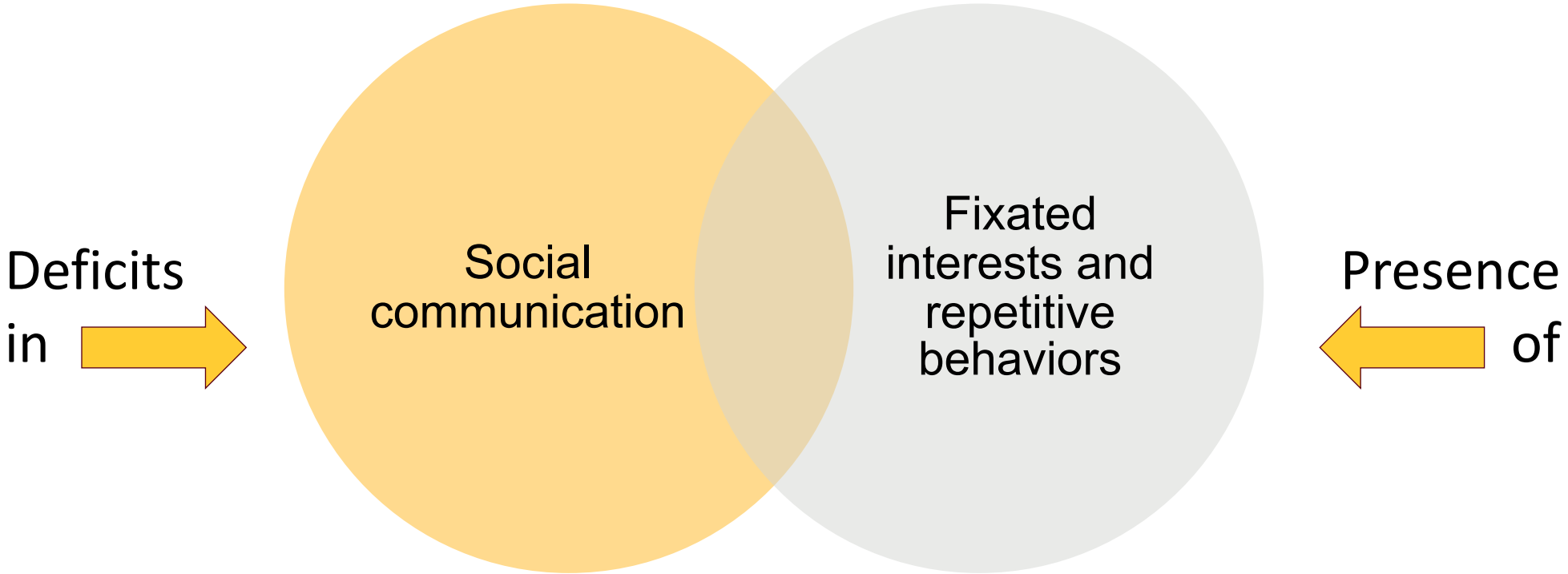
What is autism?

Core Symptoms are:



DSM-5-TR: Autism spectrum **d**isorder

A. Persistent deficits in social communication and social interaction across contexts, as manifested by all of the following currently OR BY HISTORY,

1. Deficits in social-emotional reciprocity
2. Deficits in nonverbal communicative behaviors used for social interaction
3. Deficits in developing, maintaining, and understanding relationships

B. Restricted, repetitive patterns of behavior, interests, or activities as manifested by at least two of the following currently OR BY HISTORY,

1. Stereotyped or repetitive speech, motor movements, or use of objects
2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior
3. Highly restricted, fixated interests that are abnormal in intensity or focus
4. Hyper-or hypo-reactivity to sensory input or unusual interest in sensory aspects of environment;

C. Symptoms must be present in early developmental period (but may not become fully manifest until social demands exceed limited capacities, or may be masked by learned strategies in later life)

D. Symptoms cause clinically significant impairment in current functioning

E. Disturbances not better explained by ID, DD

A. Social communication

1. **Deficits in social-emotional reciprocity**
   - Abnormal social approach
   - Lack of back-and-forth conversation
   - Reduced sharing of interests, emotions, or affect
   - Deficits in initiating or responding to social interactions

