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ECHO Idaho: Behavioral Health in Primary Care

Autism Spectrum Disorders
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#autismandmindfulness

Learning Objectives

- Describe clinical manifestations of Autism Spectrum Disorders (ASD)
- Discuss role of multi-disciplinary team and technology in comprehensive assessment and management of ASD
- Describe psychosocial-environmental-nutritional-sensory-behavioral interventions and pharmacologic interventions to treat behavioral disturbances and primary mental health disorders in individuals with ASD

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Acknowledgments

- I am grateful for the national and international expert in Autism research, Dr. Robert Hendren DO, Professor of Psychiatry and Behavioral Sciences, University of California San Francisco for generously sharing his slides and providing guidance. I have used information from his slides for my presentation.

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Pre-Test

- Question 1: All of the following are thought to be etiologic factors for Autism Spectrum Disorders except:
  - (a) Genetics
  - (b) Prenatal complications
  - (c) Restricted development
  - (d) Faulty parenting

Pre-Test

- Question 2: The prevalence of ASD in 8-year old children in the U.S. is thought to be:
  - (a) 1 in 230
  - (b) 1 in 115
  - (c) 1 in 59
  - (d) 1 in 40

Pre-Test

- Question 3: What is the ratio of prevalence of ASD in males and females?
  - (a) 4 males to 1 female
  - (b) 2 males to 1 female
  - (c) The prevalence is equal in males and females
  - (d) 2 females to 1 male

Pre-Test

- Question 4: Which of the following two are key symptoms criteria for diagnosis of ASD?
  - (a) persistent deficits in social communication and social interaction; persistent anxiety symptoms
  - (b) restricted, repetitive patterns of behaviors; persistent irritability
  - (c) persistent deficits in social communication and social interactions; restricted, repetitive patterns of behaviors
  - (d) persistent anxiety; persistent irritability

Pre-Test

- Question 5: Which of the following is currently the gold standard tool for screening ASD in toddlers?
  - (a) M-CHAT
  - (b) ADOS
  - (c) Rapid Interactive Test for Autism in Toddlers
  - (d) There is no gold standard tool for screening ASD in toddlers.

Pre-Test

- Question 6: Which of the following is currently the gold standard tool for diagnosis of ASD in children?
  - (a) M-CHAT
  - (b) ADOS
  - (c) Rapid Interactive Test for Autism in Toddlers
  - (d) There is no gold standard tool for diagnosing ASD in children.

Pre-Test

- Question 7: What is the earliest age that ASD can be reliably diagnosed?
  - (a) 1-year
  - (b) 2-years
  - (c) 3-years
  - (d) 4- years

Pre-Test

- Question 8: Which of the following two are the most common co-morbid psychiatric disorders in individuals with ASD?
  - (a) Intellectual disability and OCD
  - (b) ADHD and Bipolar disorder
  - (c) Intellectual disability and ADHD
  - (d) ADHD and OCD

Pre-Test

- Question 9: Which of the following best describes Applied Behavior Analysis?
  - (a) It is the practice of using the principles of behavior to produce socially meaningful change.
  - (b) It is a type of cognitive behavioral therapy for individuals with ASD that is supported by randomized controlled trials.
  - (c) It is generally provided by psychiatrists but can also be provided by nurse practitioners and physician assistants.
  - (d) It is an experimental treatment that needs more research before it can be recommended for individuals with ASD.

Pre-Test

- Question 10: Which of the following supplements have the most high quality research to support it's use in ASD?
  - (a) Melatonin for insomnia
  - (b) N-Acetyl Cysteine for tamper tantrums
  - (c) SAM-e for depression
  - (d) Probiotics for gastrointestinal distress

Pre-Test

- Question 11: Which two medications are approved by the U.S. Food and Drug Administration for the management of ASD with irritability?
  - (a) oxytocin and vasopressin
  - (b) sertraline and fluoxetine
  - (c) risperidone and aripiprazole
  - (d) methylphenidate and atomoxetine

Stigma, Bias, Prejudice

- In research settings, in clinical practice and in general, there is considerable stigma, bias, and prejudice faced by individuals with ASD.
- Even when they get the answer right or perform better in research setting, many well-educated and respected professionals interpret the findings as something “wrong” with the individual with ASD rather than defective functioning of individuals without ASD (the so-called “normal”).

  – Liz Pellicano PhD, Professor of Autism Education and Director, Center for Research in Autism and Education (CARE), University College Institute of Education, University College London. https://www.youtube.com/watch?v=VGR6fDeR--0

Harnessing the seven forces of wellness and healing

- Mindfulness
- Narratives
- Biomedical
- Creativity
- Spirituality
- Community
- Nature

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Case

- SS was a 15-month old boy. Parents reported: SS would not engage in pretend play; rarely responded to his name; preoccupied with things that spin. On exam: poor eye contact, preoccupied with rolling and chasing a ball, did not respond to examiner's prompt to include him in the game.
- At age 18-months, given diagnosis of ASD.
- Rx: Early intensive behavioral intervention (EIBI), speech and language therapy, augmentative communication, occupational therapy, special education with 1:1 paraprofessional.
- Outcome: Improved receptive language, well adapted at home, non-aggressive, responsive to parents' requests.

  – Constantino and Charman. Diagnosis of Autism Spectrum Disorder: reconciling the syndrome, its diverse origins, and variations in expression. Lancet Neurology 2016;15:279-291.

Conceptualizing ASD

- Neurodevelopmental disorder (traditional view).
- Whole-body disorder (new view: Dr. Robert Hendren and other top experts).
  - Intestinal inflammation
  - Digestive enzyme abnormalities
  - Metabolic impairment
  - Oxidative stress
  - Mitochondrial dysfunction
  - Immune-system dysfunction (deficiency, hypersensitivity, autoimmunity)

- Hendren R. Nevada Psychiatric Association Annual Psychopharmacology Conference, 2019, Las Vegas Nevada.
- Eissa et al. Current enlightenment about etiology and pharmacological treatment of Autism Spectrum Disorder. Frontiers of Neuroscience 2018;12:304.

Etiology of ASD

- First hit: Genetics
- Second hit: Environment (Rx: High quality prenatal and postnatal care [Universal Prevention Strategies / Primary Prevention])
- Third hit: Restricted development
- **NOTE: FAULTY PARENTING DOES NOT CAUSE ASD**

- Hendren R. Nevada Psychiatric Association Annual Psychopharmacology Conference, 2019, Las Vegas Nevada.
- Hollander, Hagerman and Fein. Editors. Autism Spectrum Disorder. American Psychiatric Association Publishing. 2018.
- McDougle CJ. Editor. Autism Spectrum Disorder. Oxford University Press, 2016.

Neurobiology of ASD

- Deficient oxytocin function.
- Vasopressin dysfunction (vasopressin antagonists in Phase 3 research study).
- Social reward system impaired.
- Impaired TOM (Theory of Mind neurocircuits [mentalizing neurocircuits]), mirror neuron system, executive function, and weak central coherence.

– Hollander, Hagerman and Fein. Editors. Autism Spectrum Disorder. American Psychiatric Association Publishing. 2018.
– McDougle CJ. Editor. Autism Spectrum Disorder. Oxford University Press, 2016.

Gut Microbiota

- Follow up of 18 research participants over two years after treatment with fecal transplant: improvement of autism-related symptoms and gastrointestinal symptoms persisted; important changes in gut microbiota persisted (increased bacterial diversity, relative abundance of Bifidobacteria and Prevotella.

  – Kang et al (Arizona State University): Long-term benefit of microbiota transfer therapy on autism symptoms and gut microbiota. Scientific Reports 2019;9:5821.

Oral Microbiome

- Microbes in the mouths of children with ASD differ from those of other children.
- These microbial changes resulted in increased lysine degradation, which may lead to increased production of neurotransmitter glutamate, and increased energy metabolism.

  – Hicks et al. Oral microbiome activity in children with ASD. Autism Research. August 14, 2018.

Neuroimaging

- Atypical trajectory of brain maturation
- This gives rise to differences in neuroanatomy, functioning, and connectivity.
- These in turn mediate autistic symptoms and traits

  – Ecker et al. Neuroimaging in Autism Spectrum Disorder: brain structure and function across the lifespan. Lancet Neurology 2015;14:271121-34.

Functional Neuroimaging

- Adolescents with ASD showed atypically increased functional connectivity involving the mentalizing and mirror neuron systems.

  – Fishman et al. Atypical cross talk between mentalizing and mirror neuron networks in Autism Spectrum Disorder. JAMA Psychiatry 2014;71(7):751-760.

Functional Neuroimaging

- Increased functional connectivity between subcortical and cortical resting-state networks (primary sensory cortex networks) have been found in individuals with ASD and may explain increased occurrence of hyposensitivity and or hypersensitivity and of difficulties in top-down regulation of behavior.

  – Cerliani et al. Increased functional connectivity between subcortical and cortical resting-state networks in Autism Spectrum Disorder. JAMA Pediatrics 2015;72(8):767-777.

Spectrum of Autism

- ASD – Mild, Moderate, Severe. With and without Intellectual disability
- Replaces Pervasive Developmental Disorders
- Asperger's disorder is ASD without Intellectual Disability (aka High functioning Autism)
- Social Communication Disorder
- Autism traits

  - Diagnostic and Statistical Manual of Mental Disorders 5. DSM-5. American Psychiatric Association 2013.
  - Nazeer et al. Autism Spectrum Disorder: A Concept in Evolution. Psychiatric Annals 2019:49(3):103-108.

Prevalence

- Approximately one in 59 school age children meet the criteria for ASD.
- Autism has increased in incidence by at least 700% since 1996.

  – Baio et al. Prevalence of autism spectrum disorder among children aged 8 years – Autism and Developmental disabilities Monitoring Network, 11 sites, United States, 2014. MMWR Surveill Summ. 2018;67(6):1-23.

Genetics

- One of the most heritable psychiatric disorders. Twin concordance rates: 77%-95%.
- Referral to a clinical geneticist for genetics evaluation may be helpful.
- Chromosomal microarray and DNA testing for fragile X syndrome for male patients may be considered.
- At least nine monogenic (single gene) “Syndromic Autism” have been identified (e.g., Fragile X syndrome, Angelman syndrome).

– Malik S et al. Genetics of Autism Spectrum Disorder: An Update. Psychiatric Annals 2019;49(3):109-114.

Genetics

- Children with older sibling diagnosed with ADHD is at increased risk of both ADHD and ASD.
- Children with older sibling diagnosed with ASD are at increased risk of both ASD and ADHD.

  – Miller et al. JAMA Pediatrics December 10, 2018.

Clinical Manifestations

- Symptoms typically visible between 12 and 24 months (e.g., delayed language patterns, unusual communication patterns, lack of social interest, atypical social interactions, odd patterns of play).
- Median age of diagnosis is after age 4 years.
- Four times more common in males compared to females.
- High variability in symptoms from one person to another.
- Many individuals show global improvement in adolescence.

  - Hollander, Hagerman and Fein. Editors. Autism Spectrum Disorder. American Psychiatric Association Publishing. 2018.
  - McDougle CJ. Editor. Autism Spectrum Disorder. Oxford University Press, 2016.

Clinical Manifestations

- Social impairment is the hallmark symptom – social motivation/drive, social cognition, social communication
- Restricted and repetitive behaviors and interests
- Sensory sensitivities (hypo and hyper)
- Behavioral disturbances (e.g., anxiety related to change, intense and prolonged outbursts/temper tantrums, self-injurious behaviors, aggression-irritability)

  - Hollander, Hagerman and Fein. Editors. Autism Spectrum Disorder. American Psychiatric Association Publishing. 2018.
  - McDougle CJ. Editor. Autism Spectrum Disorder. Oxford University Press, 2016.

Social cognition deficits

- Adults with ASD showed large impairments in theory of mind and emotion perception and processing cognitive domains.
- These findings may assist in the identification of targets for cognitive interventions.

  – Velikonja et al. Patterns of nonsocial and social cognitive functioning in adults with ASD. A systematic review and meta-analysis. JAMA Psychiatry. January 2nd, 2019.

Repetitive Behaviors

- Lower-order behaviors: lining up toys, spinning objects
- Higher-order behaviors: insistence on sameness (e.g., same routines, rituals)

  – Hollander, Hagerman and Fein. Editors. Autism Spectrum Disorder. American Psychiatric Association Publishing. 2018.

Restricted Interests

- Narrow interests that may not serve any function
- Example: preoccupation with trains (make, model, schedule)

  – Hollander, Hagerman and Fein. Editors. Autism Spectrum Disorder. American Psychiatric Association Publishing. 2018.

Reliability of early diagnosis

- Diagnosis from as young as 2 years of age is relatively stable.
- Requires direct clinician-to-child observation and generally takes several hours.
- The judgment of experienced clinicians is more reliable than that of existing diagnostic instruments for this age group.

  – Constantino and Charman. Diagnosis of Autism Spectrum Disorder: reconciling the syndrome, its diverse origins, and variations in expression. Lancet Neurology 2016;15:279-291.

Artificial Intelligence for Early Diagnosis?

- Feature tagging of home videos for machine learning classification of autism can yield accurate outcomes in short time frames, using mobile devices.
  - Tariq et al. Mobile detection of autism through machine learning on home video: A development and prospective validation study. PLOS Medicine. November 27, 2018.

Questions to ask Parents

- When did you first become worried about the way your child is communicating?
- Does your child have unusual behaviors?
- Does your child get upset if you change their routines unexpectedly? How do they show this distress?
- Is your child interested in what other children do? Does your child play with toys appropriately?.

– Vikram Patel and Charlotte Hanlon. Where There is No Psychiatrist. 2nd Edition. Royal College of Psychiatrists, 2017. London.

Screening Tools

- The American Academy of Pediatrics recommends universal screening for Autism features between ages 18 and 24 months.
- Modified Checklist for Autism in Toddlers (**M-CHAT**) is recommended for screening.
- Regular communication with parents about developmental concerns should start by age 6 months.
- Rapid Interactive (Screening) Test for Autism in Toddlers can be done in addition to M-CHAT
- Repetitive and Stereotyped Movements Scales

– Hollander, Hagerman and Fein. Editors. Autism Spectrum Disorder. American Psychiatric Association Publishing. 2018.

Diagnosis

- The Autism Diagnostic Observation Schedule (**ADOS**) is the gold standard for diagnosis (to characterize the presence and severity of Autism features)
- Mullen Scales for Early Learning may be done additionally.
- Bayley Scales of Infant Development may be done additionally.
- Stanford-Binet Intelligence Scales – 5th Edition may be considered in children 3-years and older

  – Hollander, Hagerman and Fein. Editors. Autism Spectrum Disorder. American Psychiatric Association Publishing. 2018.

Comprehensive Diagnostic Evaluation

- Medical evaluation (includes co-ordination of multidisciplinary assessment) by Primary Care Provider, needs to be an appropriately extensive assessment
- Specialist assessment (Child psychiatrist, Developmental pediatrician, Pediatric neuropsychologist, some pediatricians, some psychiatrists)
- Neuropsychological assessment
- Functional behavior assessment (FBA)
- Psychiatric evaluation
- Use of technology (e.g., telemedicine)

- Hollander, Hagerman and Fein. Editors. Autism Spectrum Disorder. American Psychiatric Association Publishing. 2018.
- McDougle CJ. Editor. Autism Spectrum Disorder. Oxford University Press, 2016.
- Volkmar et al. Practice parameters for the assessment and treatment of children and adolescents with Autism Spectrum Disorder. Journal of the American Academy of Child and Adolescent Psychiatry 2014;53(2):237-257.
- https://www.autismspeaks.org/sites/default/files/2018-08/Challenging%20Behaviors%20Tool%20Kit.pdf

Testing

- Metabolic testing (liver, kidneys, electrolytes, vitamin levels, micronutrient levels)
- Genetic testing
- EEG (overnight or long-term EEG)
- Evoked response testing (to address hearing concerns)
- Testing for inborn errors of metabolism
- Testing for heavy metal toxicity
- Sleep study
- Note: Routine brain imaging has no role currently.

– Hollander, Hagerman and Fein. Editors. Autism Spectrum Disorder. American Psychiatric Association Publishing. 2018.

Medical Assessment: The Top 7

- Allergies (e.g., food, allergic rhinitis) and food sensitivities
- Gastrointestinal problems (e.g., constipation, diarrhea, GERD, pancreatic enzyme deficiencies)
- Seizures (as many as one in three)
- Pain (e.g., headache, migraine)
- Eczema
- Ear and respiratory infections
- TBI-related
- Macro and Micro-nutrient deficiencies due to restricted diets

  - Hollander, Hagerman and Fein. Editors. Autism Spectrum Disorder. American Psychiatric Association Publishing. 2018.
  - http://nationalautismassociation.org/pdf/MedicalComorbiditiesinASD2013.pdf
  - Holingue et al 2018. Autism Research.
  - Volkmar et al. Practice parameters for the assessment and treatment of children and adolescents with Autism Spectrum Disorder. Journal of the American Academy of Child and Adolescent Psychiatry 2014;53(2):237-257.

Medical Management

- Pain sensitivity and perception may be less in some individuals with ASD, making it difficult to localize problems (e.g., inflammation, injury, infection).
- Food diary may be helpful in identifying food allergies and food sensitivities.
- Migraine headaches often emerge in early to middle adolescence.
- 20% of older individuals with ASD due to Fragile X syndrome may develop Parkinson's disease!

– Hollander, Hagerman and Fein. Editors. Autism Spectrum Disorder. American Psychiatric Association Publishing. 2018.

Food Allergies

- At least 10.8% (26 million) of US adults have food allergies (e.g., allergies to shellfish, milk, peanut, tree nuts).
- 51.1% have severe food allergies.
- 45.3% have allergies to multiple foods
- 48% develop food allergies as an adult
- 38.3% have gone to ED at least once for food-allergy related symptoms.

  – Gupta et al. Prevalence and severity of food allergies among US adults. JAMA Network Open. 2019;2(1):e185630.

Gastrointestinal symptoms

- Constipation 22%
- Diarrhea 13%
- Any GI symptom 46.8% (includes abdominal pain, nausea, vomiting).

  – Holingue et al. Gastrointestinal symptoms in Autism Spectrum Disorder: A review of literature on ascertainment and prevalence. Autism Research 2018;11:24-36.

Success Story

- MS was a 5-year old boy with ASD. He was brought for assessment of new onset of self-injurious behaviors (e.g., hitting his jaw, jumping from heights). He was found to have bilateral ear infection that responded to antibiotics. His SIBs were understood as his attempts to unblock his ear.

Psychiatric Assessment: The Big 12

- Medical causes
- Medication induced behavioral problems
- ADHD (one in three)
- Sleep disorders
- ASD related persistent aggression and or self-injurious behaviors
- ASD with persistent anxiety
- Major Depression
- Psychotic disorders
- Bipolar disorder
- OCD
- Personality disorder (e.g., Schizotypal personality disorder)
- Trauma-related disorders

  - Hollander, Hagerman and Fein. Editors. Autism Spectrum Disorder. American Psychiatric Association Publishing. 2018.
  - McDougle CJ. Editor. Autism Spectrum Disorder. Oxford University Press, 2016.

Mental Health Co-morbidity

- 53% of children age 4-years with ASD and 69% of children age 8-years with ASD have four or more co-occurring medical and or mental health conditions (Soke et al 2018).
- 32% of children with ASD have intellectual disability; 25% have borderline intelligence and 44% have average or above average intellectual ability (CDC 2016)

  - Soke et al. Prevalence of co-occurring medical and behavioral condition/symptoms among 4- and 8-year-old children with ASD in selected areas of the United States in 2010. Journal of Autism and Developmental Disorder 2018;48(8):2663-2676.
  - CDC. Prevalence and characteristics of Autism Spectrum Disorder among children aged 8-years – Autism and Developmental Disability Monitoring Network, 11 sites, 2012. Surveillance Summaries. 2016;65(3):1-23.

Challenging Behaviors

- Approximately 70% of school-age children meet criteria for at least 1 non-ASD co-occurring psychiatric disorder.
- Children with ASD represent one in eight children in psychiatrically referred population.
- The primary presenting problems are challenging behaviors and more than 80% of these children meet criteria for ADHD and or Oppositional Defiant Disorder.

  – Brookman-Frazee et al. Effectiveness of training therapists to deliver an individualized mental health intervention for children with ASD in publicly funded mental health services. JAMA Psychiatry March 6th, 2019. Researchers from UCSD

Sleep disturbances

- Sleep disorders are more than twice as common in children with ASD compared to children without ASD (Reynolds et al 2019).
- 30% of children with ASD had difficulties with sleep onset and 43% with difficulties in sleep maintenance (Trickett et al 2018).
- 50-80% of children with ASD have sleep difficulties (Veatch et al 2015).

- Reynolds et al. Pediatrics. February 2019.
- Trickett et al. A cross-sectional cohort comparison of sleep disturbances in children with Smith-Magenis syndrome, Angelman syndrome, Autism Spectrum Disorder and Tuberous Sclerosis complex. 2018;10:9.
- Veatch et al. Sleep in Autism Spectrum Disorders. Current Sleep Medicine Report 2015;1(2):131-140.

Self-Injurious Behaviors

- SIB prevalence averaged 27.7% in children with ASD.

  - Soke et al. Prevalence of self-injurious behaviors among children with Autism Spectrum Disorder: A population-based study. Journal of Autism and Developmental Disorders 2016;46(11):3607-3614.

Self-Injurious Behaviors and Ideation

- Adults with ASD are twice as likely to be hospitalized for self-harm.
- 28% of children with ASD experience Self-injurious behaviors (SIB) compared to 8%.
- 13% of hospitalizations of adults with ASD are secondary to SIB compared to 6%.
- ASD with SIB have longer stays (average 2 days) compared to controls - incurring higher costs.
- Individuals age 50 and older more likely to be hospitalized for SIB compared to controls.

  – Shields et al. Psychiatric Services, March 7, 2019.

Suicide

- High-functioning adolescents and adults with ASD (Asperger's syndrome) are at high risk of contemplating suicide (up to 66% in specialty clinics).

  - Cassidy et al. Suicidal ideation and suicide plan or attempts in adults with Asperger's syndrome attending a specialist diagnostic clinic: a clinical cohort study. The Lancet Psychiatry 2014;1(2):142-147.

Heartbreaking stories

- “Once I told my school counselor I had taken pills to kill myself, she wouldn’t let me leave. Then the police came, put handcuffs on me and took me out of the school in front of all the other kids. They took me to the emergency room where they kept me for 12 hours. Then they sent me to the hospital. It was awful. One thing I learned was never tell anyone if you are thinking of killing yourself.”

  – Asarnov et al. Child and adolescent suicide and self-harm: Treatment and Prevention. Psychiatric Services Special Report. December 2018.

ASD and Depression

- Young adults with ASD have more than 2-fold risk of a depression diagnosis.
- Risk of depression is higher in individuals with ASD without Intellectual disability than in individuals with ASD and intellectual disability.

  – Rai et al. Association between Autism Spectrum Disorders with and without intellectual disability and depression in young adulthood. JAMA Network Open 2018;1(4).

Obsessive Compulsive Symptoms

- Cleaning
- Checking
- Counting
- Yale-Brown Obsessive Compulsive Scale
- Individuals with ASD have a 2-fold higher risk of developing OCD
- Individuals with OCD have higher prevalence of Autism traits or Disorder

– Hollander, Hagerman and Fein. Editors. Autism Spectrum Disorder. American Psychiatric Association Publishing. 2018.

OCD

- OCD is more prevalent in individuals with high-functioning ASD (Asperger's syndrome) compared to controls.
- Cognitive Behavior Therapy may be useful.

  – Russell et al. Obsessions and compulsions in Asperger syndrome and high functioning Autism. British Journal of Psychiatry 2005;186:525-8.

Bipolar Disorder

- Around 7% of individuals with ASD may have Bipolar disorder (higher than general population)
- Many individuals with Bipolar disorder have Autism traits or Disorder but this is under-recognized.
- Children with ASD and Bipolar disorder have higher rates of ADHD and OCD.

  - Hollander, Hagerman and Fein. Editors. Autism Spectrum Disorder. American Psychiatric Association Publishing. 2018.

ASD and Bipolar Disorder

- A diagnosis of ASD is associated with a substantially increased risk of non-affective psychotic disorder and Bipolar disorder.

  – Selten et al. Risks for nonaffective psychotic disorder and Bipolar disorder in young people with Autism Spectrum Disorder: A Population-based study. JAMA Psychiatry 2015:72(5);483-489.

ASD and Schizophrenia

- Both ASD and Schizophrenia share multiple etiologies, phenotypic feature similarities, and risk factors, and reported to co-occur at elevated levels.

  – Chisholm et al. The association between autism and schizophrenia spectrum disorders: a review of eight alternate models of co-occurrence. Neuroscience Biobehavior Review 2015;55:173-183.

Trauma

- Over 50% of youths had experienced at least one trauma.
- Nearly one half had clinical-level mood symptomatology.
- 90% of youth with clinical-level mood symptomatology had at least one trauma compared to 40% without clinical-level mood symptomatology.

  – Taylor and Gotham. Cumulative life events, traumatic experiences, and psychiatric symptomatology in transition-aged youth with Autism Spectrum Disorder. Journal of Neurodevelopmental Disorder. 2016;6:28.

Sexual orientation

- Individuals with ASD report increased homosexuality, bisexuality, and asexuality.

  - George & Stokes. Sexual orientation in Autism Spectrum Disorder. Autism Research 2018;11:133-141.

Treatment

- Comprehensive approach includes education (of ASD symptoms and course, local and web resources), support and guidance of parents, addressing physical and mental co-morbidities.
- Interventions to improve function (e.g., Applied Behavioral Analysis, speech and language therapy, occupational therapy).
- Nutritional therapies.
- Complementary and alternative medicine approaches.

- Calles JL. Psychopharmacology of Autism Spectrum Disorder. Psychiatric Annals 2019;49(3):120-124.
- Williamson et al. Medical therapies for children with Autism Spectrum Disorder – an update. Comparative Effectiveness Review No. 189. AHRQ May 2017.
- Volkmar et al. Practice parameters for the assessment and treatment of children and adolescents with Autism Spectrum Disorder. Journal of the American Academy of Child and Adolescent Psychiatry 2014;53(2):237-257.
- Eissa et al. Current enlightenment about etiology and pharmacological treatment of Autism Spectrum Disorder. Frontiers of Neuroscience 2018;12:304.

Multidisciplinary Interventions

- Education and training of family (parents) and professional caregivers/care partners
- Occupational therapy: Sensory integration strategies
- Speech and language pathologists: Communication strategies including PECS (Picture Exchange Communication System)
- Dietician: Nutritional approaches
- Nidotherapy (modifying environment to match the strengths of the person with ASD with four key ingredients: structure, predictability, sameness, continuous activity programming [minimize surprises])
- Social skills group

- Alateeqi et al. Evidence-based treatments of Autism Spectrum Disorder. 2019;49(3):115-119.
- Hollander, Hagerman and Fein. Editors. Autism Spectrum Disorder. American Psychiatric Association Publishing. 2018.
- McDougle CJ. Editor. Autism Spectrum Disorder. Oxford University Press, 2016.