A. Social communication

2. **Deficits in nonverbal communication used for social interaction:**

- Limited, inconsistent, or atypical use of eye contact, gestures, facial expressions
- Lack of understanding of nonverbal communication
- Total lack of facial expressions and nonverbal communication

A. Social communication

3. **Deficits in developing, maintaining, and understanding relationships**

- Difficulties adjusting behavior to suit social contexts
- Difficulties in sharing imaginative play
- Difficulties making friends
- Absence of interest in peers

B. Repetitive behaviors and fixated interests

1. **Stereotyped or repetitive motor movements, use of objects, or speech**

- Body posturing, hand-flapping, finger-posturing, toe-walking
- Lining up, gathering/carrying, spinning
- Repetitive “scripting” or immediate echolalia, idiosyncratic speech, neologisms

B. Repetitive behaviors and fixated interests

2. **Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior**

- Following non-functional routines or rituals
- Having to complete a sequence
- Neophobia
- Intolerance of uncertainty
- Difficulty with minor changes in routine

B. Repetitive behaviors and fixated interests

3. Highly restricted, fixated interests that are abnormal in intensity or focus.

- Circumscribed interest: all-encompassing but focus of interest isn't unusual (e.g., trains)
- Preoccupations: all-encompassing and unusual in focus (e.g., lampposts)
- Often involves memorization of facts
- Interest is not used socially

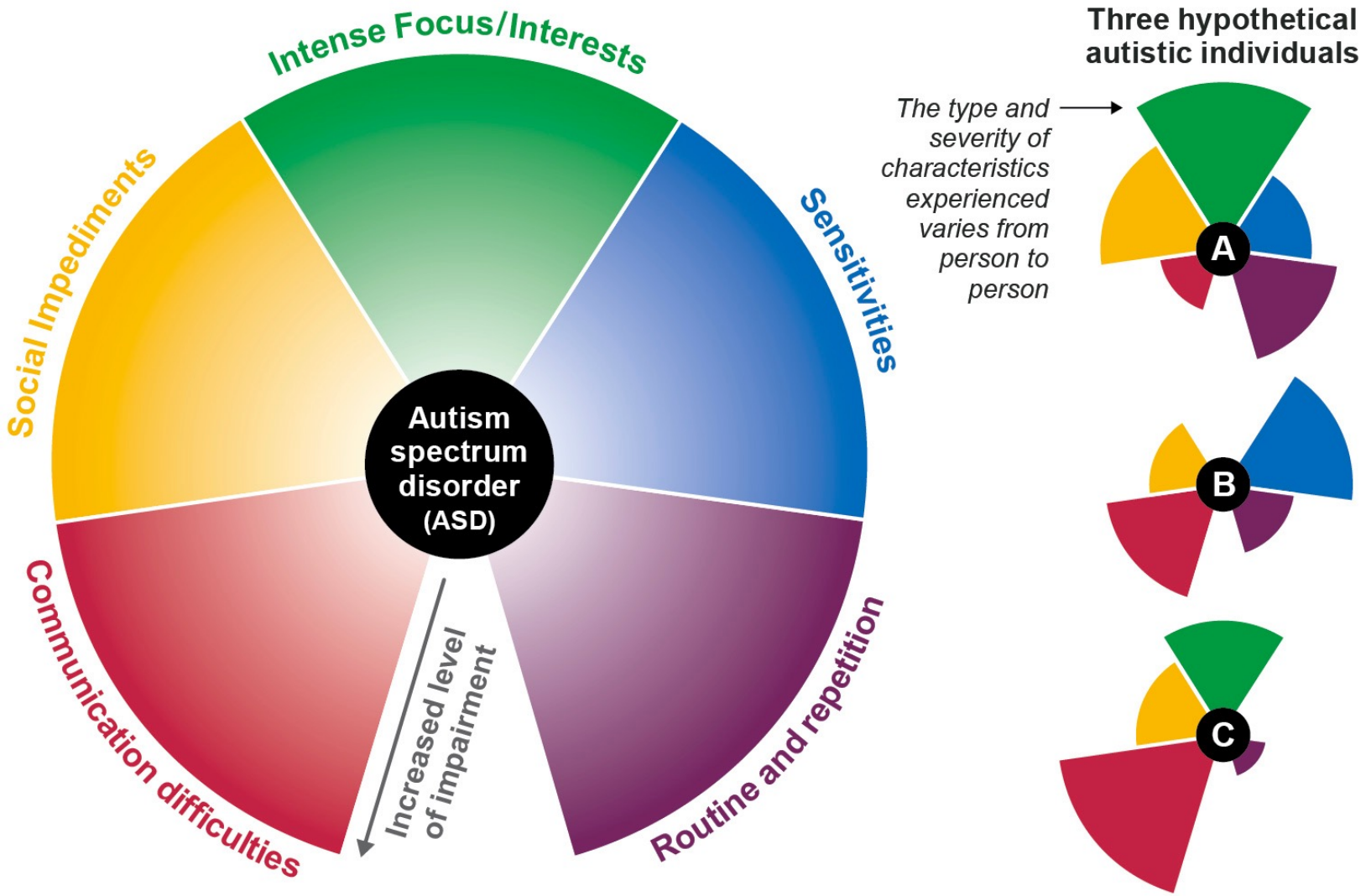
B. Repetitive behaviors and fixated interests

4. Hyper-or hypo-reactivity to sensory input or unusual interest in sensory aspects of environment.

- Hyper: oversensitive to noise, touch, etc., e.g. upset by electronic noises, light touch
- Hypo: seeking out sensory input, e.g., peering closely at objects, sniffing

Figure 2: Variation in Autism Spectrum Disorder Characteristics

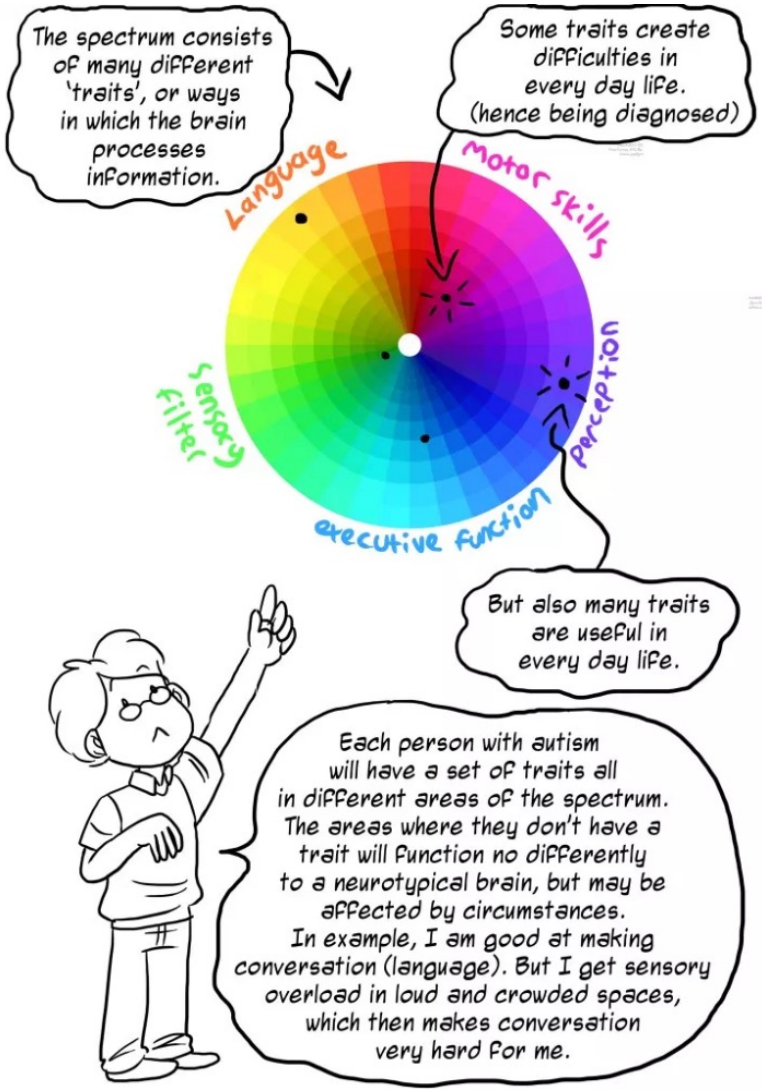
GAO grouped the characteristics associated with autism into five broad categories, with some overlap between categories.