High-Tech Approaches

- Approaches using screen-based media (e.g., tablets and smartphones) to capitalize on visual perception and visual search strengths
- Telemedicine and EMR
- Behavior Imaging (https://behaviorimaging.com)
- Technology-based augmentative communication devices and strategies (including speech generating devices using apps)
- Monitoring technology (e.g., GPS, medical alert)
- Access to healthcare provider notes and their input
- Virtual reality based approaches
- Other (e.g., video modeling)

- Hollander, Hagerman and Fein. Editors. Autism Spectrum Disorder. American Psychiatric Association Publishing. 2018.
- McDougle CJ. Editor. Autism Spectrum Disorder. Oxford University Press, 2016.
- https://www.healthychildren.org/English/health-issues/conditions/Autism/Pages/default.aspx

Applied Behavior Analysis (ABA)

- Under the supervision of Board Certified Behavior Analysts.
- Today's ABA programs are very different from those 20 years ago. ABA is now much more flexible, functional and fun for the child.
- It can address every behavior relevant to the child (both excesses and deficits) and Behavior Analysts are not distracted by the many theories of the causes of ASD.

  - Behavior Analysis Certification Board. https://www.bacb.com/bcba/
  - Association of Behavior Analysis International https://www.abainternational.org/welcome.aspx

EIBI

- Providing timely access to EIBI (early intensive behavioral intervention) optimizes outcomes, improves future independence, and lessens costs from governmental and societal perspectives.
- More than 20 hours per week, more than $30,000 per year per child.

  - Piccininni et al. Cost-effectiveness of wait time reduction for intensive behavioral intervention services in Ontario, Canada. JAMA Pediatrics 2017;171(1):23-30.

The Early Start Denver Model

- A variant of EIBI that is supported by high quality research.
- A separate training "manual" for parents is available, *An Early Start for Your Child with Autism*.

  – Dawson et al. Randomized, controlled-trial of an intervention for toddlers with autism. The Early Start Denver Model.. Pediatrics 2010;125(1):17-23.

Sexual education

- Individuals with ASD have greater difficulty adhering to privacy norms, engaging in less appropriate sexual behavior and receive less formal and informal sexual health education.

  – Hancock et al. Socio-sexual functioning in Autism Spectrum Disorder. A systematic review and meta-analysis of existing literature. Autism Research 2017;10:1823-1833.

Mental Health Interventions

- AIM HI (An Individualized Mental Health Intervention)
- Therapists were trained: Training and consultation process took 6 months
  - Introductory workshop
  - Eleven structured consultation meetings as the therapist delivers AIM HI to a client
- Case-specific performance feedback provided to trainees.
- Significant reductions in problem behaviors occurred in the intervention group.

  - Brookman-Frazee et al. Effectiveness of training therapists to deliver an individualized mental health intervention for children with ASD in publicly funded mental health services. JAMA Psychiatry March 6th, 2019. Researchers from UCSD

Success stories

- DP was diagnosed with ASD at age 8 years.
- He was enrolled in group-based social skills training, which gradually helped to resolve his more stigmatizing behaviors (e.g., blurting out inappropriate comments to peers which DP that was funny).
- He received psychiatric care for an interval during adolescence when he became depressed.
- He is now enrolled in his third year of undergraduate studies at a college that provides social support to students on the autism spectrum.

  – Constantino and Charman. Diagnosis of Autism Spectrum Disorder: reconciling the syndrome, its diverse origins, and variations in expression. Lancet Neurology 2016;15:279-291.

Success stories

- "The support I receive is very relevant….Due to my condition, I was in a position where I thought the idea of killing myself was better than carrying on."
  - Camm-Crostic et al. "People like me don't get support": Autistic adults' experiences of support and treatment for mental health difficulties, self-injury and suicidality. Autism. 2018:1-11.

Improving Outcomes

- “In many cases, improvement of autistic symptoms is achieved by a combination of nutritional recommendations, prescription medications, and addressing the underlying medical conditions seen in these individuals.”
- “I hope that by thinking of making the body healthier, we can help kids have the very best outcomes.”

  – Robert Hendren DO, Professor, Department of Child and Adolescent psychiatry, University of California San Francisco. Nevada Psychiatric Association Annual Psychopharmacology Conference, 2019, Las Vegas Nevada.

Complementary and Integrative Approaches

- Melatonin
- Omega 3
- N Acetyl Cysteine
- Methyl B12
- Sulforaphane
- Pancreatic digestive enzymes and Probiotics
- Diets
- Massage
- Meditation
- Exercise
- Sensorimotor enrichment
- Music therapy
- Animal-assisted / Equine therapy
- Neurofeedback

– Hendren et al. Complementary and Integrative Approaches. Hollander, Hagerman and Fein. Editors. Autism Spectrum Disorder. American Psychiatric Association Publishing. 2018.

Melatonin

- Best studied supplement in individuals with ASD
- Primarily given for insomnia
- Dose tested in studies: 1-9 mg at bedtime
- Long-term use is not recommended.

  - Hendren et al. Complementary and Integrative Approaches. Hollander, Hagerman and Fein. Editors. Autism Spectrum Disorder. American Psychiatric Association Publishing. 2018.
  - Calles JL. Psychopharmacology of Autism Spectrum Disorder. Psychiatric Annals 2019;49:3;120-124

N-Acetyl Cysteine

- Low quality studies have found some benefits (reductions in disruptive behaviors, skin picking behaviors, trichotillomania)
- Dose: 600-1200mg twice daily
- May cause increased agitation and irritability in some.

– Hendren et al. Complementary and Integrative Approaches. Hollander, Hagerman and Fein. Editors. Autism Spectrum Disorder. American Psychiatric Association Publishing. 2018.

Probiotics and Digestive enzymes

- Anecdotal reports of some benefits
- May be considered to treat gastrointestinal symptoms (and these symptoms may manifest as anxiety, irritability, physical aggression and self-injurious behaviors)

  – Hendren et al. Complementary and Integrative Approaches. Hollander, Hagerman and Fein. Editors. Autism Spectrum Disorder. American Psychiatric Association Publishing. 2018.

Omega-3 fatty acids

- Low quality studies indicate that a subset of individuals with ASD may benefit from Omega 3 fatty acid supplementation.
- Dose tested in studies: around 750mg of DHA and 750mg of EPA

  - Hendren et al. Complementary and Integrative Approaches. Hollander, Hagerman and Fein. Editors. Autism Spectrum Disorder. American Psychiatric Association Publishing. 2018.

Methyl B12

- Low quality studies have found some benefits
- Dose: subcutaneous injection of methyl B12; 75 micrograms / kg

  – Hendren et al. Complementary and Integrative Approaches. Hollander, Hagerman and Fein. Editors. Autism Spectrum Disorder. American Psychiatric Association Publishing. 2018.

CFSFGF Diets: Anecdotal evidence

- Dairy/Casein free diet (CF) (may need supplements like calcium and magnesium as dairy is a source of these elements in many individuals)
- Soy free (SF) diet
- Gluten free (GF) diet (may also need a variety of supplements to compensate; will make it difficult to diagnose Celiac disease [Gluten sensitive enteropathy])
- Routine use of CFSFGF diet NOT recommended
- Guidance from a dietician is recommended if parents want to give these diets a try.

- Hendren et al. Complementary and Integrative Approaches. Hollander, Hagerman and Fein. Editors. Autism Spectrum Disorder. American Psychiatric Association Publishing. 2018.
- Pangborn JB. Nutritional Supplement Use for Autism Spectrum Disorder. Autism Research Institute, San Diego, CA, 2013.

Yoga-Meditation

- Low quality evidence support benefits of manualized daily yoga program

  - Hendren et al. Complementary and Integrative Approaches. Hollander, Hagerman and Fein. Editors. Autism Spectrum Disorder. American Psychiatric Association Publishing. 2018.

Exercise

- Anecdotal reports indicate that horse-back riding and martial arts interventions may produce some benefits.

  - Hendren et al. Complementary and Integrative Approaches. Hollander, Hagerman and Fein. Editors. Autism Spectrum Disorder. American Psychiatric Association Publishing. 2018.

Music therapy

- Low quality studies indicate that music therapy may produce some benefits (e.g., improved social skills).

  - Hendren et al. Complementary and Integrative Approaches. Hollander, Hagerman and Fein. Editors. Autism Spectrum Disorder. American Psychiatric Association Publishing. 2018.

Animal-assisted/Equine therapy

- Low quality studies indicate that animal-assisted/equine therapy may produce some benefits.

  – Hendren et al. Complementary and Integrative Approaches. Hollander, Hagerman and Fein. Editors. Autism Spectrum Disorder. American Psychiatric Association Publishing. 2018.

Cannabidiol (CBD)

- Lack of high quality evidence to support its use.
- Anecdotal reports from some parents that CBD was helpful in relieving anxiety and improving sleep.

Therapies to Avoid

- Stem cell therapy
- Hyperbaric oxygen

  – Hollander, Hagerman and Fein. Editors. Autism Spectrum Disorder. American Psychiatric Association Publishing. 2018.

Pharmacological Interventions

- Currently, there is no medication that is approved by the U.S. Food and Drug Administration for the treatment of core deficits of ASD.
- Unproven therapies (e.g., stem cell therapies) may carry substantial harm (emotional, physical health, financial).

- Calles JL. Psychopharmacology of Autism Spectrum Disorder. Psychiatric Annals 2019;49(3):120-124.
- Williamson et al. Medical therapies for children with Autism Spectrum Disorder – an update. Comparative Effectiveness Review No. 189. AHRQ May 2017.
- Volkmar et al. Practice parameters for the assessment and treatment of children and adolescents with Autism Spectrum Disorder. Journal of the American Academy of Child and Adolescent Psychiatry 2014;53(2):237-257.
- Eissa et al. Current enlightenment about etiology and pharmacological treatment of Autism Spectrum Disorder. Frontiers of Neuroscience 2018;12:304.

Psychiatric Medications

- ADHD medications (stimulants [methylphenidate has the best data], atomoxetine, clonidine, guanfacine)
- Aripiprazole and risperidone approved by FDA for treatment of ASD related persistent aggression and or self-injurious behaviors
- Appropriate psychiatric medications for co-morbid major mental illnesses (e.g., True moderate to severe major depression, True Bipolar disorder, True Schizophrenia).

- Calles JL. Psychopharmacology of Autism Spectrum Disorder. Psychiatric Annals 2019;49(3):120-124.
- Williamson et al. Medical therapies for children with Autism Spectrum Disorder – an update. Comparative Effectiveness Review No. 189. AHRQ May 2017.
- Volkmar et al. Practice parameters for the assessment and treatment of children and adolescents with Autism Spectrum Disorder. Journal of the American Academy of Child and Adolescent Psychiatry 2014;53(2):237-257.
- Eissa et al. Current enlightenment about etiology and pharmacological treatment of Autism Spectrum Disorder. Frontiers of Neuroscience 2018;12:304.

SSRIs

- Often used to treat co-morbid Major Depression, OCD, disabling anxiety disorders in individuals with ASD.
- SSRIs associated with activation syndrome (agitation, insomnia, increased anxiety)
- Start low and increase slowly.

  - Hollander, Hagerman and Fein. Editors. Autism Spectrum Disorder. American Psychiatric Association Publishing. 2018.

Variable Trajectories

- Autistic symptoms:
  - Group 1 (11.4%): less severe symptoms, improving trajectory
  - Group 2 (88.6%): more severe symptoms, stable trajectory
- Adaptive functioning:
  - Group 1 (29.2%): lower functioning, worsening trajectory
  - Group 2 (49/9%): moderate functioning, stable trajectory
  - Group 3 (20.9%): higher functioning, improving trajectory

  - Szatmari et al. Developmental trajectories of symptom severity and adaptive functioning in an inception cohort of preschool children with Autism Spectrum Disorder. JAMA Psychiatry 2015;73(3):276-283.

Undertreatment Prevalence

- Almost 30% of children with ASD did not receive behavioral or medication treatment.

  - Xu et al. Prevalence and treatment patterns of Autism Spectrum Disorder in the U.S. 2016. JAMA Pediatrics December 13, 2018.

Reason to hope

- At least some forms of ASD involve time-specific developmental deficits as well as ongoing alterations in CNS functioning that might present targets for treatment, even well after the first emergence of symptoms.

  – Geschwind and State. Gene hunting in Autism Spectrum Disorder: on the path to precision medicine. Lancet Neurology 2015;14:271121-34.

Reason to hope

- Although many high-confidence ASD risk genes are most highly expressed during fetal brain development, a group of risk genes is involved in neuronal signaling, the expression of which coincides with neuronal maturation, providing another potential postnatal treatment window.

  – Geschwind and State. Gene hunting in Autism Spectrum Disorder: on the path to precision medicine. Lancet Neurology 2015;14:271121-34.

Key Points

- Early diagnosis key to achieving optimal outcomes
- Multidisciplinary team using telemedicine key to achieving optimal outcomes
- BCBAs and Psychiatrists working together with Primary Care Providers is key to minimizing psychiatric medication use and improving mental health outcomes
- Support from local community, state and federal government is key to achieving optimal outcomes.

ECHO IDAHO

Project ECHO University of Idaho

References and Resources

- *Hollander, Hagerman and Fein. Editors. Autism Spectrum Disorder. American Psychiatric Association Publishing 2018.*
- *McDougle CJ. Editor. Autism Spectrum Disorder. Oxford University Press, 2016.*
- *Upcoming Autism Mental Health conference on November 2, 2019 hosted by University of Idaho and partners.*
- American Academy of Pediatrics*: Autism: Caring for Children With Autism Spectrum Disorders.* A Resource Toolkit for Clinicians *($80)*
- *https://www.healthychildren.org/English/health-issues/conditions/Autism/Pages/default.aspx*
- *Autism Research Institute https://www.autism.com*

ECHO IDAHO

Project ECHO University of Idaho

References and Resources

- *Melmed R and Wheeler M. Autism and the Extended Family: A guide for those outside the immediate family who know and love someone with Autism. 2015.*
- *Autism Speaks https://www.autismspeaks.org 100 Day Kit: A tool kit to assist families in getting the critical information they need in the first 100 days after an autism diagnosis*
- *Autism Society of America http://www.autism-society.org*
- *American Psychiatric Association*
- https://www.psychiatry.org/patients-families/autism

Post-Test

- Question 1: All of the following are thought to be risk factors for development of ASD except:
  - (a) Genetics
  - (b) Prenatal complications
  - (c)Restricted development
  - (d) Faulty parenting

  - Answer: d. Faulty parenting is NOT a risk factor for development of ASD.

Post-Test

- Question 2: The prevalence of ASD in 8-year old children in the U.S. is thought to be:
  - (a) 1 in 230
  - (b) 1 in 115
  - (c) 1 in 59
  - (d) 1 in 40

  - Answer: c. The latest research indicates the prevalence of ASD in 8-year old children in the U.S. is around 1 in 59.

Post-Test

- Question 3: Which is thought to be the ratio of prevalence of ASD in males and females?
  - (a) 4 males to 1 female
  - (b) 2 males to 1 female
  - (c) The prevalence is equal in males and females
  - (d) 2 females to 1 male

  - Answer: a. Most recent research indicates that male to female ratio for prevalence of ASD is 4:1.

Post-Test

- Question 4: Which of the following two are key symptoms criteria for diagnosis of ASD?
  - (a) persistent deficits in social communication and social interaction and persistent anxiety symptoms
  - (b) restricted, repetitive patterns of behaviors and irritability
  - (c) persistent deficits in social communication and social interactions and restricted, repetitive patterns of behaviors
  - (d) persistent anxiety and irritability symptoms
  - Answer: c.

Post-Test

- Question 5: Which of the following is currently the gold standard tool for screening ASD in toddlers?
  - (a) M-CHAT
  - (b) ADOS
  - (c) Rapid Interactive Test for Autism in Toddlers
  - (d) There is no gold standard tool for screening ASD in toddlers.

  - Answer: a. M-CHAT (Modified Checklist for Autism in Toddlers) is the gold standard tool for screening ASD in toddlers.

Post-Test

- Question 6: Which of the following is currently the gold standard tool for diagnosis of ASD in children?
  - (a) M-CHAT
  - (b) ADOS
  - (c) Rapid Interactive Test for Autism in Toddlers
  - (d) There is no gold standard tool for diagnosing ASD in children.

  - Answer: b. ADOS (Autism Diagnostic Observation Scale) is currently the gold standard tool for diagnosing ASD in children.

Post-Test

- Question 7: What is the earliest age that ASD can be reliably diagnosed?
  - (a) 1-year
  - (b) 2-years
  - (c) 3-years
  - (d) 4- years

  - Answer: b. At 2-years of age, ASD can be reliably diagnosed.

Post-Test

- Question 8: Which of the following two most common co-morbid psychiatric disorders in individuals with ASD?
  - (a) Intellectual disability and OCD
  - (b) ADHD and Bipolar disorder
  - (c) Intellectual disability and ADHD
  - (d) ADHD and OCD

  - Answer: c

Post-Test

- Question 9: Which of the following best describes Applied Behavioral Analysis?
  - (a) It is the practice of using the principles of behavior to produce socially meaningful change.
  - (b) It is a type of cognitive behavioral therapy for individuals with ASD that is supported by randomized controlled trials.
  - (c) It is generally provided by psychiatrists but can also be provided by nurse practitioners and physician assistants.
  - (d) It is an experimental treatment that needs more research before it can be recommended for individuals with ASD.

  - Answer: a

Post-Test

- Question 10: Which of the following supplements have the most high quality research to support it's use in ASD?
  - (a) Melatonin for insomnia
  - (b) N-Acetyl Cysteine for tamper tantrums
  - (c) SAM-e for depression
  - (d) Probiotics for gastrointestinal distress

  - Answer: a. Melatonin has been studied in several randomized controlled trials and found to be useful for treatment of insomnia in individuals with ASD.

Post-Test

- Question 11: Which two medications are approved by the U.S. Food and Drug Administration for the management of ASD with irritability?
  - (a) oxytocin and vasopressin
  - (b) sertraline and fluoxetine
  - (c) risperidone and aripiprazole
  - (d) methylphenidate and atomoxetine

  - Answer: c. Risperidone and aripiprazole is approved by the U.S. FDA for the management of ASD with irritability.

Applied Behavior Analysis Treatment of Autism Spectrum Disorder:

Practice Guidelines for Healthcare Funders and Managers

SECOND EDITION

These standards are provided for informational purposes only and do not represent professional or legal advice. There are many variables that influence and direct the professional delivery of Applied Behavior Analysis (ABA) services. The BACB and authors of these standards assume no liability or responsibility for application of these standards in the delivery of ABA services. The standards presented in this document reflect the consensus of a number of subject matter experts, but do not represent the only acceptable practice. These standards also do not reflect or create any affiliation among those who participated in their development. The BACB does not warrant or guarantee that these standards will apply or should be applied in all settings. Instead, these standards are offered as an informational resource that should be considered in consultation with parents, behavior analysts, regulators, and healthcare funders and managers.

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PART II: Unique Features of Applied Behavior Analysis

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PART I:
Overview

SECTION 1:
EXECUTIVE SUMMARY

The purpose of this document is to inform decision-making regarding the use of Applied Behavior Analysis (ABA) to treat medically necessary conditions so as to develop, maintain, or restore, to the maximum extent practicable, the functioning of individuals with Autism Spectrum Disorder (ASD) in ways that are both efficacious and cost effective.[1]

The document is based on the best available scientific evidence and expert clinical opinion regarding the use of ABA as a behavioral health treatment for individuals diagnosed with ASD. The guidelines are intended to be a brief and user-friendly introduction to the delivery of ABA services for ASD. These guidelines are written for healthcare funders and managers, such as insurance companies, government health programs, employers, among others. The guidelines may also be useful for consumers, service providers, and regulatory bodies.

This document provides clinical guidelines and other information about ABA as a treatment for ASD. As a behavioral health treatment, ABA includes a number of unique clinical and delivery components. Thus, it is important that those charged with building a provider network understand these unique features of ABA.

This is the second edition of this resource manual and it will continue to be periodically updated to reflect changes in clinical practice and research findings. Additional references and information can be found in the appendices.

SECTION 2:
AUTISM SPECTRUM DISORDER AND APPLIED BEHAVIOR ANALYSIS

1 What is ASD?

ASD is characterized by varying degrees of difficulty in social interaction and verbal and nonverbal communication, and the presence of repetitive behavior and/or restricted interests.[2] Due to the variability and symptom presentation, no two individuals with an ASD diagnosis are the same with respect to how the disorder manifests and its impact on families. Because of the nature of the disorder, people with ASD often will not achieve the ability to function independently without appropriate medically necessary treatment.

2 What is ABA?

ABA is a well-developed scientific discipline among the helping professions that focuses on the analysis, design, implementation, and evaluation of social and other environmental modifications to produce meaningful changes in human behavior. ABA includes the use of direct observation, measurement, and functional analysis of the relations between environment and behavior. ABA uses changes in environmental events, including antecedent stimuli and consequences, to produce practical and significant changes in behavior. These relevant environmental events are usually identified through a variety of specialized assessment methods. ABA is based on the fact that an individual's behavior is determined by past and current environmental events in conjunction with organic variables such as their genetic endowment and physiological variables. Thus, when applied to ASD, ABA focuses on treating the problems of the disorder by altering the individual's social and learning environments.

The current guidelines are specific to ABA as a behavioral health treatment of ASD. Nevertheless, ABA has also been demonstrated as effective for treating the symptoms of a variety of conditions, including severe destructive behavior, substance abuse, dementia, pediatric feeding disorders, traumatic brain injury, among others.

The successful remediation of core deficits of ASD, and the development or restoration of abilities, documented in hundreds of peer-reviewed studies published over the past 50 years, has made ABA the standard of care for the treatment of ASD (see Appendix B).

SECTION 3: **CONSIDERATIONS**

- This document contains guidelines and recommendations that reflect established research findings and best clinical practices. However, individualized treatment is a defining feature and integral component of ABA, which is one reason why it has been so successful in treating this heterogeneous disorder.
- Some individuals diagnosed with ASD have co-occurring conditions including, but not limited to, intellectual disabilities, seizure disorders, psychiatric disorders, chromosomal abnormalities, feeding disorders, sleep disorders, elimination disorders, destructive behavior (for example, self-injury, aggression), and a variety of other conditions that require additional medical treatment. **These guidelines apply to individuals diagnosed with ASD with these co-occurring conditions, as research has established ABA as effective for these client populations as well.**
- The guidelines in this document are pertinent to the use of ABA as a behavioral health treatment to develop, maintain, or restore, to the maximum extent practicable, the functioning of an individual with ASD.
- These guidelines should not be used to diminish the availability, quality, or frequency of currently available ABA treatment services.
- Coverage of ABA treatment for ASD by healthcare funders and managers should not supplant responsibilities of educational or governmental entities.
- Specification of ABA in an educational or government program should not supplant ABA coverage by healthcare funders and managers.
- ABA treatment must not be restricted a priori to specific settings but instead should be delivered in those settings that maximize treatment outcomes for the individual client.
- This document provides guidance regarding ABA treatment only; other behavioral health treatments are not addressed.

PART II:

Unique Features of Applied Behavior Analysis

SECTION 1:
TRAINING AND CREDENTIALING OF BEHAVIOR ANALYSTS

ABA is a specialized behavioral health treatment approach and most graduate or postgraduate training programs in psychology, counseling, social work, or other areas of clinical practice do not provide in-depth training in this discipline. Thus, an understanding of the credentialing process of Behavior Analysts by the Behavior Analyst Certification Board® (BACB®) can assist health plans and their subscribers in identifying those providers who meet the basic competencies to practice ABA.

The formal training of professionals certified by the BACB is similar to that of other medical and behavioral health professionals. That is, they are initially trained within academia and then begin working in a supervised clinical setting with clients. As they gradually demonstrate the competencies necessary to manage complex clinical problems across a variety of clients and medical environments, they become independent practitioners. In summary, Behavior Analysts undergo a rigorous course of training and education, including an "internship" period in which they work under the direct supervision of an experienced Behavior Analyst.

It should be noted that other licensed professionals may have ABA included within their particular scope of training and competence. In addition, a small subset of clinicians may be licensed by another profession and also hold a credential from the BACB, thereby providing additional evidence of the nature and depth of their training in ABA.

Although healthcare funding and management of behavioral health treatments supervised by Behavior Analysts is relatively recent, Behavior Analysts– like other medical and behavioral health providers– rely upon strategies and procedures documented in peer-reviewed literature, established treatment protocols, and clinical decision-making frameworks. They continually evaluate the current state of the client and customize treatment options based on the results of direct observation and data from a range of other assessments. Behavior Analysts also solicit and integrate information from the client and family members and coordinate care with other professionals.

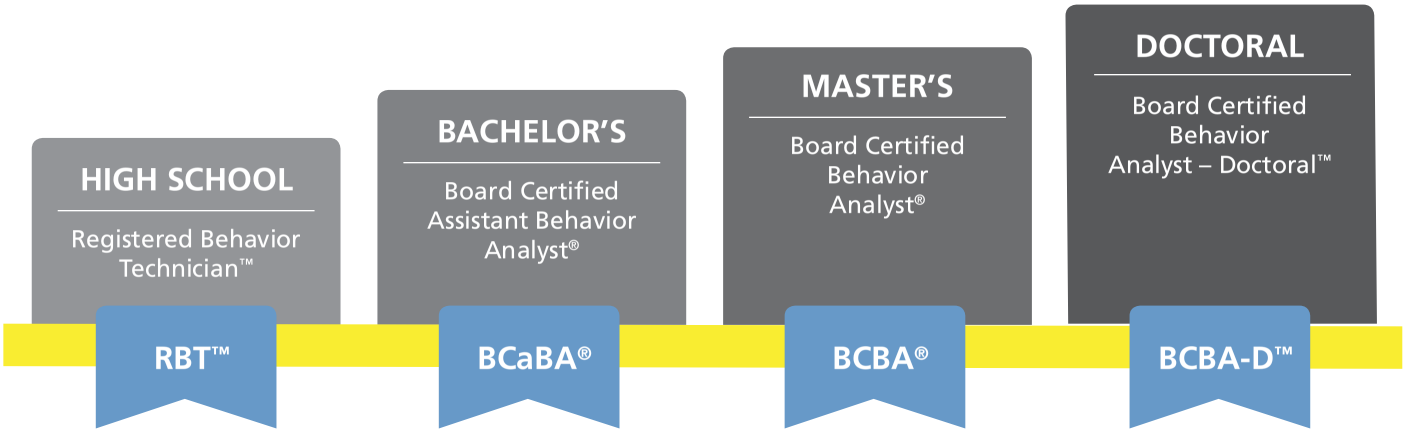
The Behavior Analyst Certification Board

The BACB is a nonprofit 501(c)(3) corporation established to meet professional credentialing needs identified by Behavior Analysts, governments, and consumers of behavior analysis services. The mission of the BACB is to protect consumers of behavior analysis services worldwide by systematically establishing, promoting, and disseminating professional standards. The BACB has established uniform content, standards, and criteria for the credentialing process that are designed to meet:

- The legal standards established through state, national, and case law;
- The accepted standards for certification programs; and
- The "best practice" and ethical standards of the behavior analysis profession.