Source: GAO analysis of the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5). | GAO-17-109

“Where is he/she on the spectrum?”…

- DSM-5 support level and other quick indicators of “severity” may not be useful or appropriate
- It is likely more meaningful to describe an individual’s particular profile:
  - How old are they?
  - What is their cognitive ability? Language ability? Adaptive skills? Academic skills?
  - How do their social-communication abilities compare to other children of a similar age and developmental level?
  - How do their RRBs compare to other children of a similar age and developmental level?
  - Are there internalizing and/or externalizing behavior problems?



New term/concept: Profound autism

The *Lancet* Commission on the future of care and clinical research in autism

Catherine Lord, Tony Charman*, Alexandra Havdahl, Paul Carbone, Evdokia Anagnostou, Brian Boyd, Themba Carr, Petrus J de Vries, Cheryl Dissanayake, Gauri Divan, Christine M Freitag, Marina M Gotelli, Connie Kasari, Martin Knapp, Peter Mundy, Alex Plank, Lawrence Scahill, Chiara Servili, Paul Shattuck, Emily Simonoff, Alison Tepper Singer, Vicky Slonims, Paul P Wang, Maria Celica Ysrraelit, Rachel Jellett, Andrew Pickles, James Cusack, Patricia Howlin, Peter Szatmari, Alison Holbrook, Christina Toolan, James B McCauley*

- Catherine Lord et al., 2021, Lancet Commission
- Defined as IQ<50 and/or minimally verbal/nonspeaking
  - Not appropriate for young children
  - May be used beginning at age 8 years
- Intended to describe autistic people who are likely to need 24-hour support throughout their lives
- Often co-occurs with epilepsy and self-injurious behavior
- Disproportionately female (although depends on cohort)