The BCBA and BCaBA certification programs are currently accredited by the National Commission for Certifying Agencies (NCCA), the accreditation arm of the Institute for Credentialing Excellence. NCCA reviews and oversees all aspects related to ensuring the development and application of appropriate credentialing processes.

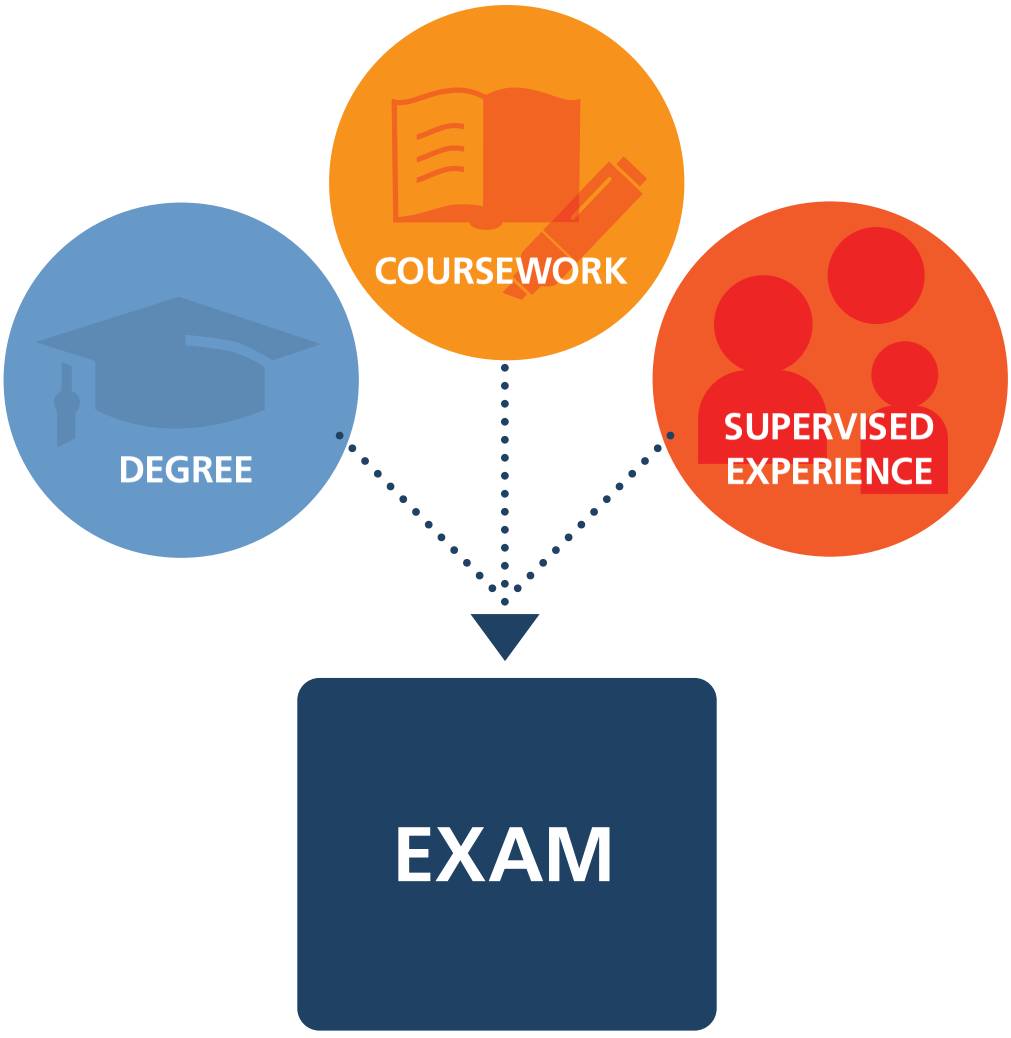
The BACB credentials and recognizes practitioners at four levels:



Practitioners credentialed at the BCBA-D and BCBA levels are defined as Behavior Analysts. The BACB requires that BCaBAs, or Assistant Behavior Analysts, work under the supervision of a BCBA-D or BCBA. RBTs must work under the supervision of a BCBA-D, BCBA, or BCaBA. Note: requirements for the RBT credential are described in Section 5 (Tiered Service-Delivery Models and Behavior Technicians).

Eligibility Requirements for Behavior Analysts & Assistant Behavior Analysts

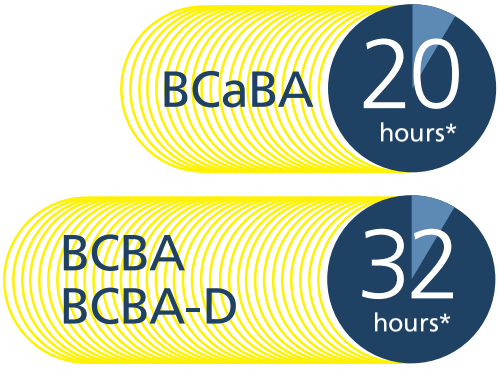
Applicants who meet the degree, coursework, and supervised experience eligibility requirements described in the next section are permitted to sit for either the BCBA or BCaBA examination (see figure below). Each examination is professionally developed to meet accepted examination standards and is based on the results of a formal job analysis and survey. In addition, all BACB examinations are offered under secure testing conditions and are professionally administered and scored.



Primary requirements for certification by the BACB.

Continuing Education and Maintaining Certification

BACB certificants are required to attest to their compliance with the organization's ethical and disciplinary rules (see below) on a biennial basis and obtain 20 (BCaBA) or 32 (BCBA, BCBA-D) hours* of continuing education every two years, 4 hours of which must relate to professional ethics. Organizations that employ Behavior Analysts and Assistant Behavior Analysts should support and provide this training as needed.



*continuing ed. credits every 2 years

Disciplinary Procedures

All certificants must regularly report any matter that might impact their ethical compliance. The BACB's ethical requirements may be found at www.BACB.com.

The BACB uses an online complaint system by which the organization is alerted to potential disciplinary violations. Each complaint is evaluated by the BACB legal department and then, based on its merit, is forwarded to a committee for review and processing. The committee members are senior BCBAs or BCBA-Ds selected for their knowledge and independence, and when advisable includes a member from the certificant's region. Disciplinary actions for certificants include, but are not limited to, advisory consultation, mandated continuing education, suspension of certification, or revocation of certification. Resulting disciplinary actions are publicly reported online.

Licensure of Behavior Analysts

BACB certification credentials or standards are currently the basis for licensure in the U.S. states where Behavior Analysts are licensed. Basing licensure on BACB credentials is cost effective and ensures that critical competencies regarding practice and research are periodically reviewed and updated by practitioners and researchers. Whether it is used as the basis for licensure or as a "free-standing" credential, BACB certification credentials are recognized in those states where insurance reform laws have been enacted and in other states as well.

SECTION 2:
APPLIED BEHAVIOR ANALYSIS IN THE TREATMENT OF AUTISM SPECTRUM DISORDER

Applied Behavior Analysis is a well-developed discipline among the helping professions, with a mature body of scientific knowledge, established standards for evidence-based practice, distinct methods of service delivery, recognized experience and educational requirements for practice, and identified sources of requisite education in universities. Professionals in ABA engage in the specific and comprehensive use of principles of learning, including operant and respondent learning, to address the needs of individuals with ASD in diverse settings. Services are provided and supervised by Behavior Analysts with expertise and formal training in ABA for the specific treatment of ASD.

1 Identifying ABA

Healthcare funders and managers must be able to recognize the following core characteristics of ABA:

1. An objective assessment and analysis of the client's condition by observing how the environment affects the client's behavior, as evidenced through appropriate data collection
2. Importance given to understanding the context of the behavior and the behavior's value to the individual, the family, and the community
3. Utilization of the principles and procedures of behavior analysis such that the client's health, independence, and quality of life are improved
4. Consistent, ongoing, objective assessment and data analysis to inform clinical decision-making

2 Essential Practice Elements of ABA

The four core characteristics listed above should be apparent throughout all phases of assessment and treatment in the form of these essential practice elements:

1. **Comprehensive assessment** that describes specific levels of behavior at baseline and informs subsequent establishment of treatment goals
2. An emphasis on **understanding the current and future value** (or social importance) of behavior(s) targeted for treatment
3. A practical focus on **establishing small units of behavior** which build towards larger, more significant changes in functioning related to improved health and levels of independence
4. Collection, quantification, and analysis of **direct observational data** on behavioral targets during treatment and follow-up to maximize and maintain progress toward treatment goals
5. Efforts to **design, establish, and manage the social and learning environment(s)** to minimize problem behavior(s) and maximize rate of progress toward all goals
6. An approach to the treatment of problem behavior that **links the function** of (or the reason for) the behavior to the programmed intervention strategies
7. Use of a **carefully constructed, individualized and detailed behavior-analytic treatment plan** that utilizes reinforcement and other behavioral principles and excludes the use of methods or techniques that lack consensus about their effectiveness based on evidence in peer-reviewed publications
8. Use of **treatment protocols that are implemented repeatedly, frequently, and consistently** across environments until discharge criteria are met
9. An emphasis on **ongoing and frequent direct assessment, analysis, and adjustments to the treatment plan** (by the Behavior Analyst) based on client progress as determined by observations and objective data analysis
10. **Direct support and training of family members and other involved professionals** to promote optimal functioning and promote generalization and maintenance of behavioral improvements
11. A **comprehensive infrastructure for supervision** of all assessment and treatment by a Behavior Analyst

3 Treatment Models

ABA treatment programs for ASD incorporate findings from hundreds of applied studies focused on understanding and treating ASD published in peer-reviewed journals over a 50-year span. Treatment may vary in terms of intensity and duration, the complexity and range of treatment goals, and the extent of direct treatment provided. Many variables, including the number, complexity, and intensity of behavioral targets and the client's own response to treatment help determine which model is most appropriate. Although existing on a continuum, these differences can be generally categorized as one of two treatment models: Focused or Comprehensive ABA Treatment.[3]

Focused ABA Treatment

Service Description

Focused ABA refers to treatment provided directly to the client for a limited number of behavioral targets. It is not restricted by age, cognitive level, or co-occurring conditions.

Focused ABA treatment may involve increasing socially appropriate behavior (for example, increasing social initiations) or reducing problem behavior (for example, aggression) as the primary target. Even when reduction of problem behavior is the primary goal, it is critical to also target increases in appropriate alternative behavior, because the absence of appropriate behavior is often the precursor to serious behavior disorders. Therefore, individuals who need to acquire skills (for example, communication, tolerating change in environments and activities, self-help, social skills) are also appropriate for Focused ABA.

Focused ABA treatment may involve increasing socially appropriate behavior … or reducing problem behavior.

Focused ABA plans are appropriate for individuals who (a) need treatment only for a limited number of key functional skills or (b) have such acute problem behavior that its treatment should be the priority.

Examples of key functional skills include, but are not limited to, establishing instruction-following, social communication skills, compliance with medical and dental procedures, sleep hygiene, self-care skills, safety skills, and independent leisure skills (for example, appropriate participation in family and community activities). Examples of severe problem behaviors requiring focused intervention

include, but are not limited to, self-injury, aggression, threats, pica, elopement, feeding disorders, stereotypic motor or vocal behavior, property destruction, noncompliance and disruptive behavior, or dysfunctional social behavior.

When prioritizing the order in which to address multiple treatment targets, the following should be considered:

- **Behavior that threatens the health or safety of the client or others or that constitute a barrier to quality of life** (for example, severe aggression, self-injury, property destruction, or noncompliance);
- **Absence of developmentally appropriate adaptive, social, or functional skills that are fundamental to maintain health, social inclusion, and increased independence** (for example, toileting, dressing, feeding, and compliance with medical procedures).

When the focus of treatment involves increasing socially appropriate behavior, treatment may be delivered in either an individual or small-group format. When conducted in a small group, typically developing peers or individuals with similar diagnoses may participate in the session. Members of the behavior-analytic team may guide clients through the rehearsal and practice of behavioral targets with each other. As is the case for all treatments, programming for generalization of skills outside the session is critical.

When the focus of treatment involves the reduction of severe problem behavior, the Behavior Analyst will determine which situations are most likely to precipitate problem behavior and, based on this information, begin to identify its potential purpose (or "function"). This may require conducting a functional analysis procedure to empirically demonstrate the function of the problem behavior. The results enable the Behavior Analyst to develop the most effective treatment protocol. When the function of the problem behavior is identified, the Behavior Analyst will design a treatment plan that alters the environment to reduce the motivation for problem behavior and/or establish a new and more appropriate behavior that serves the same function and therefore "replaces" the problem behavior.

In some cases, individuals with ASD display co-occurring severe destructive behavior disorders that require focused treatment in more intensive settings, such as specialized intensive-outpatient, day-treatment, residential, or inpatient programs. In these cases, these behavior disorders are given separate and distinct diagnoses (for example, Stereotypic Movement Disorder with severe self-injurious behavior). The ABA services delivered in these settings typically require higher staff-to-client ratios (for example, 2 to 3 staff for each client) and close on-site direction from the Behavior Analyst. In addition, such treatment programs often have specialized treatment environments (for example, treatment rooms designed for observation and to keep the client and the staff as safe as possible).

Comprehensive ABA Treatment

Service Description

Comprehensive ABA refers to treatment of the multiple affected developmental domains, such as cognitive, communicative, social, emotional, and adaptive functioning. Maladaptive behaviors, such as noncompliance, tantrums, and stereotypy are also typically the focus of treatment. Although there are different types of comprehensive treatment, one example is early intensive behavioral intervention where the overarching goal is to close the gap between the client's level of functioning and that of typically developing peers. These programs tend to range from 30-40 hours of treatment per week (plus direct and indirect supervision and caregiver training). Initially, this treatment model typically involves 1:1 staffing and gradually includes small-group formats as appropriate. Comprehensive treatment may also be appropriate for older individuals diagnosed with ASD, particularly if they engage in severe or dangerous behaviors across environments.

Initially, treatment is typically provided in structured therapy sessions, which are integrated with more naturalistic methods as appropriate. As the client progresses and meets established criteria for participation in larger or different settings, treatment in those settings and in the larger community should be provided. Training family members and other caregivers to manage problem behavior and to interact with the individual with ASD in a therapeutic manner is a critical component of this treatment model.

Typical Program Components

Treatment components should generally be drawn from the following areas (ordered alphabetically):

- adaptive and self-care skills
- attending and social referencing
- cognitive functioning
- community participation
- coping and tolerance skills
- emotional development
- family relationships
- language and communication
- play and leisure skills
- pre-academic skills
- reduction of interfering or inappropriate behaviors
- safety skills
- self-advocacy and independence
- self-management
- social relationships
- vocational skills

For information on treatment intensity and duration for various Focused and Comprehensive Treatments, see Section 4 (Service Authorization and Dosage).

4 Variations Within These Models

Treatment programs within any of these models vary along several programmatic dimensions, including the degree to which they are primarily provider- or client-directed (sometimes described as "structured vs. naturalistic"). Other variations include the extent to which peers or parents are involved in the delivery of treatment. Finally, some differ in terms of the degree to which they are "branded" and available commercially.

Decisions about how these various dimensions are implemented within individual treatment plans must reflect many variables, including the research base, the age of the client, specific aspects of the target behaviors, the client's rate of progress, demonstration of prerequisite skills, and resources required to support implementation of the treatment plan across settings.

5 ABA Procedures Employed In These Models

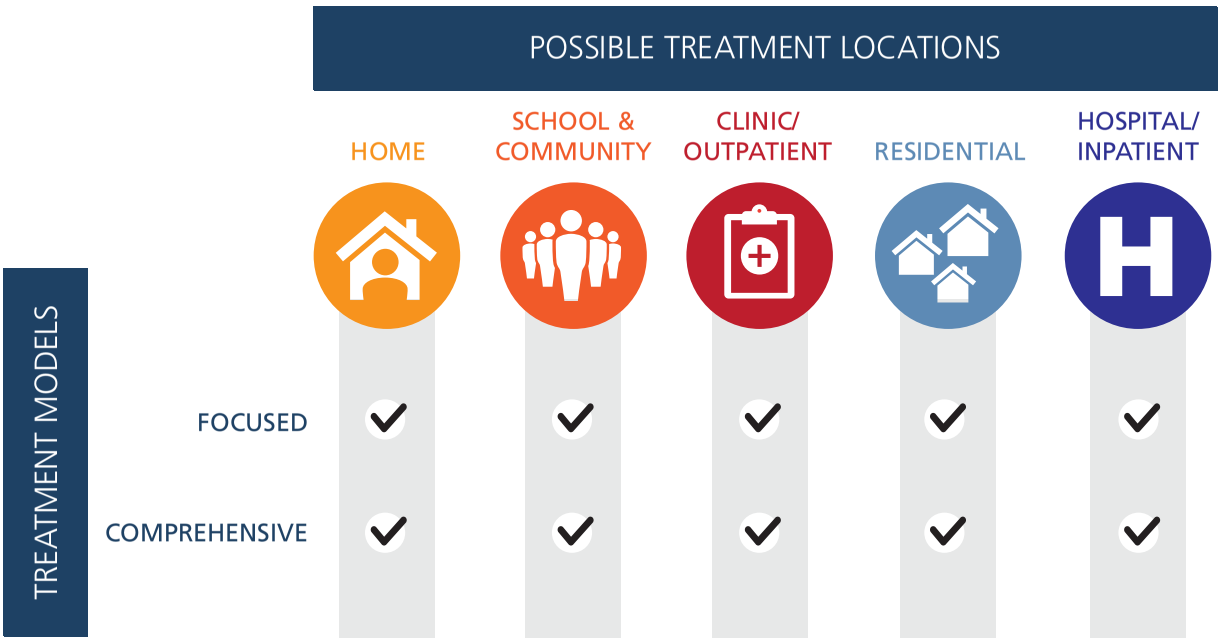
A large number of ABA procedures are routinely employed within the models previously described. They differ from one another in their complexity, specificity, and the extent to which they were designed primarily for use with individuals diagnosed with ASD. All are based on the principles of ABA and are employed with flexibility determined by the individual's specific treatment plan and response to treatment. If one ABA procedure or combination of ABA procedures is not producing the desired outcomes, a different one may be systematically implemented and evaluated for its effectiveness.

These procedures include different types of reinforcement and schedules of reinforcement, differential reinforcement, shaping, chaining, behavioral momentum, prompting and fading, behavioral skills training, extinction, functional communication training, discrete-trial teaching, incidental teaching, self-management, functional assessment, preference assessments, activity schedules, generalization and maintenance procedures, among many others (see the BACB Fourth Edition Task List). The field of behavior analysis is constantly developing and evaluating applied behavior-change procedures.

6 Locations Where Treatment is Delivered

The standard of care provides for treatment to be delivered consistently in multiple settings to promote generalization and maintenance of therapeutic benefits. No ABA model is specific to a particular location and all may be delivered in a variety of settings, including residential treatment facilities, inpatient and outpatient programs, homes, schools, transportation, and places in the community. Treatment across settings with multiple adults, siblings, and/or typically developing peers, under the supervision of a Behavior Analyst, supports generalization and maintenance of treatment gains. It should be noted that treatment might occur in multiple settings (for example, home, community, and transportation) on the same day. Treatment should not be denied or withheld because a caregiver cannot be at the treatment location consistently.

To ensure continuity of care, sufficient ABA treatment and consultation should be delivered in subsequent educational and therapeutic settings (for example, residence to school, hospital to home) to successfully support and transition individuals.



7 Client Age

Treatment should be based on the clinical needs of the individual and not constrained by age. Consistent ABA treatment should be provided as soon as possible after diagnosis, and in some cases services are warranted prior to diagnosis. There is evidence that the earlier treatment begins, the greater the likelihood of positive long-term outcomes. Additionally, ABA is effective across the life span. Research has not established an age limit beyond which ABA is ineffective.

There is evidence that the earlier treatment begins, the greater the likelihood of positive long-term outcomes.

8 Combining ABA With Other Forms Of Treatment

Findings from several studies show that an eclectic model, where ABA is combined with non-evidence-based treatment, is less effective than ABA alone. Therefore, treatment plans that combine ABA with additional procedures that lack scientific evidence as established by peer-reviewed publications should be considered eclectic and do not constitute ABA treatment.

SECTION 3:
ASSESSMENT, FORMULATION OF TREATMENT GOALS, AND MEASUREMENT OF CLIENT PROGRESS

1 The Assessment Process

A developmentally appropriate ABA assessment process must identify strengths and weaknesses across domains and potential barriers to progress. The information from this process is the basis for developing the individualized ABA treatment plan. An ABA assessment typically utilizes information obtained from multiple methods and multiple informants, including the following:

File Review

Information about medical status, prior assessment results, response to prior treatment and other relevant information may be obtained via file review and incorporated into the development of treatment goals and intervention. Examples of assessments that should be reviewed include intellectual and achievement tests, developmental assessments, assessments of comorbid mental health conditions, and evaluations of family functioning and needs. In some cases, if assessment information is incomplete, the Behavior Analyst should refer the client to other professionals for needed assessments.

Interviews and Rating Scales

Clients, caregivers, and other stakeholders, as appropriate, are included when selecting treatment goals, developing protocols, and evaluating progress. Behavior Analysts use interviews, rating scales, and social validity measures to assess perceptions of the client's skill deficits and behavioral excesses, and the extent to which these deficits and excesses impede the life of the individual and the family. Examples of rating scales include adaptive-behavior assessments, functional assessments, among others.

Direct Assessment and Observation

Direct observation and data collection and analysis are defining characteristics of ABA. The analysis of such data serves as the primary basis for identifying pretreatment levels of functioning, developing and adapting treatment protocols on an ongoing basis, and evaluating response to treatment and progress toward goals. Behavior should be directly observed in a variety of relevant naturally occurring settings and structured interactions. Examples of structured direct assessments include curricular assessment, structured observations of social interactions, among others.

Assessment from Other Professionals

Periodic assessments from other professionals may be helpful in guiding treatment or assessing progress. Examples might include assessment of general intellectual functioning, medical status, academic performance, among others.

2 Selecting and Monitoring Progress Toward Treatment Goals

Goals are prioritized based on their implications for the client's health and well-being, the impact on client, family and community safety, and contribution to functional independence. ABA treatment goals are identified based on the previously described assessment process. Each goal should be defined in a specific, measurable way to allow frequent evaluation of progress toward a specific mastery criterion. The number and complexity of goals should be consistent with the intensity and setting of service provision. The appropriateness of existing and new goals should be considered on a periodic basis.

The measurement system for tracking progress toward goals should be individualized to the client, the treatment context, the critical features of the behavior, and the available resources of the treatment environment. Specific, observable and quantifiable measures should be collected for each goal and should be sensitive enough to capture meaningful behavior change relative to ultimate treatment goals.

The results of standardized assessments may be used to monitor progress toward long-term treatment goals. However, IQ scores and other global assessments are not appropriate as sole determiners of an individual's response or nonresponse to ABA treatment. Many individuals may show substantial progress in important characteristics of the disorder (for example, language functioning, social functioning, repetitive behavior, adaptive behavior, safety and wellness, and co-morbid mental health

conditions) without a substantial change in measures of intellectual functioning. Thus, scores on such assessments should not be used to deny or discontinue ABA treatment.

3 Functional Assessment of Problem Behavior

When a client exhibits problem behavior at a level that is disruptive to the environment or dangerous to the client or others, a functional assessment is warranted. Functional assessment refers to the overall process of identifying the aspects of the environment that may contribute to the development and continued occurrence of problem behavior. That is, functional assessment is designed to identify where, when and the likely reasons why a problem behavior occurs. Such information is then directly incorporated into the problem behavior treatment plan in the form of a function-based intervention.

- The functional assessment process typically includes multiple sources of information such as interviews with caregivers, structured ratings scales, and collection of direct observation data and consideration of potential medical conditions that may impact problem behavior.
- Direct observation may take the form of assessment of ongoing interactions in the natural environment or the form of a functional analysis.
- Functional analysis refers to directly changing environmental events and evaluating the impact of those changes on the level of problem behavior via direct observation. Functional analyses can be complex and may require higher staffing ratios and more direction by the Behavior Analyst.

4 Duration and Frequency of Assessment

The assessment process required for the initial development of Comprehensive treatment programs may take 20 hours or longer. Subsequent assessments and assessments for Focused treatments that involve a small number of uncomplicated goals often require fewer hours. The functional assessment process for severe problem behavior is often complex and may require considerably longer durations.

Assessment of overall progress toward comprehensive treatment goals should be summarized at regular intervals (for example, on a semiannual basis).

SECTION 4:
SERVICE AUTHORIZATION AND DOSAGE

1 Service Authorization

Authorization periods should not typically be for less than 6 months and may involve some or all of the following services. If there is a question as to the appropriateness or effectiveness of ABA for a particular client, a review of treatment data may be conducted more frequently (for example, after 3 months of treatment). In addition, if third-party clinical review (also known as peer review) is required by a healthcare funder or manager, the reviewer should be a Behavior Analyst with experience in ABA treatment of ASD.

The following list represents common services* that should be authorized for optimal treatment outcome. Others may be appropriate.

1. Behavior-Analytic Assessment
2. Treatment Plan Development and Modification
3. Direct Treatment to Individuals or Groups with Implementation by Behavior Analysts and/or Behavior Technicians.
4. Supervision (both direct and indirect) by Behavior Analysts
5. Travel to Ensure Equitable Access to Services (for example, rural and underserved areas)
6. Parent and Community Caregiver Training to Individuals or Groups
7. Consultation to Ensure Continuity and/or Coordination of Care
8. Discharge Planning

*These services may be effectively delivered via telehealth in jurisdictions that permit such delivery systems.