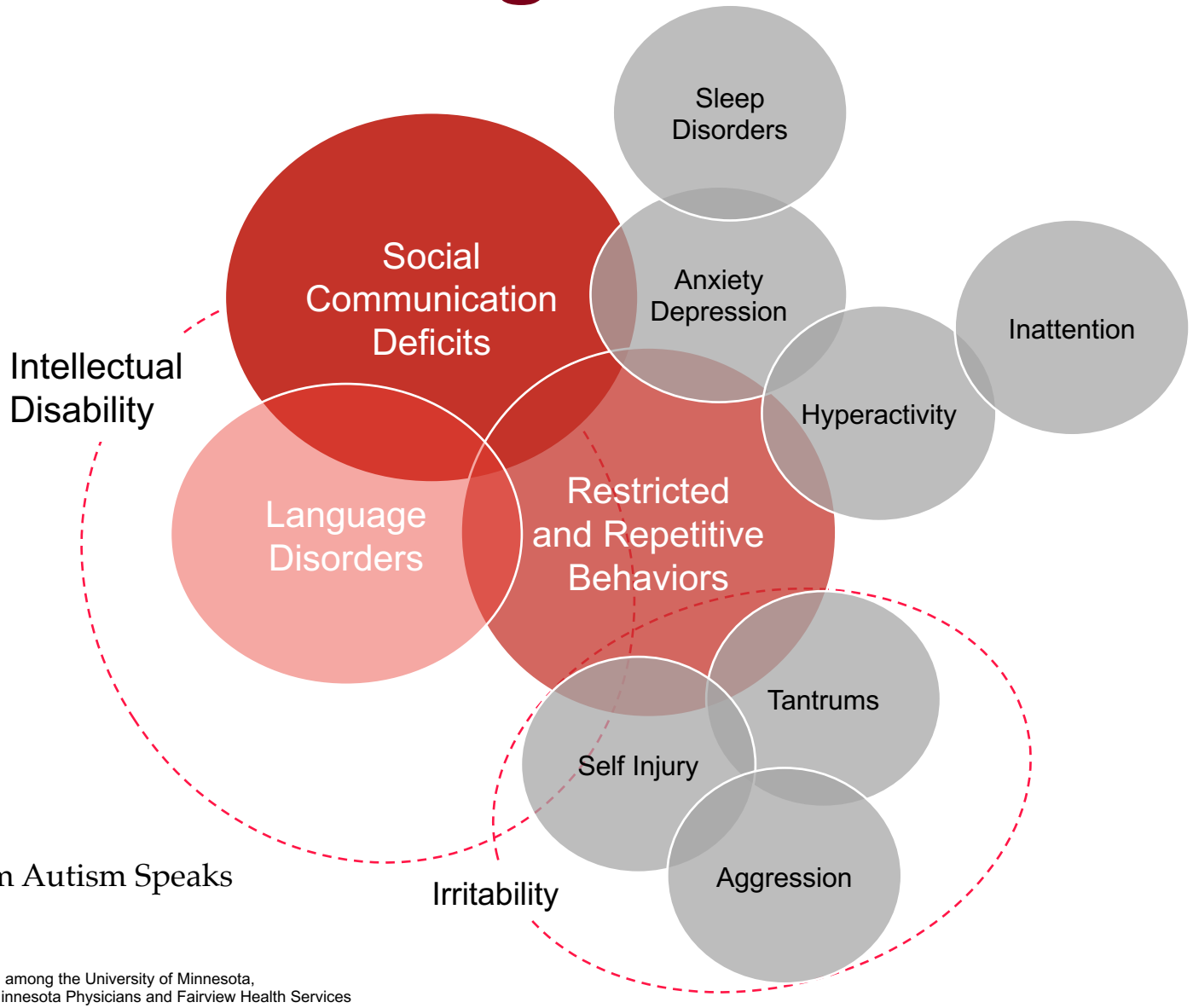
Examples of social communication deficits in profound autism

- May have only a few functional words or phrases
- May frequently use repetitive, nonfunctional phrases or vocalizations
- May not respond to their name or to someone talking to them unless attention is gotten very deliberately
- Limited use of eye contact, but this does not mean they are not listening
- Facial expressions do not match internal state
- Reduced social motivation—high preference for solitary, often repetitive, activities
- Social anxiety: Stressed out by the presence of several people, especially if unfamiliar
- Little understanding of social norms

Repetitive behaviors in profound autism

- Frequent repetitive non-speech vocalizations, may be loud and/or unusual
- Repetitive motor movements: pacing, jumping and waving arms, rocking, sometimes self-injury is present
- Repetitive sensory behaviors: pica, mouthing, close visual inspection, seeking out textures or deep pressure (can become self-injurious)
- Sensory aversions: upset by noises or touch that most people can tolerate or tune out; some have extremely restricted diets
- Rigidities: ranges from benefitting from routine to strong insistence on very specific, often non-functional routines

Co-occurring conditions



Adapted from Autism Speaks

Co-occurring
ADHD: 30-80%
Aggression: 25-68%
Anxiety: 80% of youth with ASD endorse anxiety symptoms, 40% meet criteria for anxiety disorder
Depression: 50%

Mayes et al., 2011; White et al., 2009; Kerns et al., 2014; Kanne & Mazurek, 2011; Hill et al., 2014

Anxiety in autism

General population

- Avoidance
- Anticipatory dread
- Worrying that is difficult to control
- Impacting sleep, eating
- Difficulty concentrating
- Fear/panic
- Physical symptoms

Autism

- Increased need for sameness
- Neophobia
- Meltdowns in response to new, unexpected, unpredictable
- Sensitivity to sensory stimuli, hyperarousal
- Engagement in compulsive behaviors
- Repetitive questioning
- Aggression, self-injury

Depression in autism

Depression: General population

- Hopelessness, worthlessness
- Rumination
- Irritability
- Tearfulness or numbness
- Changes in sleep, eating
- Psychomotor retardation
- No longer finding pleasure in previously pleasurable things (anhedonia)

Depression: Autism

- Increase or decrease in repetitive behaviors or fixated interests
- Irritability
- Reduction/loss of adaptive skills
- Decline in cognitive or language functioning
- Anhedonia
- Aggression, self-injury

Behaviors seen in autistic patients reflect a core ***skill*** deficit. Even those with high IQ and language skills lack understanding of social relationships, socially expected behaviors, and how their actions impact others.