Critical Features of a Treatment Plan for Service Authorization *(page 1 of 2)*

I. Patient Information

II. Reason for Referral

III. Brief Background Information

a. Demographics (name, age, gender, diagnosis)
b. Living situation
c. Home/school/work information

IV. Clinical Interview

a. Information gathering on problem behaviors, including developing operational definitions of primary area of concern and information regarding possible function of behavior

V. Review of Recent Assessments/Reports (file review)

a. Any recent functional behavior assessment, cognitive testing, and/or progress reports

VI. Assessment Procedures & Results

a. Brief description of assessments, including their purpose
    - INDIRECT ASSESSMENTS:
    - › Provide summary of findings for each assessment (graphs, tables, or grids)
    - DIRECT ASSESSMENTS:
    - › Provide summary of findings for each assessment (graphs, tables or grids)

b. Target behaviors are operationally defined, including baseline levels

VII. Treatment Plan (Focused ABA)

a. Treatment setting
b. Operational definition for each behavior and goal
c. Specify behavior management (that is, behavior reduction and/or acquisition) procedures:
    - Antecedent-based interventions
    - Consequence-based interventions

d. Describe data collection procedures
e. Proposed goals and objectives*

Critical Features of a Treatment Plan for Service Authorization *(page 2 of 2)*

VIII. Treatment Plan (Skill Acquisition – Comprehensive ABA)

a. Treatment setting
b. Instructional methods to be used
c. Operational definition for each skill
d. Describe data collection procedures
e. Proposed goals and objectives*

IX. Parent/Caregiver Training

a. Specify parent training procedures
b. Describe data collection procedures
c. Proposed goals and objectives*

X. Number of Hours Requested

a. Number of hours needed for each service
b. Clinical summary that justifies hours requested
c. Billing codes requested (for example, CPT, HCPCS)

XI. Coordination of Care

XII. Transition Plan

XIII. Discharge Plan

XIV. Crisis Plan

** Each goal and objective must include:*

- Current level (baseline)
- Behavior parent/caregiver is expected to demonstrate, including condition under which it must be demonstrated and mastery criteria (the objective or goal)
- Date of introduction
- Estimated date of mastery
- Specify plan for generalization
- Report goal as met, not met, modified (include explanation)

2 Treatment Dosage

Treatment dosage, which is often referenced in the treatment literature as "intensity," will vary with each client and should reflect the goals of treatment, specific client needs, and response to treatment. Treatment dosage should be considered in two distinct categories: intensity and duration.

Intensity

Intensity is typically measured in terms of number of hours per week of direct treatment. Intensity often determines whether the treatment falls into the category of either Focused or Comprehensive.

Focused ABA Treatment

Focused ABA generally ranges from **10-25 hours per week** of direct treatment (plus direct and indirect supervision and caregiver training). However, certain programs for severe destructive behavior **may require more than 25 hours per week** of direct therapy (for example, day treatment or inpatient program for severe self-injurious behavior).

Comprehensive ABA Treatment

Treatment often involves an intensity level of **30-40 hours of 1:1 direct treatment to the client per week**, not including caregiver training, supervision, and other needed services. However, very young children may start with a few hours of therapy per day with the goal of increasing the intensity of therapy as their ability to tolerate and participate permits. Treatment hours are subsequently increased or decreased based on the client's response to treatment and current needs. Hours may be increased to more efficiently reach treatment goals. Decreases in hours of therapy per week typically occur when a client has met a majority of the treatment goals and is moving toward discharge.

Although the recommended number of hours of therapy may seem high, this is based on research findings regarding the intensity required to produce good outcomes. It should also be noted that time spent away from therapy may result in the individual falling further behind typical developmental trajectories. Such delays will likely result in increased costs and greater dependence on more intensive services across their life span.

Duration

Treatment duration is effectively managed by evaluating the client's response to treatment. This evaluation can be conducted prior to the conclusion of an authorization period. Some individuals will continue to demonstrate medical necessity and require continued treatment across multiple authorization periods. See Section 8 for information on discharge planning.

SECTION 5:
TIERED SERVICE-DELIVERY MODELS AND BEHAVIOR TECHNICIANS

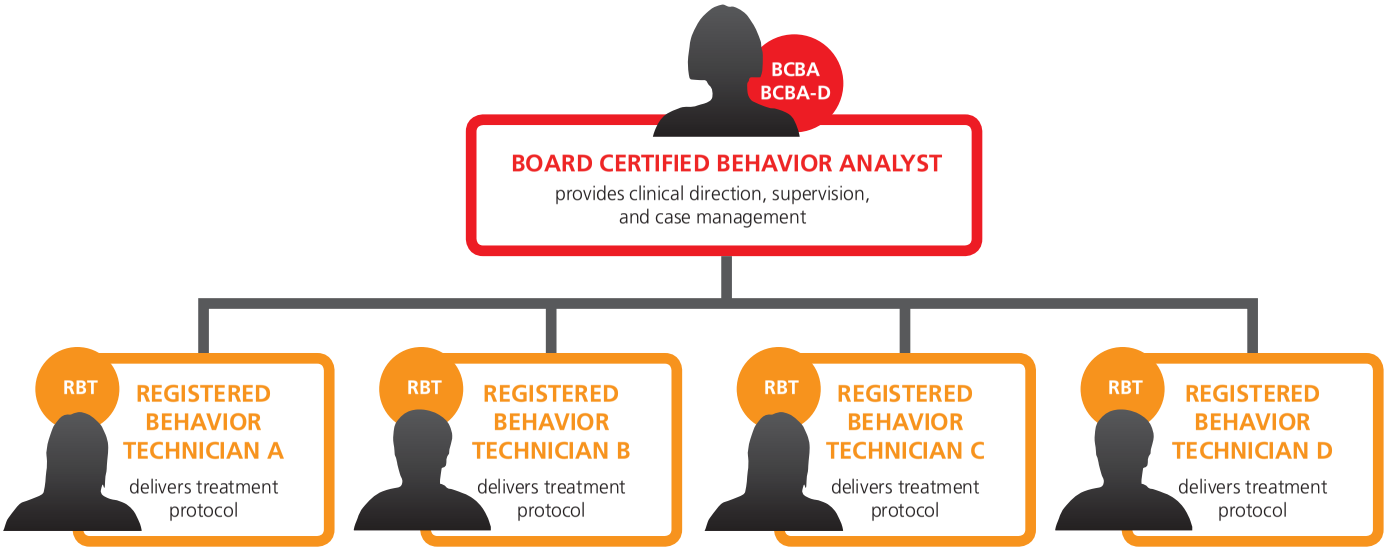
Most ABA treatment programs involve a tiered service-delivery model in which the Behavior Analyst designs and supervises a treatment program delivered by Assistant Behavior Analysts and Behavior Technicians.

1 Description of a Tiered Service-Delivery Model

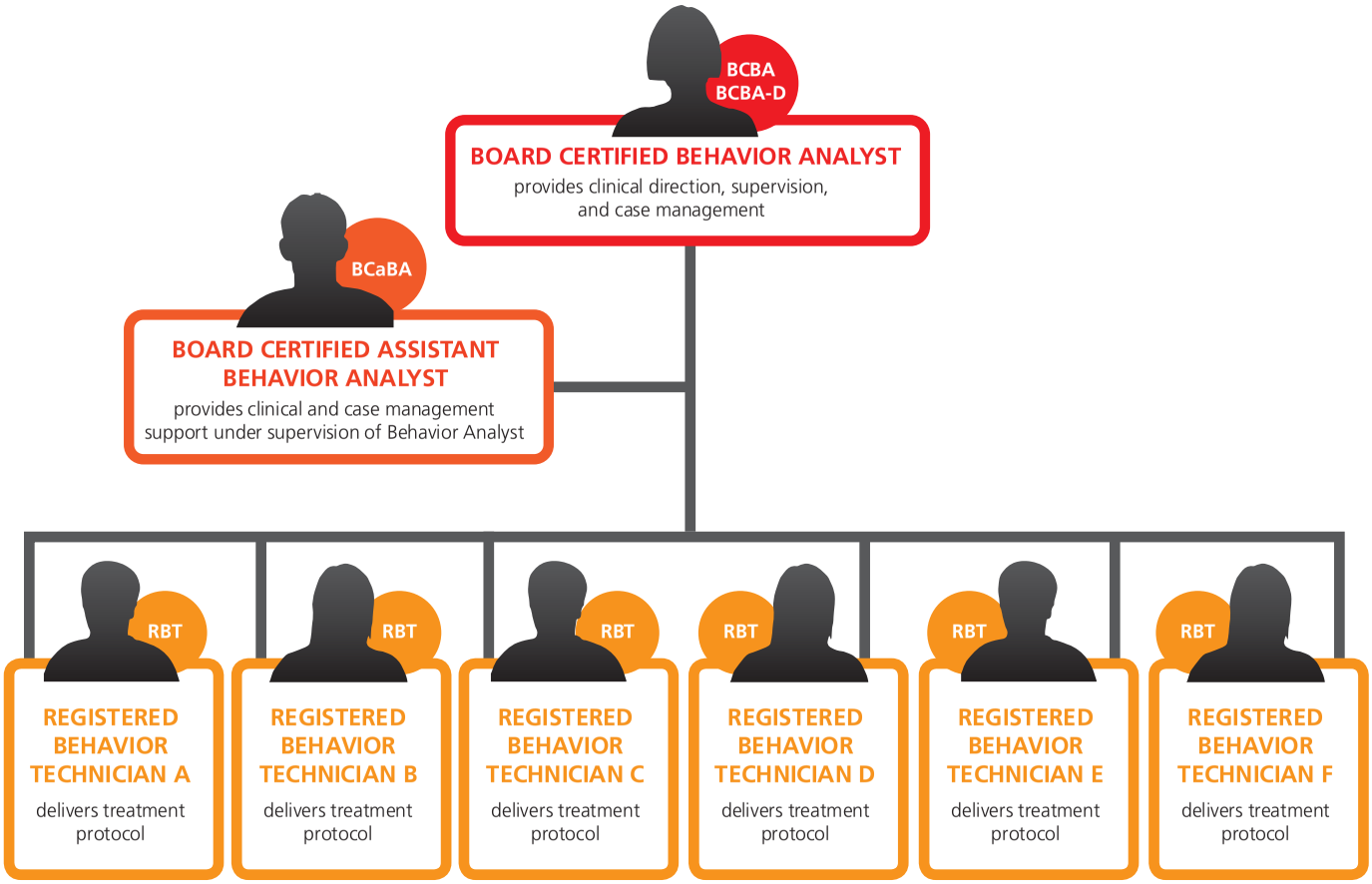
Behavior Analyst's clinical, supervisory, and case management activities are often supported by other staff such as Assistant Behavior Analysts working within the scope of their training, practice, and competence.

Following are two examples of tiered service-delivery models (among others), an organizational approach to treatment delivery considered cost-effective in delivering desired outcomes.

In the first example (below), the Behavior Analyst oversees a treatment team of Behavior Technicians.



In the second example (below), the Behavior Analyst is supported by an Assistant Behavior Analyst; the two of them jointly oversee a treatment team of Behavior Technicians.



Such models assume the following:

1. The BCBA or BCBA-D is responsible for all aspects of clinical direction, supervision, and case management, including activities of the support staff (for example, a BCaBA) and Behavior Technicians.
2. The BCBA or BCBA-D must have knowledge of each member of the treatment team's ability to effectively carry out clinical activities before assigning them.
3. The BCBA and BCBA-D must be familiar with the client's needs and treatment plan and regularly observe the Behavior Technician implementing the plan, regardless of whether or not there is clinical support provided by a BCaBA.

2 Rationales for a Tiered Service-Delivery Model

- Tiered service-delivery models that rely on the use of Assistant Behavior Analysts and Behavior Technicians have been the primary mechanism for achieving many of the significant improvements in cognitive, language, social, behavioral, and adaptive domains that have been documented in the peer-reviewed literature.[4]
- The use of carefully trained and well-supervised Assistant Behavior Analysts and Behavior Technicians is a common practice in ABA treatment.[5,6]
- Their use produces more cost-effective levels of service for the duration of treatment.
- The use of tiered service-delivery model enables healthcare funders and managers to ensure adequate provider networks and deliver medically necessary treatment.
- It additionally permits sufficient expertise to be delivered to each client at the level needed to reach treatment goals. This is critical as the level of supervision required may shift rapidly in response to client progress or need.
- Tiered service-delivery models can also help with treatment delivery to families in rural and underserved areas, as well as clients and families who have complex needs.

3 Selection, Training, and Supervision of Behavior Technicians

- Behavior Technicians should receive specific, formal training before providing treatment. One way to ensure such training is through the Registered Behavior Technician credential (see page 30).

- Case assignment should match the needs of the client with the skill level and experience of the Behavior Technician. Before working with a client, the Behavior Technician must be sufficiently prepared to deliver the treatment protocols. This includes a review by the Behavior Analyst of the client's history, current treatment programs, behavior reduction protocols, data collection procedures, etc.

- Caseloads for the Behavior Technician are determined by the:
    - complexity of the cases
    - experience and skills of the Behavior Technician
    - number of hours per week the Behavior Technician is employed
    - intensity of hours of therapy the client is receiving

- Quality of implementation (treatment integrity checks) should be monitored on an ongoing basis. This should be more frequent for new staff, when a new client is assigned, or when a client has challenging behaviors or complex treatment protocols are involved.

- Behavior Technicians should receive supervision and clinical direction on treatment protocols on a weekly basis for complex cases or monthly for more routine cases. This activity may be in client briefings with other members of the treatment team including the supervising Behavior Analyst, or individually, and with or without the client present. The frequency and format should be dictated by an analysis of the treatment needs of the client to make optimal progress.

- Although hiring qualifications and initial training are important, there must be ongoing observation, training, and direction to maintain and improve the Behavior Technician's skills while implementing ABA-based treatment.

Requirements for the Registered Behavior Technician (RBT) Credential

Eligibility Requirements

Applicants for the RBT credential must:

- ❑ Be at least 18 years of age
- ❑ Possess a minimum of a high school diploma or national equivalent
- ❑ Successfully complete a criminal background registry check at the time of application
- ❑ Complete a 40-hour training program (conducted by a BACB certificant) based on the RBT Task List
- ❑ Pass the RBT Competency Assessment administered by a BACB certificant

Ongoing Practice Requirements

RBTs must:

- ❑ Receive ongoing supervision by a BACB certificant for a minimum of 5% of the hours spent providing applied behavior-analytic services per month (including at least 2 face-to-face, synchronous supervisory contacts.
- ❑ Abide by a subset of the BACB's Professional and Ethical Compliance Code for Behavior Analysts identified as relevant for RBTs.

SECTION 6:
CASE SUPERVISION

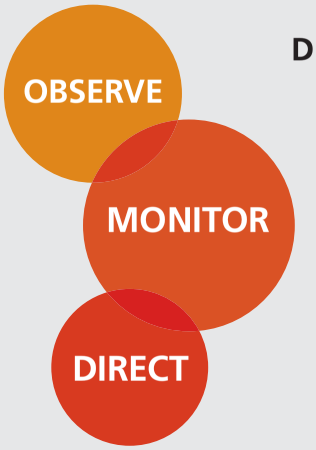
ABA treatment is often characterized by the number of direct treatment hours per week. However, it is also critical to consider the required levels of additional case supervision (aka clinical direction) hours by the Behavior Analyst. Case supervision begins with assessment and continues through client discharge. ABA treatment requires comparatively high levels of case supervision to ensure effective outcomes because of (a) the individualized nature of treatment, (b) the use of a tiered service-delivery model, (c) the reliance on frequent collection and analysis of client data, and (d) the need for adjustments to the treatment plan.

This section will describe the case supervision activities that are individualized for the client and medically necessary to achieve treatment goals. Routine organizational activities (for example, timekeeping, employee evaluations, among others) that are not involved in individualized clinical treatment are not included here.

1 Case Supervision Activities

Case supervision activities can be described as those that involve contact with the client or caregivers (direct supervision, also known as clinical direction) and those that do not (indirect supervision). Both direct and indirect case supervision activities are critical to producing good treatment outcomes and should be included in service authorizations. It should be noted that direct case supervision occurs concurrently with the delivery of direct treatment to the client. On average, direct supervision time accounts for 50% or more of case supervision.

The list below, while not exhaustive, identifies some of the most common case supervision activities:



Direct Supervision Activities

- Directly observe treatment implementation for potential program revision
- Monitor treatment integrity to ensure satisfactory implementation of treatment protocols
- Directing staff and/or caregivers in the implementation of new or revised treatment protocols (client present)

Indirect Supervision Activities

- Develop treatment goals, protocols, and data collection systems
- Summarize and analyze data[8]
- Evaluate client progress towards treatment goals
- Adjust treatment protocols based on data
- Coordination of care with other professionals
- Crisis intervention
- Report progress towards treatment goals
- Develop and oversee transition/discharge plan
- Review client progress with staff without the client present to refine treatment protocols
- Directing staff and/or caregivers in the implementation of new or revised treatment protocols (client absent)

Supervisory Staff Qualifications:

BEHAVIOR ANALYST

Qualifications

- ❑ BCBA-D/BCBA or License in related field
- ❑ Competence in supervising and developing ABA treatment programs for clients with ASD[9]

Responsibilities

- ❑ Summarize and analyze data
- ❑ Evaluate client progress towards treatment goals
- ❑ Supervise implementation of treatment
- ❑ Adjust treatment protocols based on data
- ❑ Monitor treatment integrity
- ❑ Train and consult with caregivers and other professionals
- ❑ Evaluate risk management and crisis management
- ❑ Ensure satisfactory implementation of treatment protocols
- ❑ Report progress towards treatment goals
- ❑ Develop and oversee transition/discharge plan

ASSISTANT BEHAVIOR ANALYST

Qualifications

- ❑ BCaBA (preferred)

Responsibilities

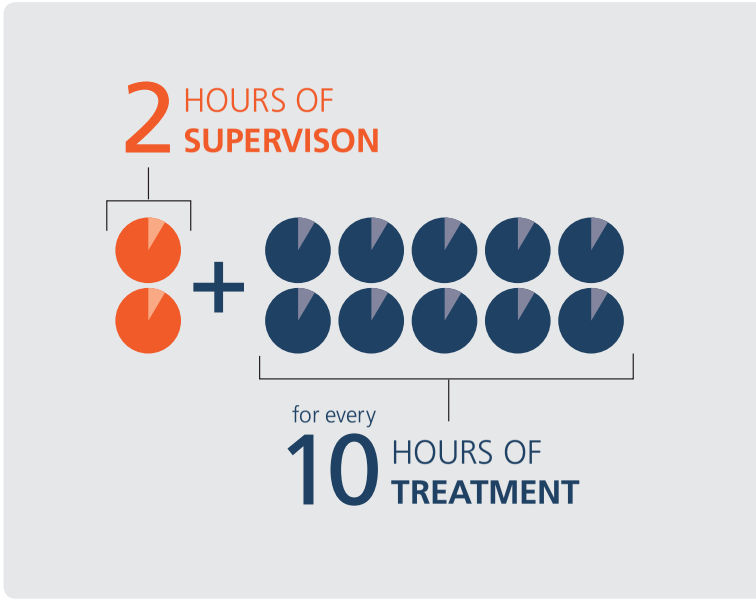
- ❑ Various supervisory tasks that have been delegated and are overseen by the Behavior Analyst

2 Modality

Some case supervision activities occur in vivo; others can occur remotely (for example, via secure telemedicine or virtual technologies). However, telemedicine should be combined with in vivo supervision. In addition, some case supervision activities are appropriate for small groups. Some indirect case supervision activities are more effectively carried out outside of the treatment setting.

3 Dosage of Case Supervision

Although the amount of supervision for each case must be responsive to individual client needs, **2 hours for every 10 hours of direct treatment** is the general standard of care. When **direct treatment is 10 hours per week or less, a minimum of 2 hours per week** of case supervision is generally required. Case supervision may need to be temporarily increased to meet the needs of individual clients at specific time periods in treatment (for example, initial assessment, significant change in response to treatment).



This ratio of case supervision hours to direct treatment hours reflects the complexity of the client's ASD symptoms and the responsive, individualized, data-based decision-making which characterizes ABA treatment. A number of factors increase or decrease case supervision needs on a shorter- or longer-term basis. These include:

- treatment dosage/intensity
- barriers to progress
- issues of client health and safety (for example, certain skill deficits, dangerous problem behavior)
- the sophistication or complexity of treatment protocols
- family dynamics or community environment
- lack of progress or increased rate of progress
- changes in treatment protocols
- transitions with implications for continuity of care

4 Caseload Size

Behavior Analysts should carry a caseload that allows them to provide appropriate case supervision to facilitate effective treatment delivery and ensure consumer protection. Caseload size for the Behavior Analyst is typically determined by the following factors:

- complexity and needs of the clients in the caseload
- total treatment hours delivered to the clients in the caseload
- total case supervision and clinical direction required by caseload
- expertise and skills of the Behavior Analyst
- location and modality of supervision and treatment (for example, center vs. home, individual vs. group, telehealth vs. in vivo)
- availability of support staff for the Behavior Analyst (for example, a BCaBA)

The recommended caseload range for one (1) Behavior Analyst supervising
Focused treatment

› ***without support of a BCaBA*** is 10 - 15.*
› ***with support of one (1) BCaBA*** is 16 - 24.*

Additional BCaBAs permit modest increases in caseloads.

The recommended caseload range for one (1) Behavior Analyst supervising
Comprehensive treatment

› ***without support by a BCaBA*** is 6 - 12.
› ***with support by one (1) BCaBA*** is 12 - 16.

Additional BCaBAs permit modest increases in caseloads.

* Focused treatment for severe problem behavior is complex and requires considerably greater levels of case supervision, which will necessitate smaller caseloads.

SECTION 7:
WORKING WITH CAREGIVERS AND OTHER PROFESSIONALS

1 Family Members/Others as Important Contributors to Outcomes

Family members, including siblings, and other community caregivers should be included in various capacities and at different points during both Focused and Comprehensive ABA treatment programs. In addition to providing important historical and contextual information, caregivers must receive training and consultation throughout treatment, discharge, and follow-up.

The dynamics of a family and how they are impacted by ASD must be reflected in how treatment is implemented. In addition, the client's progress may be affected by the extent to which caregivers support treatment goals outside treatment hours. Their ability to do this will be partially determined by how well matched the treatment protocols are to the family's own values, needs, priorities, and resources.

The need for family involvement, training and support reflects the following:

- Caregivers frequently have unique insight and perspective about the client's functioning, information about preferences, and behavioral history.
- Caregivers may be responsible for provision of care, supervision, and dealing with challenging behaviors during all waking hours outside of school or a day treatment program. A sizeable percent¬age of individuals with ASD present atypical sleeping patterns. Therefore, some caregivers may be responsible for ensuring the safety of their children and/or implementing procedures at night and may, themselves, be at risk for problems associated with sleep deprivation.
- Caring for an individual with ASD presents many challenges to caregivers and families. Studies have documented the fact that parents of children and adults with ASD experience higher levels of stress than those of parents with typically developing children or even parents of children with other kinds of special needs.

- The behavioral problems commonly encountered with persons diagnosed with ASD (for example, stereotypy, aggression, tantrums) secondary to the social and language deficits associated with ASD, often present particular challenges for caregivers as they attempt to manage their behavior problems. Typical parenting strategies are often insufficient to enable caregivers to improve or manage their child's behavior, which can impede the child's progress towards improved levels of functioning and independence.
- Note that while family training is supportive of the overall treatment plan, it is not a replacement for professionally directed and implemented treatment.

2 Parent and Caregiver Training

Training is part of both Focused and Comprehensive ABA treatment models. Although parent and caregiver training is sometimes delivered as a stand-alone treatment, there are relatively few clients for whom this would be recommended as the sole or primary form of treatment. This is due to the severity and complexity of behavior problems and skill deficits that can accompany a diagnosis of ASD.

Training of parents and other caregivers usually involves a systematic, individualized curriculum on the basics of ABA. It is common for treatment plans to include several objective and measurable goals for parents and other caregivers. Training emphasizes skills development and support so that caregivers become competent in implementing treatment protocols across critical environments. Training usually involves an individualized behavioral assessment, a case formulation, and then customized didactic presentations, modeling and demonstrations of the skill, and practice with in vivo support for each specific skill. Ongoing activities involve supervision and coaching during implementation, problem-solving as issues arise, and support for implementation of strategies in new environments to ensure optimal gains and promote generalization and maintenance of therapeutic changes. Please note that such training is not accomplished by simply having the caregiver or guardian present during treatment implemented by a Behavior Technician.

Training of parents and other caregivers usually involves a systematic, individualized curriculum on the basics of ABA.

The following are common areas for which caregivers often seek assistance. These are typically addressed in conjunction with a Focused or Comprehensive ABA treatment program.

- Generalization of skills acquired in treatment settings into home and community settings
- Treatment of co-occurring behavior disorders that risk the health and safety of the child or others in the home or community settings, including reduction of self-injurious or aggressive behaviors against siblings, caregivers, or others; establishment of replacement behaviors which are more effective, adaptive, and appropriate
- Adaptive skills training such as functional communication, participation in routines which help maintain good health (for example, participation in dental and medical exams, feeding, sleep) including target settings where it is critical that they occur
- Contingency management to reduce stereotypic, ritualistic, or perseverative behaviors and functional replacement behaviors as previously described
- Relationships with family members, such as developing appropriate play with siblings

3 Coordination with Other Professionals

Consultation with other professionals helps ensure client progress through efforts to coordinate care and ensure consistency including during transition periods and discharge.

Treatment goals are most likely to be achieved when there is a shared understanding and coordination among all healthcare providers and professionals. Examples include collaboration between the prescribing physician and the Behavior Analyst to determine the effects of medication on treatment targets. Another example involves a consistent approach across professionals from different disciplines in how behaviors are managed across environments and settings. Professional collaboration that leads to consistency will produce the best outcomes for the client and their families.

Differences in theoretical orientations or professional styles may sometimes make coordination difficult. If there are treatment protocols that dilute the effectiveness of ABA treatment, these differences must be resolved to deliver anticipated benefits to the client.

The BACB's ethical codes (the current *Guidelines for Responsible Conduct for Behavior Analysts* and the impending *Professional and Ethical Compliance Code for Behavior Analysts*) require the Behavior Analyst to recommend the **most** effective scientifically supported treatment for each client. The Behavior Analyst must also review and evaluate the likely effects of alternative treatments, including those provided by other disciplines as well as no treatment.

In addition, Behavior Analysts refer out to professionals from other disciplines when there are client conditions that are beyond the training and competence of the Behavior Analyst, or where coordination of care with such professionals is appropriate. Examples would include, but are not limited to, a suspected medical condition or psychological concerns related to an anxiety or mood disorder.

SECTION 8:
DISCHARGE, TRANSITION PLANNING, AND CONTINUITY OF CARE

The desired outcomes for discharge should be specified at the initiation of services and refined throughout the treatment process. Transition and discharge planning from a treatment program should include a written plan that specifies details of monitoring and follow-up as is appropriate for the individual and the family. Parents, community caregivers, and other involved professionals should be consulted as the planning process accelerates with 3-6 months prior to the first change in service.

A description of roles and responsibilities of all providers and effective dates for behavioral targets that must be achieved prior to the next phase should be specified and coordinated with all providers, the client, and family members.

Discharge and transition planning from all treatment programs should generally involve a gradual step down in services. Discharge from a Comprehensive ABA treatment program often requires 6 months or longer. For example, a client in a Comprehensive treatment program might step down to a Focused treatment model to address a few remaining goals prior to transition out of treatment.

Discharge

Services should be reviewed and evaluated and discharge planning begun when:

- The client has achieved treatment goals; OR
- The client no longer meets the diagnostic criteria for ASD (as measured by appropriate standardized protocols); OR
- The client does not demonstrate progress towards goals for successive authorization periods; OR
- The family is interested in discontinuing services; OR
- The family and provider are not able to reconcile important issues in treatment planning and delivery.

When there are questions about the appropriateness or efficacy of services in an individual case, including pursuant to any internal or external appeal relating to insurance benefits, the reviewing body should include a Behavior Analyst with experience in ABA treatment of ASD.

PART III:
Appendices

APPENDIX A:
ELIGIBILITY REQUIREMENTS FOR BACB CERTIFICATION

BCBA Eligibility Requirements

A. Degree Requirement (effective 2016)

Possession of a minimum of a master's degree from an accredited university that was (a) conferred in behavior analysis, education, or psychology, or (b) conferred in a degree program in which the candidate completed a BACB approved course sequence.

B. Coursework and Experience Requirements

1. Coursework:

The applicant must complete 270 classroom hours of graduate level instruction in the following content areas and for the number of hours specified:

a. Ethical and Professional Conduct – 45 hours

- The content must be taught in 1 or more freestanding courses devoted to ethical and professional conduct.

b. Concepts and Principles of Behavior Analysis – 45 hours

- The content should be based on the BACB Foundational Knowledge List.

c. Research Methods in Behavior Analysis

- Measurement (including Data Analysis) – 25 hrs
- Experimental Design – 20 hrs

d. Applied Behavior Analysis

- Fundamental Elements of Behavior Change & Specific Behavior Change Procedures – 45 hrs
- Identification of the Problem & Assessment – 30 hrs
- Intervention & Behavior Change Considerations – 10 hrs
- Behavior Change Systems – 10 hrs
- Implementation, Management and Supervision – 10 hrs

e. Discretionary – 30 hours

(any one or more of the content areas above OR for any applications of behavior analysis)

2: Experience.

1500 hours **Supervised Independent Fieldwork** (non-university based); biweekly supervision required	OR	**1000 hours** **Practicum** (university based); weekly supervision required	OR	**750 hours** **Intensive Practicum** (university based); twice-weekly supervision required

Two additional pathways to the BCBA credential exist for university faculty and senior, doctoral-level practitioners. Details on these pathways are available at www.BACB.com.

BCBA-D Eligibility Requirements

The BCBA-D is a designation that recognizes doctoral-level BCBAs who:

1. Are actively certified as a BCBA; AND
2. Have earned a doctoral degree from a graduate program accredited by the Association for Behavior Analysis International; OR
3. Have earned a doctoral degree from an accredited university in which he or she conducted a behavior-analytic dissertation (including at least 1 experiment); AND passed at least 2 behavior analysis courses as part of the doctoral program of study; AND met all BCBA coursework requirements prior to receiving the doctoral degree.

BCaBA Eligibility Requirements

A. Degree Requirement

Possession of a minimum of a bachelor's degree from an accredited university.

B. Coursework and Experience Requirements

1. Coursework:

The applicant must complete 180 classroom hours of instruction in the following content areas and for the number of hours specified:

a. Ethical and Professional Conduct – 15 hours

b. Concepts and Principles of Behavior Analysis – 45 hours

- The content should be based on the BACB Foundational Knowledge List.

c. Research Methods in Behavior Analysis

- Measurement (including Data Analysis) – 10 hrs
- Experimental Design – 5 hrs

d. Applied Behavior Analysis

- Fundamental Elements of Behavior Change & Specific Behavior Change Procedures – 45 hrs
- Identification of the Problem & Assessment – 30 hrs
- Intervention & Behavior Change Considerations – 5 hrs
- Behavior Change Systems – 5 hrs
- Implementation, Management and Supervision – 5 hrs

e. Discretionary – 15 hours
(any one or more of the content areas above OR for any applications of behavior analysis)

2. Experience:

1000 hours Supervised Independent Fieldwork (non-university based); biweekly supervision required	OR	**670 hours Practicum** (university based); weekly supervision required	OR	**500 hours Intensive Practicum** (university based); twice-weekly supervision required

APPENDIX B:
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APPENDIX C:
FOOTNOTES

[1] Throughout this document the term Autism Spectrum Disorder (ASD) is used to refer to a group of complex neurological disorders that are sometimes referred to as Autistic Disorder, Pervasive Developmental Disorder Not Otherwise Specified, Asperger's Syndrome, High Functioning Autism, among others.

[2] ICD and DSM systems for Autistic Disorder and Autistic Spectrum Disorder.

[3] Focused and Comprehensive ABA exist on a continuum that reflects the number of target behaviors and hours of direct treatment and supervision.

[4] These staff are competent to administer treatment protocols and are often referred to by a variety of terms including ABA therapist, senior therapist, paraprofessional tutor, or direct line staff.

[5] The training and responsibilities of Behavior Technicians who implement treatment protocols are distinctly different from those of workers who perform caretaking functions.

[6] When possible, several Behavior Technicians are often assigned to each case to promote generalized and sustained treatment benefits for the client. This also helps prevent a lapse in treatment hours due to staff illness, scheduling availability, and turnover, etc. Intensive, comprehensive treatment programs may have 4-5 Behavior Technicians assigned to a single case. Each Behavior Technician may also work with several clients across the week.

[7] Depending on the needs of the individual client, Behavior Technicians may also require training in commercially available risk management programs for aggression and assaultive behavior. Other trainings may relate to informing employees of policies and procedures at the agency, state, and national levels.

[8] Given the intensity of the program, frequent review of the data and the treatment plan are needed. The Behavior Analyst should generally review direct-observation data at least weekly.

[9] See also consumer guidelines for identifying Behavior Analysts with competence in treating ASDs from the Autism Special Interest Group of the Association for Behavior Analysis International: http://www.asatonline.org/research-treatment/book-reviews/abai-autism-special-interest-group-consumer-guidelines.

Development of the Guidelines

The BACB Board of Directors authorized the development of practice guidelines for ABA treatment of ASD in early 2012. The following procedures were followed to develop the initial and revised versions of the guidelines.

Version 1.0: A coordinator was appointed who then created a five-person oversight committee that designed the overall development process and content outline. The oversight committee then solicited additional content-area leaders and writers from a national pool of experts that included researchers and practitioners to produce a first draft of the guidelines. The coordinator, oversight committee, and BACB staff then generated a second draft that was reviewed by dozens of additional reviewers, which in addition to being comprised of experts in ABA, also included consumers and experts in public policy. This second draft was also sent to all BACB directors for additional input. The project coordinator and BACB staff then used this feedback to produce the final document, which was approved by the BACB Board of Directors. The professionals who served as coordinator, oversight committee members, content-area leaders, content writers, and reviewers were all subject matter experts in ABA as evidenced by publication records, substantial experience providing ABA services, and leadership positions within the discipline.

Version 2.0: The original project coordinator and BACB leadership identified a team of doctoral-level behavior analysts, all of whom were experts in the ABA treatment of ASD. The team carefully reviewed the initial guidelines and, using a consensus process, proposed revisions and additions to the document to enhance clarity and supplement existing guidance. BACB staff then generated a revised draft that was sent to the project coordinator, revision team members, and public policy experts for additional feedback, after which the guidelines were finalized.

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PARENT GUIDELINES

for Identifying, Selecting, and Evaluating Behavior Analysts Providing Treatment for Individuals Diagnosed with Autism Spectrum Disorder

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Autism Special Interest Group (SIG) of the Association for Behavior Analysis International

Original Version Adopted: May, 1998
1st Revision Adopted: September, 2004
2nd Revision Adopted: May, 2007
3rd Revision Adopted: October, 2013
Parent Version Adopted: January, 2018

Table of Contents

About the Autism Special Interest Group

The Autism Special Interest Group (SIG) of the Association for Behavior Analysis International (ABAI) asserts that all children and adults diagnosed with autism spectrum disorder (ASD) have the right to effective education and treatment based on the best available scientific evidence. Unfortunately, many interventions for individuals diagnosed with autism spectrum disorder have not been shown to be effective with empirical research while others have been shown to be harmful.

Research has long documented the effectiveness of methods based upon applied behavior analysis (ABA) in the education and treatment of individuals diagnosed with autism spectrum disorder.

Although it is not the purpose of these guidelines, the Autism SIG urges parents/guardians to inquire about scientific support for all treatments for individuals diagnosed with autism spectrum disorder.

There are two websites which provide parents/guardians with information about autism treatments, please visit www.asatonline.org and/or www.behavior.org for more information.

Consumer Advisory

I. All parents/guardians should exercise extreme caution when choosing a service provider to work with their children.
II. All parents/guardians are encouraged to obtain references from any potential service provider.
III. All parents/guardians are encouraged to report unprofessional and/or unethical behavior to appropriate regulatory bodies.

Disclaimers/Warnings

I. The trademarks “Behavior Analyst Certification Board®”, “BACB®”, “Board Certified Behavior Analyst®”, “BCBA®”, “Board Certified Associate Behavior Analyst®”, “BCaBA®”, “Registered Behavior Technician®”, and “RBT®” are owned by the Behavior Analyst Certification Board®. All rights reserved.

II. This document provides guidelines for parents to determine who may be qualified to supervise ABA based programs for individuals diagnosed with ASD, as recommend by the Autism SIG of the Association for Behavior Analysis International. The Association for Behavior Analysis International, its members, and Executive Council have not adopted an official policy, position, or opinion regarding these guidelines.

III. The BACB® has two certifications which are Board Certified Assistant Behavior Analysts (BCaBA®) and Registered Behavior Technicians (RBTs®) both of which are not qualified to design and oversee intervention.

IV. There are other certifications on the market today. The Autism SIG wants parents/guardians to be aware that these additional certifications are not equal to the BACB® certifications.

V. There are other paths professionals could take in terms of training and education that may not meet BACB® standards. Therefore, parents/guardians need to be cautious with these other paths.

VI. Parents/guardians should be cautious of any certification not accredited by the National Commission of Certifying Agencies or the American National Standards Institute.

VII. Parents/guardians should be aware that degrees from universities are not the same as certification.

VIII. The Autism SIG recommends not working with professionals who provide ABA services as well as other interventions that have not been shown to effective in studies published in scientific journals or have little objective evidence that they work.

What is a Supervisor's Role?

I. A supervisor develops intervention plans to target language, social, academic, self-help/care, and leisure development.
II. A supervisor develops behavioral intervention plans to help reduce disruptive behaviors (e.g., stereotypic/self-stimulatory, aggression, self-injurious, elopement, PICA, non-compliance).
III. A supervisor trains staff and family members in the implementation of various intervention plans (stated above).
IV. A supervisor provides ongoing training on the plans and programs (stated above).
V. A supervisor constantly evaluates the performance of the staff and parents/family members.
VI. A supervisor constantly evaluates the progress of the individual diagnosed with ASD.
VII. A supervisor assists in future planning, and helps the team consider next environments and future-relevant skills.

Who Is Qualified to Supervise an ABA-Based Program for Individuals Diagnosed With ASD

Overview
To an ethical and effective supervisor, a professional must have advanced training and competence in ABA that is evidence by one of the four following options:

- **Option One**
  a. The professional is currently certified as a Board Certified Behavior Analyst® (BCBA®) or as a Board Certified Behavior Analyst-Doctoral Level® (BCBA-D®).
  b. Both a BCBA® or a BCBA-D® must be certified by the Behavior Analyst Certification Board (BACB®).
  c. Ensuring that professional is certified:
     1. Go to www.bacb.com
     2. Click on "Find a Certificant"
     3. Click on "Find a BCBA/BCaBA"
     4. Enter the last name of the Professional and click "Search"
     5. Read the Terms of Use
     6. Click "I agree to these terms"
     7. Find the Professional
     8. Ensure that under the certification column it states BCBA® or BCBA-D® (not a BCaBA®)

- **Option Two**
  a. The professional is licensed by a governmental agency (e.g., state or regional licensing board) to practice behavior analysis.
  b. The professional must not be at an assistant level or a technician level.
  c. The governmental agency should have at least the same requirements the BACB®.
  d. The majority of the members of the government agency should be BCBAs® or BCBA-Ds®.
  e. It should be noted that the regulations and licensing vary from state to state.
  f. It should also be noted that some regulations align with the BACB® and some regulations may not align with the BACB®.
  g. The parent/guardian should verify licensure with the governmental agency.

- **Option Three**
  a. The professional could be a licensed psychologist by a governmental agency.
  b. The license should be verified by the government agency.
  c. The licensed psychologist should have training in ABA.
  d. The licensed psychologist should demonstrate competence in ABA.
  e. All training needs, at a minimum, to be comparable to the training and education that is equivalent to BCBA® and BCBA-D® training; however, more extensive training is desirable.
  f. Methods of Verification of training and competence:
    - Certification from the American Board of Professional Psychology
    - Transcripts from University graduate courses
    - Syllabi from University graduate courses
    - Documentation of supervision and training

- **Option Four**
  a. Completion of a graduate program (masters or doctoral) that has been approved by ABAI.
  b. ABAI accreditation ensures that training meets the educational and training standards to practice and supervise ABA.
  c. To find a list of ABAI accredited programs go to the following link: www.abainternational.org/BA/education.accredited_programs.asp

Training a Professional Should Have Prior to Supervising

Initial Training

a. The professional should have at least 1000 hours of hands on training.
b. The training should be in the delivery of ABA services as it relates to individuals diagnosed with ASD.
c. The professional should have been supervised by a person that meets one of the four options stated above.

Continuing Training

a. Five years of providing ABA intervention for individuals diagnosed with ASD under a supervisor who meets one of the four options stated above.
b. Training should help develop following skills:
    - Using assessments for individuals diagnosed with ASD that have been found to be effective in peer-reviewed studies.
    - Using interventions for individuals diagnosed with ASD that have been found to be effective in peer-reviewed studies.
    - Using assessments for individuals diagnosed with ASD that have not yet to be effective in peer-reviewed studies.
    - Using interventions for individuals diagnosed with ASD that have not yet to be effective in peer-reviewed studies.
c. Training on interventions to address following skills for individuals diagnosed with ASD:
    - Learning how to learn skills
    - Social skills
    - Language/Functional Communication Skills
    - Reduction of disruptive behaviors
    - Play and leisure skills
    - Pre-academic and academic skills
    - School readiness skills
    - Vocational skills
    - Motor skills
    - Community living skills
    - Personal safety skills
    - Self-care skills
    - Self-management skills

Additional Documented Experience and Competence

a. The supervisor will have experience implementing multiple procedures.
b. The supervisor will have experience targeting multiple target behaviors for the individual diagnosed with ASD.
c. The supervisor will have implemented ABA procedures to at least 8 individuals diagnosed with ASD.
d. The supervisor will have implemented ABA procedures to a variety of age ranges.
e. The supervisor will have implemented ABA procedures to a variety of functioning levels.
f. The supervisor has implemented at least the following procedures:
    - Reinforcement/Rewards
    - Extinction/Ignoring
    - Discrete Trial Teaching
    - Modeling
    - Incidental Teaching
    - Task Analysis
    - Chaining
    - Activity Schedules
    - Scripts and Script Fading
    - Prompting
    - Errorless Teaching
    - Error Correction
    - Motivating Operations
    - Stimulus Control
    - Preference Assessment
    - Choice
    - Augmentative Communication
g. The supervisor has implemented ABA-based procedures with one child and the teacher alone or with one teacher and multiple children together all at once.
h. The supervisor has implemented ABA-based procedures in a manner that the individual with ASD can display behaviors across various settings, time, individuals, and materials.
i. The supervisor changes the intervention(s) based upon data showing how the child is doing on a given program.
j. The supervisor conducts functional assessments to determine:
    - Why the behavior is occurring.
    - How to minimize the occurrence of disruptive behaviors.
    - What behaviors to teach to replace the disruptive behaviors.
k. The supervisor has trained at least 5 different family members using ABA-based procedures.
l. The supervisor has worked collaboratively with professionals from other disciplines (e.g., occupational therapist, speech language pathologist, teachers).

Ongoing Training

a. Even after a supervisor has met all the requirements stated above the supervisor still needs to earn continuing education credits (CEUs).
b. The CEUs should be in the following:
    - Best scientific evidence in ASD as it relates to implementing interventions to individuals diagnosed with ASD and their families.
    - Screening, diagnosis, and evaluation of individuals diagnosed with ASD.
    - Ethical behavior from multiple disciplinary standards.
    - Curriculum development.
    - State and federal laws.
    - Knowledge of evidence of other procedures.
c. General Warning:
    - Education occurs during formal degree seeking education and after receiving a degree.
    - Parents should ask for documentation of continuing education training.

Other Considerations for Parents to Determine if a Professional is Qualified

I. Is the supervisor a member of any professional organizations?
   a. Association of Professional Behavior Analysts (APBA)
   b. Association for Behavior Analysis International (ABAI)
   c. American Psychological Association-Division 25 (APA)
   d. Regional ABAI Chapters (e.g., MoABA, CalABA, MassABA)
   e. The Autism SIG

II. At least 10 years of professional experience following receiving their degree which includes experience in:
   a. Designing programs for individuals diagnosed with ASD
   b. Implementing programs for individuals diagnosed with ASD
   c. Overseeing programs for individuals diagnosed with ASD

III. Publishing studies of treatment effects in peer-reviewed journals.

IV. Presenting studies of treatment procedures and data on their effects in behavior analysis conferences on ABA interventions.

Glossary of Terms

Association for Behavior Analysis International (ABAI) Accreditation. The Association for Behavior Analysis International (ABAI) Accreditation Board is the governance body responsible for the accreditation of training programs in behavior analysis at the bachelor's, master's, and doctoral levels. The Accreditation Board operates as a board of the Association for Behavior Analysis International (ABAI) and carries out its responsibilities in a manner consistent with the ABAI bylaws and articles of incorporation. (https://accreditation.abainternational.org/)

Activity Schedule. A visual schedule comprised of picture or words that 1) show the sequence of steps needed to complete an activity, 2) list the order of occurrence of daily events, and/or 3) provide structure for unstructured play time.

Advanced Training. Refers to graduate level training.

American National Standards Institute. An Institute that oversees the creation, promulgation and use of thousands of norms and guidelines that directly impact businesses in nearly every sector: from acoustical devices to construction equipment, from dairy and livestock production to energy distribution, and many more. ANSI is also actively engaged in accreditation - assessing the competence of organizations determining conformance to standards. (https://www.ansi.org)

American Board of Professional Psychology. A professional organization whose mission is to increase consumer protection through the examination and certification of psychologists who demonstrate competence in approved specialty areas in professional psychology lists who is a licensed psychologist. (https://www.abpp.org/)
Applied Behavior Analysis (ABA). A psychological/educational approach to teach individuals. The philosophy is largely based on the theory that behavior is learned and maintained through interaction with the environment.

Assessments. Various evaluations or tests that are used to determine an individual's level of various behaviors.

Assistant Level. A professional who may help out in supervision, but supervision it is not his/her primary duty. This individual also routinely implements intervention.

Association for Behavior Analysis International (ABAI). A professional membership organization group that has been the primary membership organization for those interested in the philosophy, science, application, and teaching of behavior analysis. (https://www.abainternational.org/)

Association of Professional Behavior Analysts (APBA). A professional membership organization group whose mission is to promote and advance the science-based practice of applied behavior analysis. (http://www.apbahome.net)

American Psychological Association-Division 25 (APA). Behavior Analysis promotes basic research, both animal and human, in the experimental analysis of behavior; it encourages the application of the results of such research to human affairs, and cooperates with other disciplines whose interests overlap with those of the division. It publishes Division 25 Recorder, a newsletter distributed two times a year to all members and affiliates. The division participates in the APA annual convention, sponsoring individual speakers, symposia, and special events, such as receptions and an annual dinner. Div. 25 is also an active co-sponsor of social hours and presentations dealing with the field of behavior analysis. (http://www.apa.org/about/division/div25.aspx)

Augmentative Communication. Augmentative and alternative communication is an umbrella term that encompasses the communication methods used to supplement or replace speech or writing for those with impairments in the production or comprehension of spoken or written language.

Autism Special Interest Group (Autism SIG). An organization of professionals and parents as part of ABAI that has been created to promote evidence based practices to individuals diagnosed with ASD, to promote the principles of ABA, to help individuals diagnosed with ASD, and to help families who have members diagnosed with ASD.

Behavior Analyst Certification Board®/BACB®. The Behavior Analyst Certification Board®, Inc. (BACB®) is a nonprofit 501(c)(3) corporation established in 1998 to meet professional credentialing needs identified by behavior analysts, governments, and consumers of behavior analysis services. The BACB's certification requirements, exam content, and procedures undergo regular review according to international standards for organizations that grant professional credentials. All BACB requirements and exam content are established by content experts in the discipline. (https://www.bacb.com)

Board Certified Associate Behavior Analyst®/BCaBA®. The Board Certified Assistant Behavior Analyst® (BCaBA®) is an undergraduate-level certification in behavior analysis. Professionals who are certified at the BCaBA level may not practice independently, but must be supervised by someone certified at the BCBA/BCBA-D level. In addition, BCaBAs can supervise the work of Registered Behavior Technicians, and others who implement behavior-analytic interventions.

Board Certified Behavior Analyst®/BCBA®. The Board Certified Behavior Analyst® (BCBA®) is a graduate-level certification in behavior analysis. Professionals who are certified at the BCBA level are independent practitioners who provide behavior-analytic services. In addition, BCBAs supervise the work of Board Certified Assistant Behavior Analysts, Registered Behavior Technicians, and others who implement behavior-analytic interventions.

Board Certified Behavior Analyst-Doctoral Level®/BCBA-D®. The BACB offers a doctoral designation for Board Certified Behavior Analysts with doctoral training in behavior analysis -Board Certified Behavior Analyst-DoctoralTM (BCBA-DTM). It is not a separate credential and it does not grant any special privileges above or beyond the BCBA credential. Professionals who are credentialed at the BCBA-D level function in the same capacity as a BCBA (i.e., they are independent practitioners who provide behavior-analytic services). BCBA-Ds supervise the work of Board Certified Assistant Behavior Analysts, Registered Behavior Technicians, and others who provide behavior-analytic interventions.

Behavior Intervention Plan. A behavior intervention plan (BIP) considers the data gathered through an individual's functional behavior assessment (FBA) and employs that data to create a plan of action toward changing and improving that individual's behavior.

Chaining. Taking the steps of a task analysis and teaching the first step (i.e., forward chaining) or last step (i.e., backwards chaining) and systematically introducing additional steps in a set sequence.

Choice. Providing an individual with opportunities to select an item/activity to work toward or a variety of activities with which to engage throughout the day.

Continuing Education Units (CEUs). Training opportunities that professionals take to increase and sustain their knowledge about ABA and Autism.

Community Living Skills. Behaviors that are taught so an individual can function in the community. These skills can include, but are not limited to, ordering food at a restaurant, banking skills, and crossing the street.

Discrete Trial Teaching. A systematic form of intervention which is commonly included with other treatment approaches/procedures to teach individuals diagnosed with ASD a variety of skills. Each discrete trial consists of 1) an instruction from the therapist, 2) a response by the learner, 3) and (c) a consequence from the therapist based upon the learner's response.

Extinction/Ignoring. Anytime that the professional does not provide (i.e., withholds) a reward or reinforcement when an individual is displaying an unwanted behavior.

Errorless Teaching. A teaching procedure in which the professional minimizes the number of errors an individual will make.

Error Correction. A teaching procedure in which the professional allows the individual to make mistakes and provides feedback (e.g., saying "No") when an error is made.

Functional Assessments. A procedure with which a professional determines why a behavior or behaviors are occurring. Usually consisting of interviews, observation, and changing things within the environment while observing the effects on the target behavior.

Governmental Agency. A licensing body that oversee professionals in a given field that is regulated by either a given state or that is regulated by the federal government.

Hands on Training. Training that involves direct implementation with an individual or individuals diagnosed with ASD.

Incidental Teaching. A teaching procedure that involves arranging the environment to create learning opportunities (e.g., placing preferred snacks in sealed bins), following the individual's initiations, promoting elaborations in language, and capturing learning opportunities as they present themselves.

Intervention Plan. Is a plan that is developed by the supervisor on how to teach different behaviors to the individual diagnosed with ASD.

Language/Functional Communication Skills. Behaviors that are taught to improve an individuals' language and communication skills.

L**earning How to Learn Skills**. Behaviors that help an individual better understand the learning process. Skills include, but are not limited to, sitting, waiting, giving back toys, and responding to the word "no."

Licensed Psychologist. A professional who has a doctoral degree in psychology, who has passed examinations in psychology, and has been certified as a licensed psychologist by a governmental agency.

Modeling. Anytime the professional or parent/guardian models the targeted behavior for the learner. This can be done live or with a video.

Motivating Operations. Events that strengthen or weaken reinforcement or punishment (e.g., preventing access to a favorite food for a period of time, providing free access to a preferred activity for long periods of time).

Motor Skills. Behaviors that are taught to improve physical movement. These can include, but are not limited to, walking, jumping, and tying shoes.

National Commission for Certifying Agencies (NCCA). A professional accreditation body that accredits different agencies that meets the NCCA's standards. (http://www.credentialingexcellence.org/ncca)

Peer-Reviewed Journals. Journals that are published where professionals submit research studies and other professionals evaluate each study's scientific merit.

Peer-Reviewed Studies. Research studies that are published in a journal where each article is reviewed by professionals to ensure a high degree of quality.

Personal Safety Skills. Behaviors that are taught to ensure that the person is safe. Examples include, but are not limited to, not giving out personal information, stranger danger, and crossing the street.

Play and Leisure Skills. Behaviors that are taught to increase the individual playing structured or unstructured games or used to teach activities that an individual can do in his or her spare time.

Pre-academic and academic skills. Behaviors that are routinely taught in school. Examples include, but are not limited to, counting, writing, math facts, and science facts.

Preference Assessment. Procedures that are used to determine which materials/food/objects/praise are most and least preferred.

Prompting. Any time the teacher provides assistance to increase the likelihood for an individual to display the correct target behavior. Prompts can include, but are not limited to, pointing to the correct answer, verbally stating the correct answer, and physically guiding the student to the correct answer.

Reduction of Disruptive Behavior. Reducing behaviors that interfere with learning and social opportunities. These can include, but are not limited to, injuring one self, injuring others, and destruction of property.