Potential underlying triggers of aggression in autism

Physical disease

- Pain
- Delirium
- Catatonia
- Intoxication
- Acute Neurological Illness

Psychiatric Illness

- Anxiety/PTSD
- Psychosis
- Mania
- DMDD

-

Sensory Triggers

- Noise
- Light
- Intrusive procedures

Physical distress

- Hunger
- Fatigue

Relationship triggers

- Fear of strangers
- Parental Distress
- Separation from caregivers

Consensus Guidelines for Pharmacologic Management of Children in the ED; Ruth Gerson, MD, NYU, Dept of Child & Adolescent Psychiatry

Basic principles of behavior management: ABC

Antecedent

Behavior

Consequence

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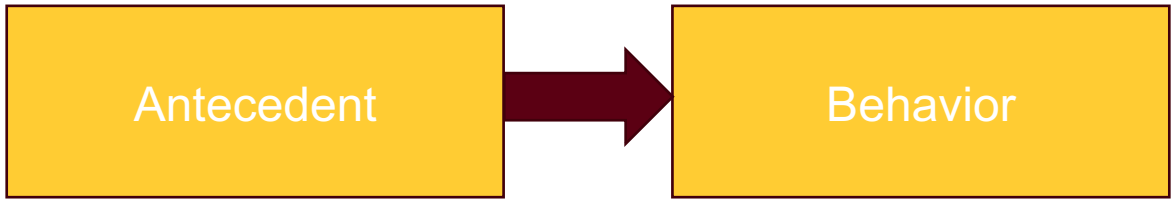


Basic principles of behavior management: ABC

Antecedent

Behavior

Consequence

How to Change Behavior

2 Core Strategy Categories

Antecedent Interventions

- Occurs **before** the behavior
- Antecedent interventions should be 90% of the focus

Response to behaviors

- Occurs **after** the behavior
- Targeted behavior plans
- Consistent across staff and environments

Antecedent Strategies

- Environmental arrangement
- Supporting child's communication
- Interaction styles that match child's communication level, affect, sensory tolerance
- Avoiding unstructured time

Behavioral momentum

AKA: Get them in the mood to cooperate.

Give them an instruction that is easy and preferred, then praise or provide reinforcement for compliance.

- Reinforce a behavior in the same “family” as the target behavior
  - Target behavior: following instructions
  - Behavior momentum: give instructions they already like or follow routinely

Prompting

Occurs **after** the demand is placed

Is recommended for “can’t do” versus “won’t do” tasks

- Can be dialed up or down by intrusiveness of prompt
  - Full physical (you move the person’s hand to complete the task)
  - Partial physical (you guide the hand toward the object or place child’s hand on and let them do the rest)
  - Modeling (you show how)
  - Gestural (you act out how, point to where/what to do)
  - Full verbal
  - Partial verbal
  - Visual (pictures or video demo)
  - Environmental

Successive Approximation

Reinforce behaviors closer and closer to the target behaviors

- Goal: Patient will tolerate blood pressure
  - Stay calm with cuff nearby
  - Stay calm while holding cuff
  - Stay calm while cuff is on arm but not constricting
  - Stay calm while cuff is on and constricting – Target!