Registered Behavior Technician™/RBT®. The Registered Behavior TechnicianTM (RBT®) is a paraprofessional who practices under the close, ongoing supervision of a BCBA, BCaBA, or FL-CBA. The RBT is primarily responsible for the direct implementation of behavior-analytic services. The RBT does not design intervention or assessment plans. It is the responsibility of the RBT supervisor to determine which tasks an RBT may perform as a function of his or her training, experience, and competence. The BACB certificant supervising the RBT is responsible for the work performed by the RBT on the cases they are overseeing.

Regulatory Bodies. An organization that oversees professionals and their implementation of intervention and supervision.

Reinforcement/Reward. Anytime a professional provides and individual with an object, food, or praise contingent upon a behavior that increases the occurrence of that behavior in the future (i.e., positive reinforcement) or anytime a professional takes away an object, food, activity contingent upon a behavior that increases the occurrence of that behavior in the future (i.e., negative reinforcement).

School Readiness Skills. Behaviors that are taught to help an individual succeed in school. These skills can include, but are not limited to, raising hands, responding to the bell, and walking in a line.

Scientific Evidence. Evidence which serves to either support or counter a scientific theory or hypothesis. Such evidence is expected to be empirical evidence and interpretation in accordance with scientific method. Standards for scientific evidence vary according to the field of inquiry, but the strength of scientific evidence is generally based on the results of statistical analysis and the strength of scientific controls.

Scripts and Script Fading. Scripts are verbal statements in either written or in an audio format. An individual is taught to repeat the script in appropriate specific social situations (e.g., "At the park I play on the slide."). As individuals learn to use the scripts, they are faded, typically one word at a time, from end to beginning (e.g., "At the park I play on the ___").

Self-Care Skills. Behaviors that are taught so an individual can take care of him or herself. These skills include, but are not limited to, bathing, brushing teeth, and toileting.

Self-Management Skills. Behaviors that are taught so an individual can manage his or her day.

Service Provider. A professional who provides intervention or supervision to individuals diagnosed with ASD and their families.

Stimulus Control. When an individual responds a certain way when one environmental event occurs and might not respond a different way and responds a different way without that event.

Social Skills. Behaviors that are taught to improve social relationships with peers and others. These skills can include, but are not limited to, eye contact, joining in, greetings, and asking someone out on a date.

Supervisor. A professional that is in charge of developing an individual's program, supervising staff on that program, and training parents/guardians.

Target Behaviors. The behavior(s) the professional and/or parents are currently targeting for intervention.

Task Analysis. It is taking a large behavior (e.g., brushing teeth) and breaking it down into steps (e.g. first you do this, then you do this).

Technician Level. A professional whose sole duty is to implement behavioral intervention.

Vocational Skills. Behaviors that are taught to prepare an individual for a job/career. These can include, but are not limited to, sorting, working on a car, or accounting skills.

Supervision Determination Checklist for Parents According to Autism SIG Guidelines

Part A (Certifications)

Question	Yes	No
Is the professional a BCBA or a BCBA-D?		
Is the professional licensed by a governing agency to practice behavior analysis and meets all other requirements from option two (p. 7)?		
Is the professional a licensed psychologist and meets all other requirements from option three (p. 8)?		
Did the professional complete a graduate program that is accredited by ABAI and all other requirements from option four (p. #)?		
If you have one check mark in the yes box then proceed to Part B. If all four rows have a "No" then the professional is not qualified to supervise according to these guidelines.		

Part B (Initial Training)

Question	Yes	No
Did the professional have at least 1000 hours of initial training?		
Did the initial training consist of implementing ABA-based interventions with individuals with ASD?		
Was the initial supervision conducted by a supervisor from one of the four options stated above (pp. 7-8)?		
If you have one check mark in the yes box then proceed to Part C. If any of the rows have a "No" then the professional is not qualified to supervise according to these guidelines.		

Supervision Determination Checklist for Parents According to Autism SIG Guidelines

Part C (Continuing Training)

Question	Yes	No
Does the professional have at least 5 years of providing ABA-based intervention under the supervision of another professional who meets the qualifications stated above?		
Did the training include the use of assessment and interventions found in peer reviewed studies or that have not been reviewed in peer reviewed studies?		
Did the training include how to teach learning how to learn, social, language/functional communication, reduction of disruptive behaviors, play and leisure, pre-academic and academic, school readiness, vocational, motor, community living, personal safety, self-care, self-management skills?		
If you have one check mark in the yes box then proceed to Part D. If any of the rows have a "No" then the professional is not qualified to supervise according to these guidelines.		

Supervision Determination Checklist for Parents According to Autism SIG Guidelines

Part D (Additional Training)

Question	Yes	No
Has the professional had experience implementing multiple ABA-based procedures?		
Has the professional had experience teaching multiple target behaviors?		
Has the professional worked with at least 8 individuals diagnosed with ASD?		
Has the professional worked with a variety of individuals diagnosed with ASD across age and functioning levels?		
Has the professional had experience with the 18 teaching procedures (p. 10; note: some may not be applicable for all clients)?		
Has the professional had experience implementing ABA-based procedures in a one-to-one teaching format?		
Has the professional had experience implementing ABA-based procedures in a group teaching format?		
Has the professional implemented teaching in a way that the student can display the behavior in different environments or with different people?		
Has the professional modified interventions based upon objective data?		
Has the professional had experience with conducting functional assessments?		
Has the professional trained at least 5 different family members?		
Has the professional trained with other professionals collaboratively?		
If you have one check mark in the yes box then proceed to Part E. If any of the rows have a "No" then the professional is not qualified to supervise according to these guidelines.		

Supervision Determination Checklist for Parents According to Autism SIG Guidelines

Part E (Continuing Education)

Question	Yes	No
Can the professional provide proof of CEUs?		
Did some of the continuing education consist of ABA-based intervention as it applies to individuals diagnosed with ASD?		
Did some of the CEUs relate to ensuring ethical behavior?		

If you have one check mark in the yes box, then the professional has met all of the criterion set forth on this document. Although, the Autism SIG cannot determine if any professional is truly qualified or not; having checking marks in all yes columns and rows shows that the criteria set forth by these guidelines has been met.

If there was a "No" marked on any of the rows then the professional is not qualified to supervise according to these guidelines.

ABA applied behavior analysis Q&A

What is applied behavior analysis?

Applied behavior analysis (ABA) is a methodology that involves the application of basic behavioral practices (positive reinforcement, repetition, and prompting) to facilitate the development of language, positive skills, and social behavior. ABA also helps reduce everyday social problems and serious behavior disorders.

Data collected and analyzed at May Institute support the findings of hundreds of other studies that indicate ABA is the most effective method to teach children and adolescents with autism spectrum disorders (ASD) and other developmental disabilities, as well as brain injury and other traumas.

Is ABA safe?

Tested by research and experience for more than 40 years, ABA practices have been endorsed by the Surgeon General, the National Institutes of Health (NIH), and the Association for Science in Autism Research. The skills and experience of an ABA professional are essential for success. Continuous and systematic evaluation of effectiveness is a fundamental component of the ABA methodology.

What type of problems can ABA address?

ABA can be used to teach a variety of skills and positive behaviors, including functional living skills, language, reading, social skills, positive peer support, academic engagement, and more. ABA methodology is also effective in decreasing inappropriate behaviors such as noncompliance, tantrums, bedwetting, feeding problems, aggression, and self-injury.

At what age can my child benefit from the ABA approach?

ABA can be effective in working with individuals of all ages. However, research shows that skill development programs that are provided at a young age foster better outcomes and can often reduce the likelihood of more severe or dangerous behaviors later in life.

What is an example of ABA?

Professionals at May Institute used ABA to successfully teach a 4-year-old boy with ASD to share toys with other children. Before intervention, Andy tended to play by himself and hoard his toys. When a peer or adult would ask him to share, he would vigorously refuse. This behavior left him very much isolated.

Using ABA techniques, clinical staff and teachers at a May Center School helped Andy learn to share and be more agreeable to giving up a toy when asked. At the start of play opportunities, teachers practiced sharing with Andy, gently guiding him to share and praising him each time he did so. Later, when he was with his peers, teachers periodically prompted sharing. As Andy began sharing more, they faded the intervention.

The teachers also measured sharing among 4-year-olds without ASD in Andy's class. They found that, before intervention, Andy shared far less than his peers. After intervention, however, he shared as often and sometimes more often than the other children. In this case, ABA was used to teach an essential social skill that was otherwise undeveloped as a consequence of ASD.

In what environments are ABA techniques used?

ABA techniques work across all environments—work, home, and school. Home-based services require a significant commitment of time and energy

from parents and other caregivers. Some of the advantages of working in the home are the early identification of problems, the ability to incorporate elements that are relevant to the child into practice, and the opportunity to include those people who are closest to the child as teachers. At May Institute, in-home therapists assist parents as they learn how to help their child acquire appropriate communication skills and functional living techniques.

Likewise, children in school benefit from being in a familiar setting and doing activities that are relevant to them. May Institute professionals work with hundreds of schools across the country to provide services using ABA techniques to help individual students, teachers, and entire classrooms.

May Institute also employs ABA methodology in its four private schools that serve children and adolescents with ASD and other developmental disabilities. May Institute also uses ABA techniques in its school for children and adolescents with brain injury.

How can I identify a qualified ABA professional and what should I expect?

Professionals utilizing ABA techniques should have solid practical experience in the field and meet high educational and professional standards—ideally a Ph.D. or Psy.D., licensure, and board certification by either the Behavior Analyst Certification Board (BACB) or the American Board of Professional Psychology (ABPP). May Institute employs some of the most highly trained and experienced ABA professionals in the country. Our nationally recognized ABA experts teach at top universities, publish regularly in professional journals, and make presentations at national and international conferences.

Before utilizing ABA practices, qualified professionals should evaluate a child with behavioral problems to identify his or her specific needs for intervention and support. They will observe a child in several situations to determine where and why the problem behavior occurs. Once an evaluation is complete, a recommendation can be made regarding the type of program and setting that is best for the child and the family.

Is ABA right for my child?

Parents who feel their child might be helped by ABA-based procedures should take several things into consideration: the time and resources of the family, the severity of the behaviors, and the help available in the community.

Proven Effectiveness

Hundreds of scientific studies have shown that ABA is the most effective method to teach children and adolescents with autism and other developmental disabilities, and neurological problems. ABA has been endorsed by the National Institutes of Health and the Association for Science in Autism Treatment, and has been identified by the Surgeon General of the United Sates as the most effective way to treat autism. According to the National Autism Center's *National Standards Report* (2009, 2015), data collected through hundreds of studies indicate that ABA is a highly effective method to teach children and adolescents with ASD.

www.mayinstitute.org

May Institute is a nonprofit organization that provides educational, rehabilitative, and behavioral healthcare services to individuals with autism spectrum disorder and other developmental disabilities, brain injury, and behavioral health needs. Since its founding more than 60 years ago, May Institute has evolved into an award-winning national network that serves thousands of individuals and their families every year at nearly 140 service locations across the country. The Institute operates several schools for children and adolescents with ASD and other developmental disabilities. They are located in Randolph, West Springfeld, and Woburn, Massachusetts; and Santa Cruz, California. Its also operates a specialized school for children and adolescents with brain injury and neurobehavioral disorders; it is located in Brockton, Mass.

For more information, contact May Institute at 800.778.7601 or info@mayinstitute.org.

Screening for Autism Spectrum Disorder

The US Preventive Services Task Force (USPSTF) has published new recommendations on screening for autism spectrum disorder (ASD).

What Is Autism Spectrum Disorder?

Autism spectrum disorder is a disorder of brain development in children. It affects a child's behavior and his or her ability to interact with others. Children with ASD have trouble communicating with and relating to others and may have different interests than children without ASD. Some signs and symptoms of ASD include avoiding eye contact, not playing with other children, repetitive behaviors, language difficulties, and showing an intense focus on certain objects while having no interest in other things. Autism spectrum disorder can range from mild to severe. Symptoms of ASD are usually first seen in the second year of life but can start earlier or later. The February 16, 2016, issue of *JAMA* contains the new USPSTF recommendations on screening for ASD.

What Tests Are Used to Screen for ASD?

Several tests can be used to screen for ASD in children younger than 30 months. A commonly used tool is the Modified Checklist for Autism in Toddlers—Revised With Follow up (M-CHAT-R/F), which is a questionnaire filled out by parents, with a follow-up questionnaire given by a health care professional if needed. If the results of these screening tests are positive, further diagnostic testing is required.

What Is the Patient Population Under Consideration for Screening for ASD?

The USPSTF recommendation applies to children aged 18 to 30 months who do not have a prior diagnosis of ASD or developmental delay and for whom no concerns about ASD have been raised by parents, other caregivers, or health care professionals.

What Are the Potential Benefits and Harms of Screening for ASD?

The potential benefit of screening for ASD is that diagnosing ASD at an earlier age may lead to earlier intervention and treatment, which typically includes behavioral, educational, and speech/language therapy. There is evidence that earlier intervention and treatment may lead to better outcomes in children with autism detected because of symptoms. The harms of screening and subsequent interventions for ASD are likely to be small but may include anxiety and financial costs associated with misdiagnosis, further testing, and potential interventions.

How Strong Is the Recommendation to Screen for ASD?

Although there is evidence supporting the benefit of early treatment for ASD, there are currently no studies that focus on outcomes in young children identified with ASD through screening alone in whom no concerns for ASD have been raised by family members, caregivers, or health care professionals.

Bottom Line: Current Recommendation for Screening for ASD

The USPSTF concludes that the current evidence is insufficient (called an "I" recommendation) to assess the balance of benefits and harms of screening for ASD.

Screening for autism spectrum disorder in young children

USPSTF recommendation grade

There is **insufficient** evidence to make a recommendation.

FOR MORE INFORMATION

- Centers for Disease Control and Prevention *www.cdc.gov/ncbddd/autism/families.html*
- US Preventive Services Task Force *www.uspreventiveservicestaskforce.org*

To find this and previous JAMA Patient Pages, go to the Patient Page link on *JAMA*'s website at *www.jama.com*. Spanish translations are available in the supplemental content tab.

Author: Jill Jin, MD, MPH

Source: Siu AL; US Preventive Services Task Force. Screening for autism spectrum disorder in young children: US Preventive Services Task Force recommendation statement. *JAMA*. doi:10.1001/jama.2016.0018.

Autism Spectrum Disorder:

Parents' Medication Guide

American Academy of Child & Adolescent Psychiatry
www.aacap.org

American Psychiatric Association

Autism Parents' Medication Guide Work Group

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Introduction

What is ASD? Autism spectrum disorder (ASD) is a developmental disorder characterized by problems with social communication, unusual behaviors such as fixed interests, being inflexible, having repetitive behaviors, or abnormal responses to sensations. Communication problems include difficulty understanding and responding to social cues and nonverbal communication such as gestures and tone of voice, which can result in challenges in making or keeping friends. Although people with ASD may want to make friends, difficulties in understanding social norms or correctly interpreting language and facial expressions can get in the way.

In recent years, it has become clear that individuals with ASD, despite sharing some behavioral challenges, can be quite different from one another. Some people with ASD may be very intelligent, while others may have cognitive challenges. Some may have advanced vocabularies and others may speak very little or not at all. Previous attempts to subdivide the population on the basis of language and cognitive ability have not been supported by research. Thus, people in the same family with autism or who share the same genetic risk factor(s) can end up with very different symptoms and outcomes.

Why consider medication in ASD? People with ASD often experience a host of difficulties that can be as problematic as the symptoms of ASD itself. Anxiety, mood instability, impulsivity, hyperactivity, sleep problems, and even aggression and self-injurious behavior can occur in some people. Just as it would be for other medical problems, medication may be helpful in treating some of these difficulties. The use of medication is more often aimed at treating the symptoms of these associated conditions, which we can characterize as emotional and behavioral challenges, than for core symptoms of ASD itself, as no medications have shown clear benefit for social communication impairment or restricted, repetitive behaviors.

Sitting down with an expert to discuss whether it is a good idea to try medication for certain troublesome symptoms in your child with ASD is reasonable. Although the best approach to addressing those symptoms may not include medication, it can be helpful to learn about various options and/or begin to gather information on the frequency and intensity of behaviors that may ultimately be targets for medication treatment.

Assessment of the Child with ASD Experiencing Emotional or Behavioral Problems

When a challenge presents itself, it is time for an assessment. The first step in helping a child with ASD to get assistance with an emotional or behavioral challenge is to have him or her evaluated by an expert or team of experts. Since many factors may contribute to these emotional and behavioral problems in a child with ASD, it is ideal to have the child assessed by a team whose members can consider different causes and approaches. In reality, most children will only have access to a single provider, or the child's emotional or behavioral problems are severe enough that there is a need to act quickly. Even in these situations, it is important for the clinician who evaluates the child to consider multiple sources for the problem, and refer the child for further assessment if needed.

A thorough assessment of emotional or behavioral problems will take into account the possible role of communication, family functioning, factors that contribute to or exacerbate the behavior, physical health, co-existing mental health disorders, sensory factors, and daily living skills. The child's ability to communicate should be considered and a speech and language pathologist can perform more formal assessments of language and social communication abilities. Mental health providers can assess the functioning of the family and how family relationships could relate to problems, as well as evaluate for co-existing mental health disorders in the child such as anxiety or ADHD. Psychologists and other experts in behavior can assess factors that may maintain or reinforce the problem behavior(s), and can use applied behavioral analysis techniques, as outlined below. The possibility of a medical issue underlying the emotional or behavioral symptoms can be assessed by a physician or other medical provider. Finally, an occupational therapist can assess the role of over or under sensitivities and challenges in daily living and self-help skills, such as dressing, bathing, and eating.

Primary Non-Medication Treatment Strategies for Emotional and Behavioral Challenges

Applied Behavioral Analysis (ABA)

As demonstrated in a number of well designed research studies, Applied Behavioral Analysis (ABA) has been shown to be effective for addressing and often reducing challenging behaviors, as well as teaching many skills and routines. Parents frequently have questions about how ABA works and how it will help their child.

Children with ASD often have difficulty learning. Applied Behavior Analysis (ABA) is an educational and therapeutic approach that involves breaking down tasks and skills into their smallest parts, then teaching them slowly while encouraging, shaping, and reinforcing functional behaviors and discouraging harmful or disruptive behaviors. ABA focuses on the relationship between a certain behavior, the factors that were present before the behavior ("antecedents") and the results of the behavior ("consequences"). ABA has been successful in helping children with ASD improve communication, academic performance, social behavior, and adaptive living skills as well as addressing specific problem behaviors.[1]

Communication supports

While speech is generally the preferred method of communication in our society, not all children with ASD can use speech effectively. For children who have limited or no verbal ability, alternative methods of communicating have been developed to improve communication.

Communication supports are tools to help children with ASD communicate. A non-electronic method that has been shown to increase communication in children with ASD is the Picture Exchange Communication System (PECS), where the child uses pictures to communicate.[2] Electronic assisted communication devices include speech generating devices (SGD), which can produce an electronic voice that communicates words. These SGDs come in two main forms, dedicated devices (e.g. DynaVox, AlphaSmart, DynaWriter) or software (e.g. Proloquo2Go or Touchchat) that can be used on personal computers, tablets, or mobile phones.

Speech-language pathologists can recommend an assistive communication system after a careful evaluation of the unique abilities, needs, and communication goals of the child. Preliminary studies have shown that assistive communication devices are generally liked by users and may improve functional communication in children with ASD.[3]

Cognitive Behavioral Therapy

Cognitive Behavioral Therapy (CBT) is a type of psychotherapy in which a person's negative thoughts are challenged in order to reduce associated troubling emotions and behaviors. CBT is "problem-based," meaning that it is used to address the specific concerns of a patient. CBT has been shown to be an effective treatment for anxiety in individuals with high functioning ASD (HF-ASD), and it may also be helpful in addressing disruptive behaviors, like aggression, and in improving social and communication skills.[4] CBT is typically administered by a therapist, but parents and teachers may also access books or web-based CBT guides.

Social Skills/ Social Cognitive Training

Social skills are verbal and non-verbal behaviors necessary for positive and effective social interactions, and include eye contact, smiling,

Social skills are verbal and non-verbal behaviors necessary for positive and effective social interactions, and include eye contact, smiling, and asking and responding to questions.

and asking and responding to questions. The value of developed social skills is well-documented and can boost academic performance, mental health, and positive developmental outcomes.[5] Social skills training programs are designed to teach the skills necessary to navigate social environments.[6] There is also preliminary evidence supporting programs that address social cognitive impairments, such as helping children develop the skill of understanding the perspective of others.[7]

Life Skills

The countless tasks of daily living—including dressing, bathing, mealtimes, homework, free time, toileting, and waiting—present many opportunities for challenging behavior each day. As children become adolescents and young adults, new tasks to learn include keeping their own schedules or appointments, asking for help, caring for their own belongings, preparing meals, navigating transportation, and learning a trade. An occupational therapist and other providers can help establish routines and teach these life skills. By breaking tasks into parts, making visual charts outlining steps, presenting rewards for step completion, and implementing this plan consistently, caregivers can teach life skills to children with ASD. Before trying to manage problem behaviors through other means, consideration should be given to whether the child has adequate support to meet the goals being set for them.

Sensory Interventions

Possible contributing causes of challenging behavior in a child with ASD include abnormal sensory responses. Children may avoid sensory input, including certain textures (mushy foods, scratchy labels in clothing), excessive movement (crowded stores, busy city streets), or noises (fire alarms, barking dogs). They may also seek out sensory experiences, such as tickling or deep pressure, or more frequent and intensive movement, such as running, climbing, or spinning in circles. Preventing a child's sensory-seeking or sensory-avoiding behaviors can cause distress and/or tantrums. Interventions for sensory-related problems include weighted vests, swinging, or regular sessions of jumping or bouncing, and applying deep pressure, especially to the shoulders. The evidence for such interventions is not convincing so far, however, due to problems with study methods and research design. Occupational therapists can assess the child's sensory system and direct these interventions to help address sensory factors.

Occupational therapists can assess the child's sensory system and direct these interventions to help address sensory factors.

Treatment of Medical Problems

Prior to starting any therapy for a behavioral or emotional problem in ASD, consideration should be given to a possible medical cause. The extent of a medical evaluation should be decided in collaboration with an experienced medical provider. A sudden or drastic change in behavior may warrant a more thorough evaluation. The medical problems mentioned here do not represent an exhaustive list, but are often causes of behavioral problems in children with ASD.

- ***Sleep problems*** are present in many children with ASD. Inadequate sleep can certainly contribute to behavioral problems and should be considered prior to more rare causes. Poor sleep patterns should be initially addressed with good sleep hygiene, such as removing television and video screens from the bedroom, having a set bedtime and a bedtime routine, and learning to fall asleep without a parent present.
- ***Medication side effects*** themselves can contribute to problem behaviors. Possible medication side effects include changes in sleep, sedation, cloudiness of thinking, constipation, and agitation, among others.
- When a child experiences ***pain***, yet is unable to express clearly the nature or source and intensity of the pain, behavioral changes may result. For

instance, headaches may cause head banging or hitting. Dental problems may go unnoticed if the child will not allow examination of his or her teeth. Bodily injuries can result from a high level of activity and a low pain threshold.

- ***Gastrointestinal discomfort*** may be caused by constipation or diarrhea, acid reflux, food allergies, or inflammatory bowel diseases. Constipation is by far the most common gastrointestinal problem in children with ASD and should always be considered as a possible source of problems.
- ***Seizures*** are more prevalent in children with ASD than in the general population. Symptoms of seizures can include staring spells, involuntary movements, confusion, or headaches. Less common features are sleep changes, behavioral problems, or otherwise unexplained emotional changes or severe emotional shifts.

Family Interventions

Although raising a child with ASD can be fulfilling and rewarding, it can also be an overwhelming experience that can negatively impact the health and well-being of parents and families. Interventions intended to provide support and education for families of children with ASD can provide stress reduction to reduce tension in the home environment, which in turn may positively impact the behavioral functioning of the child.[8]

Comprehensive treatment should attend to the well-being and functioning of the entire family. Parent and sibling support groups can help family members feel less alone. Supportive therapy for parents or families can address the challenge of raising a child with special needs. Family therapy aims to create new interactions or awareness that highlight the family's strengths and successes. At the same time, family therapy changes the interactions among family members that may accidentally encourage unwanted behaviors.

The most researched parent interventions are those that help parents to manage the child's behavior (e.g. parent management training (PMT)) and those that enhance skill-based therapies (e.g. parent ABA training). Although less researched than PMT or ABA, there are also treatments that foster parent-child emotional connections in order to improve communication, skills, and emotional balance. Families should be encouraged to talk with other families and their providers about different treatment options. They should also consider the first meeting with a new therapist as an evaluation in which they learn what can be offered and whether there is a good fit between the family's difficulties and the therapist's skills.

Medication as a Treatment Tool for Emotional or Behavioral Challenges

In addition to the interventions outlined in the previous chapter, medication is another tool that may play a role in the treatment of the child with ASD. It is important to recognize, however, that the medications currently used to treat symptoms and behaviors associated with ASD have not at this point in time been shown to improve the core features of autism. In other words, there is no medication to treat the autism itself.

Medication may be recommended to reduce symptoms of an emotional or behavioral disorder in a child with ASD. These co-occurring disorders are more common than once thought, and include ADHD, anxiety, and depression, among others. The symptoms and findings that lead to these diagnoses are the same as those for children without ASD, but may require a provider with experience in ASD to recognize them.

Armed with this knowledge, it may be easier to understand some of the reasons for use of medication in children with ASD. Use of medication in ASD is common, but the number of children with ASD that are prescribed medications has also raised concerns among some doctors and parents. A study in 2013[9] reported that nearly two out of three children with ASD had been prescribed a psychoactive medication during the three-year study period, and one in seven children had been treated with three or more medications at the same time.

Appropriate use of medication requires an ongoing trusting relationship between parents and providers, and clear information about when to use and not use medication for symptoms in children with ASD. When parents have questions about medication use in their children, they should seek the advice of a professional with training in ASD. Board certified pediatricians and family physicians often see many children with ASD, and many times can appropriately recommend a medication for symptoms. Others with more specialized training include child and adolescent psychiatrists, child neurologists, and developmental-behavioral pediatricians. Parents should feel free to ask doctors about their level of training and experience with patients with ASD, and if they feel comfortable prescribing medication, or if they prefer to seek consultation from more specialized or experienced providers.

Important Factors to Consider for Medication Treatment

- **Informed consent.** A clear and thorough discussion between the parent or guardian and the prescriber should explain the diagnosis, symptoms, non-medication treatment options, and expected duration of treatment. For the child or adolescent taking medication, the provider can obtain his/her permission by offering information about why they are taking medication and the symptoms that the medication is meant to treat. These discussions should take place not just at the beginning of medication treatment, but be ongoing, so that as issues arise and symptoms change, treatment can be modified to meet the child's needs.

- **Risks and expected benefits**. Risks include the known side effects from the product label (if studied in children and adolescents), adult use side effects (may have different side effects than in youth), published research, and the experience of the treating clinician with the medication. Expected benefits would be to reduce the target symptoms. If the medication is effective in reducing target symptoms, other benefits may arise, including improved functioning in school, with peers, and at home.

These co-occurring disorders are more common than once thought, and include ADHD, anxiety and depression, among others.

- **Which medication will work?** Medication trials are exactly that—trials. Prescribers do not have good enough information to predict which medication will be the best option for each individual child. A medication trial is a time-limited period of testing a medication for the individual child. Most clinicians start at a low dose to minimize side effects and increase slowly to a target dose based on the child's age, weight, and his/her response. Once on the target or maximum tolerated dose, for many medications, the prescriber will then wait four to eight weeks for the full benefit to take effect. If a child does not benefit after that time period, it is time to reassess the situation, taper off the ineffective medication, and consider starting the child on an alternate medication.

- **Level of evidence supporting the use of a particular medication for a particular problem.** When considering which medication to use for a particular set of symptoms, clinicians and families can refer to several sources of information about effectiveness, including the table provided at the end of this guide. Two medications are approved by the Food and Drug Administration (FDA) to treat irritability in autism: aripiprazole and risperidone. Other medications may have been originally studied in youth or adults without autism.

- **Understanding "off-label" uses of medication.** When the FDA approves a medication, it allows a pharmaceutical company to advertise that medication for a specific purpose. When a medication is not FDA-approved for a particular clinical purpose, it is termed "off-label." There are numerous off-label medications that physicians use to treat problems associated with ASD. The provider should explain to a parent or guardian whether or not a medication is off-label. This does not mean the medication should not be prescribed to the child with ASD. The decision to use a certain medication should be based on available research, but when research is limited, it may be based on evidence from studies on children or adults without ASD and clinical judgment.

There are numerous off-label medications that physicians use to treat problems associated with ASD. The provider should explain to a parent or guardian whether or not a medication is off-label.

- **Adequate dose and length of medication trial.** It is important to speak with your child's provider about how long to stay on a medication. Some medications may take effect sooner than others. For example, stimulant medications like methylphenidate may take effect very quickly compared to selective serotonin reuptake inhibitors (SSRIs) like citalopram, fluoxetine, or sertraline, which may take several weeks to take effect. While it can be difficult to predict the duration of treatment needed, addressing this topic can be informative and build an understanding between prescriber and family.

- **Understanding placebo effects.** In general, prescribers, families whose child is being treated with a medication, and often the patients themselves would like medications to be helpful and have a positive response. This is a natural reaction. It is important to understand that even in large, well designed drug studies where families and prescribers do not know if the child is receiving an active drug or a placebo (inactive sugar pill), one in three or four of those receiving placebo will report significant treatment-associated improvement. Clearly, this placebo effect can make it more difficult to understand if a drug is truly providing clinical benefit. Given this fact, it is important to try to be as objective as possible when assessing the impact of a drug on your child. Sometimes it can be helpful to receive input from others who know your child, such as teachers, therapists, or other family members. Families will sometimes ask if they should inform school administrators or teachers about a medication change. This common question is designed to increase the strength of objective or unbiased assessment. Depending on the drug and the need to have others observe the child for adverse effects, this option can be considered. Some providers may ask the parent or caregiver or teacher to complete standardized rating scales to measure changes.

- **When to stop a medication.** First, it is generally a good idea to discuss stopping a medication with the prescriber before

doing so. This is important because some medications may require lowering the dose in gradual steps to avoid potential withdrawal effects. It is also important to have an open dialogue with your prescriber about what criteria will be used to determine success and when to stop a medication. Prior to starting a new drug it is important for families to understand what symptoms and/or behaviors the prescriber is hoping to alleviate with the medication. Families can take an individual approach to defining "success" in response to the medication, and discuss this with the prescriber at the time the medication is started and at follow-up visits.

There can be many reasons for stopping a medication: the medication may have adverse effects on the child, the child's symptoms may not respond to the medication, or the child's family may not be able to pay for the medication. Stopping a medication is a personal decision best made in consultation with the prescriber.

- **Combining medication treatment with other forms of treatment.** We know that combining medication for behavioral issues with interventions such as occupational, speech, physical, and behavioral therapies may provide the best chance for some patients and families to achieve the best outcomes. It would be rare to find that use of a medication completely replaces the need for other types of therapies. In many instances, effective medication use may maximize the benefits patients with ASD receive from other types of therapy.

- **It is important to share information about the use of all natural remedies and/or alternative treatments with your child's clinician.** Certain supplements and alternative treatments can interact with prescription medicines. For instance, St. John's Wort, which some people take as a natural treatment to alleviate depression symptoms, may have a negative interaction with prescribed selective serotonin reuptake inhibitor (SSRI) drugs. Given this fact, it is imperative to provide a complete list of supplements and other alternative treatments your child may be receiving to his or her treating clinician to increase safety and effectiveness.

What if medications fail? ASD is a complex disorder that can be difficult to treat. If a medication fails, it is time to reassess the problem and see if an alternate explanation, therapy, or medication may be helpful. If the child's symptoms do not improve after multiple medications and other treatment trials, other options may be considered, particularly if severe aggressive and/or self-injurious behaviors pose a threat to the child or others.

- There are approximately 10 *specialized child psychiatry hospital units* in the U.S. These specialized psychiatric units for children and adolescents with developmental disabilities typically use a multi-modal approach that combines medication and behavioral treatment with communication and occupational therapy strategies. Although waiting lists for these units may be long, there is preliminary evidence that such an intensive approach can be helpful.[10] There are also many day treatment, specialized school, and residential treatment programs that focus on children with developmental disabilities and emotional and behavioral challenges. While evidence for the effectiveness of these programs is generally not available, programs that use evidence-based practices, such as applied behavioral analysis (ABA), and that take a multi-disciplinary approach are more likely to be beneficial.

- *Electroconvulsive therapy (ECT)* In rare instances, ECT can be considered in the treatment of patients who have very severe aggressive and/or self-injurious behaviors that do not respond to other interventions and are driven by a co-existing psychiatric condition, such as a mood disorder or catatonia (a state of muscle rigidity and stupor or great excitability). While there is no controlled evidence, several case studies have reported ECT to be helpful in a few such individuals, though common side effects of ECT include headache and nausea, and short-term memory loss during the initial course of treatment.

Are there treatments that should not be used? Approximately three-quarters of children with autism have been given alternative treatments. Although there is little evidence supporting the vast majority of alternative therapies (with the exception of melatonin for sleep), many of these popular remedies, such as diet or vitamins, are relatively harmless. It should be noted, however, that any treatment always requires effort and expense, consuming resources that could be used for more evidence-based treatments. There are some treatments, however, that parents should not consider. These treatments not only do not work and are expensive, but may pose serious health risks to the child.

- **Chelation** removes toxic metals from the blood and is used to treat cases of severe lead poisoning and elevated iron associated with particular blood disorders. Scientific tests of chelation as a treatment for ASD have not shown it to be effective and the procedure can have dangerous side effects, including kidney and liver failure, cardiac arrest, and has even resulted in the deaths of at least two children with autism.

- **Hyperbaric oxygen treatment** (HBOT) is the administration of oxygen to a patient in a pressurized chamber, and is used for a handful of conditions, including decompression sickness and different types of soft tissue damage. There is a lack of scientific evidence for using this costly procedure in children with autism, which can cause lung, vision, and sinus damage, as well as rupture of the middle ear.

- **Secretin** is the most studied medication in children with autism, and has repeatedly been shown in multiple scientific studies to have no effect. Side effects can include diarrhea, vomiting, fever and blood clots.

- **Stem cell re-implantation** is a potentially promising therapy for many diseases. However, experts have cautioned that the field is at least a decade away from the development of effective treatments. There is no scientific evidence for the use of stem cell procedures in autism, costs can exceed six figures, and injecting dead or deteriorating stem cells into a person can cause potentially fatal side effects, including stroke and brain inflammation.

Symptoms and Medications

Medications can be used to target a wide range of specific symptoms in children and adolescents with ASD, some of which are listed below. A table summarizing the controlled research evidence for medications in children with autism is located at the end of this guide.

- **Irritability, tantrums, and aggression:** Irritability, tantrums and aggression are common reasons for families to seek treatment for their child with ASD. Children who are irritable are prone to become upset or angry easily, sometimes leading to tantrums, property destruction, or aggression. Irritability can range from mild, where the only noticeable problem is that a child cries more easily than peers when frustrated; to severe, where a child may be so prone to aggression that they need to be hospitalized. Addressing symptoms when a child is young may prevent them from worsening as a child gets older and physically larger. Clinicians should evaluate the potential contributing factors to irritability and aggression in a particular child before prescribing medication, as detailed in the assessment section of this guide.

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Medication can be considered to reduce irritability and aggression when contributing factors do not appear to explain the symptoms or these contributing factors have been addressed without resolving the problem. Two anti-psychotic medications, risperidone (Risperdal) and aripiprazole (Abilify) have been shown to reduce tantrums and aggression in multiple large controlled studies in children with ASD, but each of them can also lead to significant side effects, including increased appetite and weight gain, changes in cholesterol, sedation, and movement disorders. Haloperidol (Haldol), another anti-psychotic, also has evidence of benefit for irritability and aggression, suggesting that this general class of medications may be helpful in children with ASD. Little evidence supports other types of medications; although the side effects associated with antipsychotics can lead parents and physicians to try medications that have single controlled studies to support their use, including clonidine or guanfacine (Tenex or Intuniv).

- **Self-injurious behavior (SIB)** can be a significant and distressing problem for children and their families. Almost 11% of children with ASD in a community survey were stated to have SIB, including hitting, biting, or scratching directed at themselves.[11] SIB can range from mild to very severe. Some children will engage in a mild self-injurious behavior, such as lightly hitting their chin, but may do it so often that over time they eventually produce an injury. Other children may only occasionally engage in self-injury, such as banging their head on an object, but may do it with such force, that even a single episode could cause serious injury. Self-injury that is part of a suicidal episode (such as cutting one's wrists) is less common in children with ASD, though some higher-functioning individuals may engage in suicidal actions.

The best evidence for effective treatment of SIB is with applied behavioral analysis (ABA). In this method, the provider performs an analysis to try to determine the source of the SIB, which is typically escaping from demands, accessing preferred items or activities, attention-seeking, or changing sensory input or pain.[12] Functional communication strategies have also been shown to reduce problem behaviors in ASD, including self-

injury.[13] Medication may play a role in addressing SIB, particularly if the SIB is determined to be related to other mental health problems, such as anxiety or depression.

The atypical anti-psychotics, risperidone and aripiprazole, have been studied for treatment of irritability in children with ASD, which can include self-injury.[14,15]

- **Inattention, hyperactivity, and impulsivity**, the cluster of symptoms referred to as attention deficit-hyperactivity disorder (ADHD), are common in children with ASD and can be a treatable source of challenges. Most recent surveys have identified ADHD symptoms in 30–60% of children with autism.[16] While reduced interest and attention to the social environment is a typical feature of ASD, significant inability to focus on tasks, or high levels of motor activity that are present across different settings, such as school and home, are not typical of ASD alone and could indicate the presence of co-occurring ADHD.

There are a number of reasons a child could be very hyperactive, impulsive, or inattentive across settings besides ADHD. Hyperactivity or impulsivity may occur in younger children who do not have enough structure in their day, or do not have a functional means of communication. Inattention may occur in children who are highly anxious and distracted by their worries or are overly sensitive to stimuli in the environment. In these cases, structuring the environment, providing visual and positive behavior supports, and addressing anxiety may reduce ADHD-like symptoms. As always, a careful consideration of why the child may be hyperactive, impulsive, or inattentive should precede treatment.

For children with inattention, hyperactivity, or impulsivity that do not respond to environmental and/or behavioral approaches, methylphenidate (Ritalin and similar forms) has been shown to be effective in approximately half of children with autism and ADHD.[17] Appetite suppression is common, and headaches, insomnia, or irritability can occur. While it has not been specifically tested in children with autism, a similar type of medication, amphetamine salts (Adderall and similar forms), has been shown to be effective for ADHD in children without ASD, and may be helpful if methylphenidate is ineffective.[18] Atomoxetine (Strattera) has also been researched in controlled studies for treatment of ADHD in children with autism, and showed some improvements, particularly for hyperactivity and impulsivity,[19,36] and common side effects were nausea and vomiting, decreased appetite, and drowsiness. Guanfacine (Intuniv, Tenex) has also shown benefit in a large study of children with ADHD and ASD.[20] In small single studies of children with autism, naltrexone[21] and clonidine[22] showed possible benefit for children with ADHD.

- **Repetitive behavior and insistence on sameness:** In their play activities and daily routines, children with ASD may display repetitive behaviors and insistence on sameness. These behaviors can manifest as:
  - Repeated motor mannerisms (such as hand flapping)
  - Atypical sensory interests (manifested as touching or rubbing certain textures)
  - Complex body movements
  - Repeating a sound, word, or phrase many times

Interruption of these repetitive patterns or the daily environments of children with autism may cause anxiety or even aggression due to their insistence on sameness and inflexible adherence to specific routines.

It is important to note that repetitive behaviors vary greatly among children with autism, in both types and frequency of behaviors, and while some individuals only engage in repetitive behaviors when feeling anxious, others may do so constantly. Therefore, when considering medication treatment, it is essential to determine whether these behavioral patterns are a problem or not. Repetitive behaviors can be unobtrusive or even adaptive (for example, obsessing about model airplanes and developing a passionate interest in learning how to build them), or can be interruptive and cause difficulties for academic and social functioning.

Because selective serotonin reuptake inhibitor (SSRI) medications have been successful in improving repetitive symptoms of obsessive compulsive disorder (OCD) in children without ASD, clinicians have attempted to treat repetitive behaviors in ASD with SSRIs. However, controlled studies of SSRIs—including fluoxetine, fluvoxamine, and citalopram—have shown little or no benefit in improving repetitive behaviors in ASD.[23–25] The atypical antipsychotics, risperidone and aripiprazole, have shown limited evidence of reducing repetitive behavior in children with ASD.

There are a number of other areas that can be a focus of clinical concern in children with ASD, and practitioners and families may consider medication, though there is little or no controlled evidence for effectiveness. These areas include **anxiety and depression, inappropriate sexualized behavior, insomnia, pica, psychosis, bruxism, and social communication.**

- **Anxiety** or **depression** can occur in children with ASD, and cognitive behavioral therapy has been shown to be helpful for high functioning children with ASD and anxiety. While no medication has been directly studied for anxiety or depression in ASD, most practitioners will consider the use of a SSRI, such as fluoxetine or sertraline, both of which have strong evidence for reducing anxiety and depression in children without ASD. As part of assessing anxiety, the possibility of post-traumatic stress should be considered.

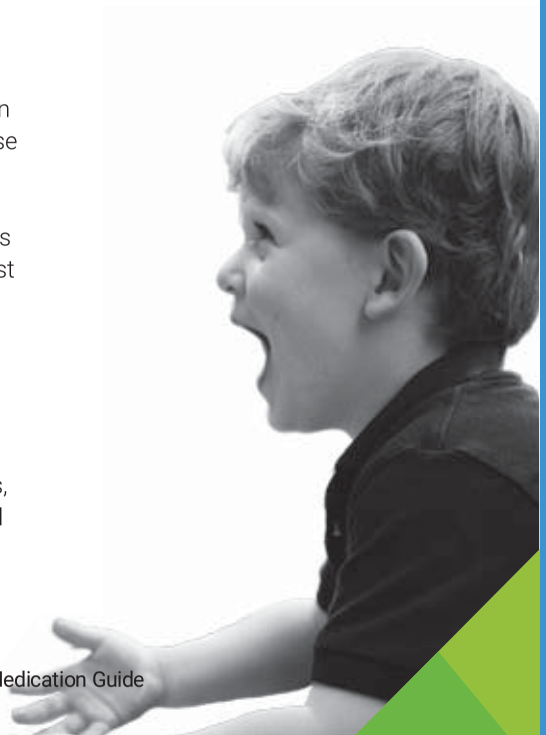
- **Inappropriate sexualized behavior (ISB):** When a person does not follow recognized social rules, socially unacceptable behaviors often occur, and sometimes this includes disinhibited or inappropriate sexualized behavior (ISB). Adolescents with ASD are often discouraged from expressing their sexuality and many are deprived of adequate sexual education. It is also important to note that people with developmental disabilities are particularly vulnerable to abuse, and ISB can be a possible indicator of child sexual abuse.[26] To treat ISB, most clinicians recommend starting with educational or behavioral approaches.[27] There are case reports describing use of mirtazapine (Remeron) to treat ISB in adolescents with ASD, though there is no controlled evidence.[28–30]

Medications such as antidepressants (SSRIs) or antipsychotics may decrease libido, which could be helpful, though this is untested.[31,32] Leuprolide was described in one case report to reduce ISB in a young adult male with ASD,[33] but has potential side effects of depression, seizures, and anaphylaxis, as well as ethical considerations.

- **Insomnia (sleep problems)** appears to be prevalent in children with ASD and should be first addressed by removing electronics and other stimulating activities from the bedroom, developing a consistent bedtime routine, and addressing bed-wetting if needed. For children who continue to have trouble falling or staying asleep, melatonin has been shown in a number of controlled studies to improve sleep in some children with ASD.
- **Social communication** is a core deficit area in ASD and a number of psychosocial treatments have been developed to address this area. Medication is limited to the possible use of methylphenidate, which was shown in one study to potentially improve social communication, perhaps by increasing attention and focus.
- **Pica** is the eating of non-nutritive substances and can have serious medical consequences. Although historically attributed to nutritional deficiencies, many people with pica do not have demonstrable vitamin or mineral deficits, though they are typically evaluated. Nevertheless, iron deficiency is the most common cause of pica, and pica behaviors usually disappear once the deficiency is corrected.[34] Applied behavior analysis (ABA) continues to have the strongest evidence for treatment of pica.
- **Bruxism** is the repetitive clenching and grinding of teeth, often occurs during sleep, and appears to be more frequent in patients with developmental delays, including ASD.[35] To date, behavioral interventions remain the mainstay of treatment.
- **Psychosis** (the loss of reality-based, organized thinking) can occur rarely in children with ASD. Antipsychotic medications that have evidence of benefit in children without ASD are typically used in these cases.

Resource links:

- AACAP practice parameter http://www.jaacap.com/article/S0890-8567%2813%2900819-8/pdf
- Autism speaks https://www.autismspeaks.org/
- CDC website http://www.cdc.gov/ncbddd/autism/index.html
- Others
  - ChildTrends http://www.childtrends.org/?indicators=autism-spectrum-disorders
  - NIMH http://www.nimh.nih.gov/health/publications/a-parents-guide-to-autism-spectrum-disorder/index.shtml
- ATN tool kits https://www.autismspeaks.org/family-services/tool-kits
- Autism Speaks challenging behaviors toolkit https://www.autismspeaks.org/family-services/tool-kits/challenging-behaviors-tool-kit



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CONTROLLED MEDICATION STUDIES IN ASD

	Medication		Participants		Dose (mg/day)	Treatment Response	Side effects Associated with Study Medication		FDA Approval Status	
Target Symptom(s)	**Generic Name (Trade Name)**	**Controlled Trial in ASD**	**Age Range (years)**	**Study Duration**	**Mean Dose (Dose Range)**	**Target symptom**	**Side Effects (SEs)**	**Serious SEs**	**A=Approved in autism, B=Approved in youth**	
	Serotonin Reuptake Inhibitor									
Repetitive behaviors	**Fluoxetine (Prozac)**	Hollander et al., 2005	Youth (5–16)	Short-term (8-week)	10mg ±4 (2.5–20) [once a day]	YES	None (AEs were *less* likely on fluoxetine than placebo)	None		**B** • Major Depressive Disorder (≥8 yo) • OCD (≥7 yo)
Repetitive behaviors	**Citalopram (Celexa)**	King et al., 2009	Youth (5–17)	Short-term (12-week)	16.5mg ±6.5 (2.5–20) [once a day]	NO (Irritability)	97% on study medication experienced AEs: • Insomnia (38%) • Increased energy (38%) • Diarrhea (26%) • Nausea/Vomiting (19%) • Impulsivity (19%) • Hyperactivity (12%) • Stereotypy (11%) • Nightmares (7%)	12% (N=9) on study medication terminated treatment due to AEs: • Seizures (N=2)		
Repetitive behaviors	**Clomipramine (Anafranil)**	Gordon et al., 1993	Youth (6–18)	Short-term (10-week)	152mg ±56 25–250 [in 2 divided doses a day]	YES • Irritability • Hyperactivity	• Insomnia (29%) • Constipation (25%) • Sedation (25%) • Twitching (21%) • Tremor (17%) • Flushing (17%) • Dry mouth (13%) • Decreased appetite (13%)	• Seizure (4%; N=1)		**B** OCD (≥10 yo)
Autism		Remington et al., 2001	Youth + Adults (10–36) Youth [10–18] =27/36	Short-term (7-week)	128mg (100–150) [in 2 or 3 divided doses a day]	NO	NR	38% (N=12) on study medication terminated treatment due to AEs: • Lethargy (13%) • Tremors (6%) • Tachycardia (3%) • Insomnia (3%) • Diaphoresis (3%) • Nausea/ vomiting (3%) • Anorexia (3%)		
	Typical Antipsychotic Agents									
ASD	**Haloperidol (Haldol)**	Anderson et al., 1984	Children (2–6)	Short-term (14-week) [4-week on study medication]	1mg (0.5–3) [in 2 divided doses a day]	YES • Withdrawal • Stereotypies • Relatedness • Hyperactivity • Temper tantrums	• Sedation (78%) • Irritability (28%) • EPS (>25%)	None		**B** • Psychosis • Tourette's Disorder (both ≥3 yo)
		Anderson et al., 1989	Children (2–7)	Short-term (14-week) [4-week on study medication]	0.8 ±0.6mg (0.25–4) [in 2 divided doses a day]	YES • Withdrawal • Stereotypies • Relatedness • Hyperactivity • Temper tantrums	• Sedation • EPS	None		

CONTROLLED MEDICATION STUDIES IN ASD

	Medication		Participants		Dose (mg/day)	Treatment Response	Side effects Associated with Study Medication		FDA Approval Status	
Target Symptom(s)	Generic Name (Trade Name)	Controlled Trial in ASD	Age Range (years)	Study Duration	Mean Dose (Dose Range)	Target symptom	Side Effects (SEs)	Serious SEs	A=Approved in autism, B=Approved in youth	
	Atypical Antipsychotic Agents									
Irritability**	**Risperidone (Risperdal)**	RUPP, 2002	Youth (5–17)	Short-term (8-week)	1.8 ±0.7mg (0.5–3.5) [in 2 divided doses a day]	YES • Hyperactivity • Stereotypies • Repetitive behaviors	• Increased appetite (73%) • Fatigue (59%) • Sedation (49%) • Drooling (27%) • Dizziness (16%) • Weight gain	None	**A** Irritability (5–17 yo)	**B** • Schizophrenia (≥13 yo) • Bipolar Disorder (≥10 yo)
		Shea et al., 2004	Children (5–12)	Short-term (8-week)	1.2mg [once a day]	YES • Anxiety • Hyperactivity • Inappropriate speech • Social withdrawal • Stereotypies	All participants (100%) on study medication experienced AEs: • Somnolence (73%) • EPS (28%) • Increased appetite (23%) • Headache (13%) • Constipation (13%) • Weight gain (10%)	None		
	RUPP Open-label Continuation Trial									
		RUPP, 2005		Long-term (6-month)	2.1 ±0.8mg (up to 4.5)	YES • Repetitive behaviors • Stereotypies • Affectual reaction • Sensory response	• Increased appetite (6%) • Drowsiness (2%) • Weight gain (2%)	• Constipation (N=1)		
		Williams et al., 2006				Adaptive behaviors: • Socialization • Communication • Daily living skills				
Irritability**	**Aripiprazole (Abilify)**	Marcus et al., 2009	Youth (6–17)	Short-term (8-week)	5–15mg	YES • Hyperactivity • Stereotypies At higher dose (15 mg/day): • Inappropriate speech • Repetitive behaviors	88% on study medication experienced AEs: • Sedation (24%) • Fatigue (15%) • Vomiting (13%) • Increased appetite (12%) • Tremors (10%) • Drooling (9%) • EPS (7%) • Weight gain (4%)	10% on study medication terminated treatment due to AEs: • Sedation (N=7) • Drooling (N=4) • Tremor (N=4)	**A** Irritability (6–17 yo)	**B** • Schizophrenia (≥13 yo) • Bipolar Disorder (≥10 yo) • Tourette's Disorder (6–18 yo)
		Owen et al., 2009	Youth (6–17)	Short-term (8-week)	8.5mg (2–15)	YES • Hyperactivity • Inappropriate speech • Stereotypies • Repetitive behaviors	• Weight gain (29%) • Fatigue (21%) • Somnolence (17%) • Vomiting (15%) • EPS (15%) • Increased appetite (15%) • Sedation (11%) • Drooling (9%) • Diarrhea (9%) • Pyrexia (9%)	11% on study medication terminated treatment due to AEs: • Fatigue • Vomiting • Weight gain • SIB • Agitation		