Avoid Unstructured Time

- Non-contingent reinforcement

  --Or--

- Reinforcement Sampling

- One of the best ways to know what a child is interested in is to get to know them! **Pairing** yourself/other staff with more reinforcing opportunities than negative interactions is **critical**

- **In general, we aim for 4:1**

Finding Reinforcement

- Ask
- Observe
- Sample
- Choices
- Try and See

Responses to Challenging Behaviors

- De-escalation always
  - Train staff in de-escalation or “nonviolent crisis intervention” approaches
- Avoiding power struggles
  - Decide as a team what are the "nice to haves" and what are the "need to haves" in terms of information and procedures.
  - Start with "need to haves" and build to the "nice to haves"
  - Insert opportunities for choice when possible
    - "It's time to take your blood pressure. Would you like the cuff on your left arm or right arm?"
  - Only ask questions where you can honor their answer
    - "Should we take your blood pressure?” should not be asked if they can’t say no.

Behavior Intervention Plans

A – B - C

- The goal of a BIP:
  - Define the behavior
  - Identify what leads to the behavior through observation and data collection of the antecedents
  - Identify antecedent strategies to prevent the behavior
  - Identify response strategies to decrease the behavior's frequency in the future

Case Example

- 17-year-old male patient
- Non-verbal
- Engages in head banging

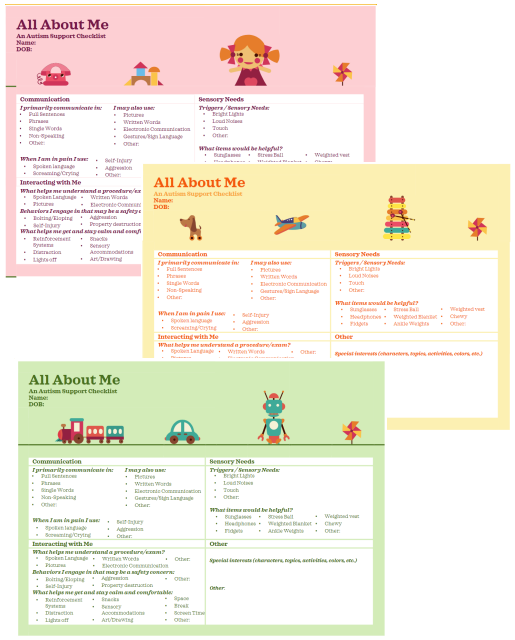
Antecedent	Behavior	Consequence
Nurse enters the room for vitals	Head banging	Mother rushes in, vitals discontinued
Attending enters the room to talk to mom	Head banging	Mom and attending leave the room while patient watches iPad
Medications are presented	Head banging	Patient is given a snack instead

Mini Behavior Intervention Plan

Example

Target behavior	What leads to the behavior (antecedents)	Prevention strategies	Response strategies
Aggression: throwing items, scratching people, kicking people	• Transitioning from iPad • People greeting him with a loud voice • Too many people in room at once • When not engaged in any activity	• Use quiet voice • 1-2 people in room at a time • Remove throwable items • Use timer to signal when iPad is done • Visual schedule of preferred activities throughout day	• Keep physical distance • Offer calming activity • Keep talking to a minimum • Define when emergency procedures will be used: e.g., if child is pursuing aggression toward staff who are not in his space and not engaging

About Me Pages



Sensory Toolkit

- Weighted vest
- Ankle weights
- Headphones
- Bubbles
- Light-up toys
- Fidgets
- Stress balls
- Massagers

Reinforcement Systems

- Token Boards
- Theme/character tokens
- Prizes

Communication supports

- Pictures of common activities, items, people, etc.
- First/Then
- Order of Events

Tools for working with challenging behaviors in autism

Communication and care coordination

Coordination of care teams	Discharge planning	Follow-up care
		Monitoring support needs Identifying when we are at-risk for higher level of care Booster trainings for community and home

Key contacts per system

Have contact information for these people!

Home	School	Medical	Social services	Intervention
Primary parent/caregivers	Special education case manager	Primary care physician—medical home?	County case manager	Mental health therapist
Custody and guardianship	School social worker	Psychiatric/med management	County case manager's supervisor	Speech-language therapist, OT, PT
Emergency contacts	School psychologist	Specialists (e.g., neurology, GI)	Crisis social worker	Behavioral consultant
Close family supports	General education teacher	Care coordinator	In-home care team (DSPs)	Family or individual skills
Friends and important people	Paraprofessional			Intensive developmental behavioral intervention

Acknowledgments

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Thank you!