CONTROLLED MEDICATION STUDIES IN ASD

	Medication		Participants		Dose (mg/day)	Treatment Response	Side effects Associated with Study Medication		FDA Approval Status	
Target Symptom(s)	Generic Name (Trade Name)	Controlled Trial in ASD	Age Range (years)	Study Duration	Mean Dose (Dose Range)	Target symptom	Side Effects (SEs)	Serious SEs	A=Approved in autism, B=Approved in youth	
		Marcus et al., 2011a Marcus et al., 2011b		Long-term (52-week)	10mg (1–15)	YES • Hyperactivity • Inappropriate speech • Stereotypies • Repetitive behaviors	87% on study medication experienced AEs: • Decrease in BP (33%) • Weight gain (23%) • Vomiting (19%) • EPS (15%) • Increased appetite (13%) • Pyrexia (12%) • URI (12%) • Insomnia 10%)	11% on study medication terminated treatment due to AEs: • Aggression (2%) • Weight gain (2%) • Suicidal ideation (N=1)		
ASD	**Olanzapine (Zyprexa)**	Hollander et al., 2006	Children (6–14)	Short-term (8-week)	10 ±2mg (7.5–12.5)	YES (in global functioning)	• Sedation (67%) • Weight gain (67%) • Increased appetite (50%) • Constipation (50%)	None		**B** • Schizophrenia • Bipolar Disorder (both ≥13 yo)
	Anti-ADHD Agents									
Hyperactivity/ Impulsivity	**Methylphenidate (Ritalin)**	RUPP, 2005	Children (5–14)	Short-term (4-week)	7.5–50mg [in 3 divided doses a day]	YES	• Decreased appetite (18%) • Insomnia (15%) • Irritability (10%) • Emotional outbursts (10%)	18% on study medication terminated treatment due to AEs: • Irritability (8%)		**B** ADHD (≥6 yo)
				Long-term (8-week)		YES		1 participant discontinued study medication due to AE		
		Ghuman et al., 2009	Pre-schoolers (3–6)	Short-term (1+2-week)	14 ± 4mg (5–20) [in 2 divided doses a day]	YES	50% on study medication experienced AEs: • Increased stereotypy (21%) • Upset stomach (21%) • Sleep difficulties (14%) • Emotional lability (7%)	• Dysphoria (N=1)		
ADHD	**Atomoxetine (Strattera)**	Arnold, et al., 2006	Children (5–15)	Short-term (6-week)	1.4mg/kg/day (divided into 2 doses a day; total of 20–100mg)	YES	• Mood swings/irritability (44%) • Decreased appetite (38%) • Upset stomach (31%) • Nausea/vomiting (31%) • Tiredness/fatigue (31%) • Racing heart (19%) • Insomnia (19%) • Headache (13%) • Rash (13%) • Restlessness (13%) • Constipation (6%) • Diarrhea (6%) • Dry mouth (6%)	• Tiredness (N=1) • Rage outburst with violence and hospitalization (N=1)		**B** ADHD (≥6 yo)
ADHD	**Atomoxetine (Strattera)**	Harfterkamp et al., 2013	Youth (6–17)	Short-term (8-week)	20–100mg (1.2 mg/kg/day) [in 2 divided doses a day]	YES	81% on study medication experienced AEs: • Nausea/vomiting (29%) • Decreased appetite (27%) • Fatigue (23%) • Early morning awakening (10%)	• Fatigue (N=1)		**B** ADHD (≥6 yo)

CONTROLLED MEDICATION STUDIES IN ASD

	Medication		Participants		Dose (mg/day)	Treatment Response	Side effects Associated with Study Medication		FDA Approval Status	
Target Symptom(s)	Generic Name (Trade Name)	Controlled Trial in ASD	Age Range (years)	Study Duration	Mean Dose (Dose Range)	Target symptom	Side Effects (SEs)	Serious SEs	A=Approved in autism, B=Approved in youth	
ADHD	**Guanfacine (Tenex)**	Handen et al., 2008	Children (5–8)	Short-term (4-week)	2.8mg (2–3) [in 3 divided doses a day]	YES	• Drowsiness (50%) • Enuresis (14%)	None		**B** ADHD (6–17 yo)
ADHD	**Guanfacine (Intuniv)**	Scahill et al., 2015	Children (5–14)	Short-term (8-week)	1–4mg/day	YES	• Drowsiness (86.7%) • Fatigue (63.3%) • Decreased appetite (43.3%) • Emotional/tearful (40%) • Dry mouth (40%) • Irritability (36.7%) • Anxiety (30%)	• Verbal and physical aggression requiring police contact and ER visit (N=1)		**B** ADHD (6–17 yo)
ADHD symptoms	**Clonidine (Catapres)**	Jaselskis et al., 1992	Children (5–13)	Short-term (6-week)	0.15–0.20mg (4–10 micro-gm/kg/day) [in 3 divided doses a day]	NO • Irritability	• Drowsiness (38%) • Hypotension (25%) • Decreased activity	None		**B** ADHD (6–17 yo)
	Anticonvulsants / Mood Stabilizers									
Repetitive behaviors	**Divalproex sodium (Depakote)**	Hollander et al., 2005	Youth (5–17) Included participants with ID	Short-term (8-week)	823 ± 326mg (500–1500)	YES	77% on study medication experienced side effects: • Irritability (33%) • Weight gain (22%) • Aggression (11%) • Anxiety (11%)	None		**B** Seizure Disorder (≥10 yo)
Irritability/ Aggression		Hollander et al., 2010	Youth (4–15) Majority	Short-term (12-week)	≥500 (dosed to mean serum level of 90 mg/mL) [in 2 divided doses a day]	YES	• Agitation (13%) • Skin rash (13%) • Polyuria (13%) • Weight gain (6%)	• Irritability & insomnia (N=1)		
Autism	**Lamotrigine (Lamictal)**	Belsito et al., 2001	Children (3–11) NR	Short-term (18-week) [12-week on study drug]	60–200mg (5 mg/kg/day)	NO	• Insomnia • Hyperactivity	• Insomnia (N=2) • Insomnia+ Aggression (N=1) • Stereotypy (N=1)		**B** Seizure Disorder (≥2 yo)
ASD	**Levetiracetam (Keppra)**	Wasserman et al., 2006	Children (5–10) Majority	Short-term (10-week)	863 ±279 mg(350–2500) 20–30 mg/kg/day	NO	• Agitation/Aggression (30%)	None		**B** Seizure Disorder (≥1 yo)
	Cholinergic Agents									
Irritability	**Galantamine (Razadyne)**	Niederhofer et al., 2002	Children (7.4 ± 3.2) Majority	Short-term (Duration NR)	NR	YES Parent-rated (and not Clinician-rated) improvement in: • Hyperactivity • Social withdrawal • Inappropriate speech	None	None		

CONTROLLED MEDICATION STUDIES IN ASD

	Medication		Participants		Dose (mg/day)	Treatment Response	Side effects Associated with Study Medication		FDA Approval Status	
Target Symptom(s)	**Generic Name (Trade Name)**	**Controlled Trial in ASD**	**Age Range (years)**	**Study Duration**	**Mean Dose (Dose Range)**	**Target symptom**	**Side Effects (SEs)**	**Serious SEs**	**A=Approved in autism, B=Approved in youth**	
Core Symptoms	**Donepezil (Aricept)**	Chez et al., 2003	Children (2–10) NR	Short-term (6-week)	1.25–2.5mg	NO (Refer to comments)	• Irritability (22%) • Diarrhea (11%)	• Irritability (N=4) • Diarrhea (N=2)		
Core Symptoms	**Mecamylamine (Inversine)**	Arnold et al., 2012	Children (4–12)	Short-term (14-week)	0.5–5mg	NO	• Constipation 50%	None		
	Glutamate Modulating Agents									
Irritability + Hyperactivity	**Amantadine (Symmetrel)**	King et al., 2001	Youth (5–15)	Short-term (4-week)	168mg (90–200) [5 mg/kg/day] [in 2 divided doses a day]	NO Clinician-rated (and not parent-rated) improvement in: • Hyperactivity • Inappropriate speech	74% on study medication experienced AEs: • Insomnia (21%) • Somnolence (11%)	None		**B** Flu (≥1 yo)
Irritability	**N-acetylcysteine (Mucomyst, Acetadote)**	Hardan et al., 2012	Children (3–10)	Short-term (12-week)	900-2700mg (900 mg once, twice, or thrice a day for 4-week each)	YES • Stereotypies • Social cognition • Social motivation	• Nausea/vomiting (43%) • Constipation (21%) • Diarrhea (21%)	• Irritability (N=1)		
	GABAergic Agents									
Core Symptoms	**Bumetanide (Bumex)**	Lemonnier et al., 2012	Children (3–11)	Short-term (12-week)	1mg	YES	• Hypokalemia (22%)	• Enuresis (N=1) • Hypokalemia (N=1)		
	Miscellaneous Agents									
Core Symptoms	**L-Carnitine (Carnitor)**	Geier et al., 2011	Children (3–10)	Short-term (12-week)	50 mg/kg/day	YES	• Irritability • Stomach discomfort	1 participant discontinued study medication due to AE		
Insomnia	**Melatonin**	Cortesi et al., 2012	Children (4–10)	Short-term (12-week)	3mg (Controlled-release formulation)	YES	None	None		

* Intellectual Disability=IQ<70;

** Behaviors under irritability include aggression, deliberate self-injury, and temper tantrums; NR=Not reported; AEs=Adverse effects; OCD=obsessive compulsive disorder; EPS=Extra-pyramidal symptoms; SIB=Self injurious behaviors; URI=Upper respiratory tract infection; LDL=Low-density lipoprotein; HDL= High- density lipoprotein; TG=Triglycerides; MPH=Methylphenidate;

Medication Tracking Form

Use this form to track your child's medication history. Bring this form to appointments with your provider and update changes in medications, doses, side effects and results.

Date	Medication	Dose	Side Effects	Reason for keeping/stopping

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Challenging Behaviors Tool Kit

AUTISM SPEAKS®

Autism Speaks does not provide medical or legal advice or services. Rather, Autism Speaks provides general information about autism as a service to the community. The information provided in this tool kit is not a recommendation, referral or endorsement of any resource, therapeutic method, or service provider and does not replace the advice of medical, legal or educational professionals. Autism Speaks has not validated and is not responsible for any information or services provided by third parties. You are urged to use independent judgment and request references when considering any resource associated with the provision of services related to autism.

Aggressive and Challenging Behaviors Tool Kit

Johnny runs away and requires constant supervision. Susie screams and covers her ears whenever an airplane is overhead—and she always hears them before anyone else. She screams other times too and it is hard to get her to stop. Tommy refuses to wear shoes and throws them at anyone who tries to get him to put them on. Maria doesn't like riding the bus, and bites her mom each day as it rolls up to the bus stop. Jose will only eat three foods, and they can never touch each other on his plate or everybody is sorry. Sally hits herself in the head whenever someone tells her 'no.'

Sometimes the difficulties of autism can lead to behaviors that are quite challenging for us to understand and address. Most individuals with autism will display *challenging behaviors* of some sort at some point in their lives. These behaviors can often be the result of the underlying conditions associated with autism.

Purpose and Scope of this Tool Kit

Challenging behaviors represent some of the most concerning and stressful features of autism. These behaviors can often cause harm or damage, family and staff stress, isolation, and caregiver burnout. Parents may feel guilty or responsible, but it is important to know that you should not blame yourself for behaviors that you find difficult. Sometimes, the extraordinary steps parents go through for their children with complex needs might not be enough, and additional supports and resources might be necessary. It is important not to think of your child, or these behaviors, as 'bad,' but to learn how to better understand and respond to challenging situations to make them more manageable for everyone. Hopefully this kit will help provide you with strategies and resources, and lead you to professionals within your community.

For the purposes of this tool kit, we classify challenging behaviors as behaviors that:

- are harmful (to the individual or others)
- are destructive
- prevent access to learning and full participation in all aspects of community life
- cause others to label or isolate the individual for being odd or different

Challenging behaviors can occur throughout the lifespan of an individual with autism. The core and associated symptoms of autism can adjust over time and as a result, many individuals with autism experience changes at various stages of life that might result in new behaviors. An individual's behavior can often vary considerably even minute by minute in response to internal (such as stomach pain) or external (people, places, noises, activity levels, etc.) issues. In addition, many individuals with autism experience other associated concerns and co-occurring (*co-morbid*) conditions that can layer on additional concerns, such as those described here and here.

As time passes, families and caregivers adapt to meet the needs and demands of their loved ones. At times their responses and expectations can drift into a place that becomes difficult for everyone. These feelings often increase stress levels and may even limit access to their own friends and community.

Sometimes as children age and become stronger, challenging behaviors can reach crisis levels. Many families who have previously managed the trials presented by autism might experience crisis situations when their child hits older childhood or the teenage years. This may be because the challenges have grown as the child becomes bigger and stronger, or because of new factors that accompany growing up or *puberty*. To address more significant concerns that might create risk to the child or others, later in the kit there is section to help with Managing a Crisis.

"When James reached age 18, he was 6'2" and 210 pounds, and strong. He was learning that aggression was an effective way to avoid tasks that he didn't like because it worked – I was afraid of him. Every morning when I asked James to make his bed, he would usually begin doing it correctly but would often make mistakes. When I told him that he had made a mistake, he would start biting himself and hitting me, so I would back away and leave the room. But this allowed James to escape the task of making his bed and taught him (and me) that his aggression worked! With a little help from a behavioral consultant, I decided that whenever James began to get upset while making his bed, I would prompt him to say, "Help me please." It was explained to me that this behavior served the same purpose as his aggression and self-injury. When James asked for help, I'd give him some assistance, which made us both a lot less frustrated."

– AG, mother

The guiding principle used in developing this kit is that each individual with autism and his family should feel safe and supported, and live a healthy life filled with purpose, dignity, choices, and happiness. With this in mind, positive approaches and suggestions are highlighted throughout the kit. The general framework and *intervention* principles included are relevant at any stage of life, and we have included basic background information, with links to further information and resources on a variety of topics.

In this tool kit, the term autism will be used to include all *Autism Spectrum Disorders* that result in the social, communication and behavioral differences characteristic of this population. While we recognize that the autism spectrum encompasses both males and females, for the sake of simplicity, we have used 'he' throughout to represent an individual of either gender.

The kit is broken into different sections. You may want to read the kit in its entirety or work through a section at a time. Please visit the Autism Speaks Resource Guide to find services, contacts or resources in your area, as well as information specific to your state. If you have resources to share, you can add them to the Resource Guide here.

Document Key

- The definitions of the words highlited in the *clay colored italic text* can be found in the Glossary.
- The *blueberry italic text* are quotes from *Targeting the Big Three: Challenging Behaviors, Mealtime Behaviors, and Toileting* by Helen Yoo, Ph.D, New York State Institute for Basic Research *Autism Speaks Family Services Community Grant recipient*
- The blue text are links you can click on for further information.

Table of Contents

As a companion to the information in this kit, we have two video series of frequently asked questions regarding challenging behaviors. One is from a legal perspective and the other from a clinical perspective. You can find them on the homepage of the Challenging Behaviors Tool Kit. The questions addressed in these videos are listed below.

Legal FAQ's

General Crisis Information:

- Can you tell me what a crisis is?
- What's my first objective in a crisis situation?

Crises & Schools:

- What is a school's immediate responsibility if a crisis happens in school?
- What about after the crisis?
- Can my child get kicked out of school for this kind of behavior?
- What should I do if my child does get kicked out of school?
- What is a manifestation hearing?
- What is a school's responsibility if the crisis happens at home?
- If my school isn't helping or can't help with the situation, what should I do?

Adults & Guardianship:

- Is there anybody responsible for helping adults who are having crisis behavior?
- What happens in a crisis situation if the family has no guardianship and the individual is over 18?
- Is there emergency or temporary guardianship for a situation like this?
- If I want to obtain emergency or temporary guardianship, how would I do that?
- What's the advantage of seeking guardianship before a child turns 18?

Hospitals & Residential Placement:

- What are the responsibilities of a hospital and your rights regarding medical interventions?
- Is the hospital required to provide behavioral supports?
- If my child is in the hospital, what happens to their schooling?
- What happens if my child is being repeatedly kicked out of school and sent to hospital settings? Are there any other options?
- If an adult is in residential placement, what is the responsibility of the facility or home in a crisis situation?

Calling 911:

- If I call 911 for an emergency, what should I tell the dispatcher?
- Are there specific terms or phrases that should be used to get help in a crisis situation?
- When the first responders arrive, what information should I give them?

Other Advice:

- What other legal advice do you have for families in crisis?

Clinical FAQ's:

Understanding Challenging Behaviors:

- What are challenging behaviors?
- What's the most important thing to know about challenging behaviors?
- What's important to know about aggressive or self-injurious behaviors?

Addressing Challenging Behaviors:

- Why is it important to address challenging behaviors?
- What should I know before addressing challenging behaviors?
- How important is consistency in addressing challenging behaviors?
- What if I'm having trouble carrying out a behavior plan?

Dealing With A Crisis At Home:

- What should families do in a crisis situation?
- Where can families turn if they feel unsafe in a crisis situation?

Other Advice:

- Can you use Applied Behavior Analysis (ABA) on adolescents and adults with autism?
- What role can medication play in addressing challenging behaviors?
- When should I consider residential placement?
- Where do siblings fit in with all of this?
- Do you have any general advice for families dealing with challenging behaviors?

With gratitude, we thank the members of our Advisory Committees for generously donating their time, experience and resources to this project.

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Why is Autism Associated With Aggressive and Challenging Behaviors?

Autism itself does not cause challenging behaviors. It is likely, however, that some of the underlying biological processes that result in autism might also result in behaviors that are outside of a person's control—similar to how the tremors associated with Parkinson's Disease are brought on by impulses that the person cannot direct. In addition, some behavioral responses are simply reflexes—no more of a choice for your child than when your leg jerks upward when the doctor uses his hammer on your kneecap.

"Some of those behaviors that most professionals and many families would not consider challenging, such as making odd noises, repeating phrases over and over, closing and opening doors in a repetitive fashion, might not be dangerous or destructive. But they sure can be annoying, and raise everyone's stress levels. And when the individual is told to stop again and again but still doesn't, those little things can lead to big things. They can create a tension that makes everyone behave in ways that become problematic. Learning how to think about and deal with these low-level, irritating behaviors certainly changed how we functioned as a family and improved our quality of life."

– NM, mother

In addition, the core features of autism are areas in which difficulties can lead to feelings of frustration, confusion, anxiety or lack of control, resulting in behavioral responses. Since behavior is often a form of communication, many individuals with autism (as well as those without autism) voice their wants, needs or concerns through behaviors, rather than words. This does not mean that they are always knowingly communicating. For example, running away from a barking dog might be the child's biological fight or flight response to scary situations, or even to something that you might not view as frightening. Similarly, shutting down and retreating to a quiet place might be a child's way of saying 'this situation is far too noisy and crowded for me to handle.' This may be an automatic response in the moment, not a choice he is making.

Challenging behaviors are more likely to appear when a person is feeling unhappy or unhealthy. Medical concerns, mental health issues, or sensory responses that we cannot see might bring pain or discomfort to a person with autism that we might not understand, especially when he is unable to say so.

"All of a sudden when Mark was about 8 years old, he needed order. The change came overnight. If we opened a cabinet, he closed it. Loading and unloading the dishwasher was impossible—he could not tolerate the door being open. It was maddening to us, and so clearly compulsive for him. He became anxious and acted out if the order was not maintained. Thankfully, our doctor ran some tests and determined that he had high antibodies to strep, and the compulsiveness was likely due to a sort of obsessive compulsive disorder called PANDAS. The biological factors were not easy to treat and took a long time to resolve, but how we responded to his behavior changed completely when we realized that he wasn't doing this to drive us crazy, and that he was no more in control of what he was doing than we were. We worked a lot on building his tolerance for flexibility, in tiny bits and using positive rewards. Eventually, he returned to his flexible self, but we had to adapt our behavior to help him through this in a way that worked for all of us."

– SP, father

Many behaviors are also responses to previous experiences. A baby who gets a smile when he coos usually learns to coo more often. The same is true for challenging behaviors. If a child has learned that screaming gets him out of a difficult task, he might scream in the future to escape.

How we respond to his actions can have a significant effect on what he does the next time he is in a similar situation.

Because of the learning differences that autism can bring, people with autism might need specialized approaches to learning appropriate behavior. For example, the scolding look that stops your typical two-year-old in his tracks may mean nothing to a 30-year-old with autism who has not learned to recognize emotions and facial expressions.

Without some of the abilities and skills that most of us have developed as children and adults, people with autism are often just using the tools they know how to use. Therefore, it is likely that behavior can be improved by helping them to increase the tools they have available—to communicate, to recognize their own biological and behavioral responses, and to build an increased ability to self calm and self regulate.

Research on Aggression in Autism

A recent study of aggression in autism showed some interesting trends in terms of *risk factors*, which may give some insight into challenging behaviors overall.

- There is a much higher rate of aggression towards caregivers in autism than in the general population and in others with intellectual disabilities.
- Unlike the risk factors in a typical population, aggression was equally common in girls as boys with autism. Several other usual risk factors (lower IQ, lower parental education, less language ability) were not associated with greater risk in autism.
- The research also showed that just like in the typical population, age was a risk factor, with higher levels of aggression occurring at younger ages, which may suggest that learning and growth may help behaviors improve.
- Those children with autism at highest risk of aggression exhibited the following characteristics:
  1. More repetitive behaviors, especially self-injurious or ritualistic behaviors, or extreme resistance to change
  2. More severe autistic social impairment

These results show that core symptoms of autism are associated with the risk of aggression. Perhaps underlying conditions such as a lack of social understanding or the discomfort associated with breaking a routine might promote aggressive behavior.

What is helpful to know about behavior?

Before considering challenging behavior in isolation, it is helpful to think about human behavior in general. Some behavior is biologically driven (we eat when we are hungry) or reflexive (we cover our ears when a noise is too loud). But for the most part, *behavior occurs because it serves a function and/or produces an outcome.* Eating serves the function of satisfying hunger, and covering our ears softens the impact of the loud noise. Behavior also serves as a form of communication. Seeing someone cover his ears, even when we did not find a noise to be offensive, can communicate that he is particularly sensitive to sound.

It is critical to remember that any individual is doing the best he can do in each situation, given his skills, education, physical and emotional state, and past experiences. We classify certain behaviors as challenging because we as individuals or a society find them to be difficult to accept. It will be important for you to become a careful observer, working to understand the purpose of behaviors. Taking a step back and considering why a person might behave in a certain way is the first important step toward understanding and learning how to help. It is also essential to reducing your own frustration. In fact, it is often helpful to think of an individual's actions as a response, rather than a pre-determined or willful behavior.

However, there is a difference between understanding behaviors that we or society might not find appropriate and accepting those behaviors. For example, determining why a child needs to kick, and then developing his skills for communication should be the objective (e.g. ' I need a break.'), instead of allowing kicking as a form of speech. Similarly, working to understand and treat biological conditions that might cause challenging behaviors is essential.

"Sam's teacher moved to another city, so he entered his second year of high school with a familiar but less skilled instructor. Soon he was headed to the nurse's office each morning and spending first period on her bed. Clearly the new teacher had anxiety, and the school staff believed that this was being reflected in Sam's behavior and increasing his anxiety as well. Or perhaps it was task avoidance, as there were a lot of language demands in that first period social skills class. Then one morning, he actually gagged and vomited, but once he got home it was clear that Sam was not sick. Soon after, other staff noticed that he would turn his head to the side and his eyes would roll during the period immediately after lunch. We also noticed a tendency to retreat to the couch at home after dinner. That's when we consulted the gastroenterologist, and sure enough, he was diagnosed with reflux. All of these odd behaviors and the trips to the nurse's office subsided once he was treated."

– ED, mother

When thinking about your loved one with challenging behaviors, it is also important to consider his positive features and strengths. Show respect for his thoughts, feelings and the likelihood that he understands far more — or alternately, perhaps far less—than you might consider. Take care not to speak about him in his presence, for it is likely that he understands more than he is able to show. Talk to him and provide him with information, even if you are not sure that he understands what you are saying. It is important to build your child's trust in your support, and shape his motivation and purpose into more acceptable behaviors.

Function of Behavior

Whenever behavior occurs, it is important to consider its purpose, or what is most often called its function. Although some behavior is biologically driven, much behavior is learned over time and through experiences, and shaped by what happens before and after the behavior takes place. Other behaviors may have begun as biologically driven (such as scratching an itch) but may turn into something that serves a different function (perhaps scratching to gain a teacher's attention).

"Special educators [and parents] need to look at what a child can do instead of what he/she cannot do. There needs to be more emphasis on building up and expanding the skills a child is good at. Too often people get locked into a label such as dyslexia, ADHD, or autism, and they cannot see beyond the label. Kids that get a label often have uneven skills. They may be talented in one area and have a real deficiency in another. It is important to work on areas where a child is weak, but an emphasis on deficits should not get to the point where building the area of strength gets neglected."

– Temple Grandin, Ph.D.

An example of a productive behavior might be asking for something to eat, then receiving a cookie. The function of making the request is to get the cookie. For a child with limited language skills, the strategies involved in getting a cookie might look very different. But if the end result is the same, whatever the individual needed to do to be fed is the method by which he has learned to 'get a cookie.' Over time, an individual with significant communication challenges is likely to develop some creative and interesting methods for communicating—some of which might be considered challenging.

The Function of Challenging Behaviors

Challenging behaviors, such as aggression, disruption, or self-injury are often a chief concern of caregivers of individuals with autism and other developmental disabilities. Many of these challenging behaviors are learned and maintained by what happens immediately before and after the problem behavior. Because they are learned behaviors, problem behaviors can be modified by manipulating or changing situations in the environment, especially the events before and after the problem. In most cases, challenging behavior is seen as a way to request or communicate a preferred outcome (e.g., access to toys, food, social interaction, or cessation of unpleasant activity). Therefore, the goal is to replace the inappropriate "request" with more adaptive (appropriate and effective) communication.

-p.13 Targeting the Big Three

Questions you might ask about why a person is behaving in a certain way include:

- Did this behavior start suddenly? If so, might my child be sick or is there another change that might have caused this?
- Is there some underlying medical concern or condition that is making him reactive? Tired? Stressed?
- What is my child attempting to gain from this behavior? Is he trying to escape something?
- What is he trying to tell me? What can I learn from this?
- Does it happen in certain places, with specific people or in situations where he is hungry or tired? Is there something we might adjust in his surroundings that might improve the situation?

- What happens before the behavior? Is there something that makes it more likely to occur?
- What happens after the behavior occurs? What is helping this behavior persist? What maintains it or makes it work as a tool for this individual?
- What do I typically do to get my child to stop engaging in the behavior? Am I (or is someone else) giving him more attention then, or doing something that might be making the behavior work to get him what he wants?

If you can develop an idea of when or why a behavior is happening, you may realize there are simple solutions that help to improve a situation and make an undesired behavior less likely to occur.

It is also essential to remember that behavior changes, and people adapt. The same behavior that serves a specific function in one situation may serve a different purpose in another setting. In other words, one bite might be out of frustration when a child wants something he is unable to ask for. Another might occur when he is afraid and needs to get away, and yet another might be an automatic response to intense stress. And although biting is the same behavior, the reasons it happens (the function) can be very different.

Behavior generally serves one of several functions:

- Obtaining a desired object or outcome
- Escaping a task or situation
- Getting attention, either positive (praise) or negative (yelling)
- Trying to self-calm, self-regulate or feel good (*sensory input*)
- Blockingor staying away from something painful or bothersome (*sensory avoidance*)
- Responding to pain or discomfortAttempting to gain control over an environment or situation (*self-advocacy*)

Improvements can often be made by changing the situations and environment, or the things that come before and after problem behaviors occur. And since behavior is often a form of communication, teaching more adaptive and appropriate ways of communicating can often reshape problem behaviors into more appropriate requests, protests and responses.

"Before I was able to express myself with my speech, the only way I knew how to escape from situations and people I didn't like was to hit and bite and run. I didn't want to hurt anyone, but I just couldn't stand being there anymore and I couldn't explain my thoughts or feelings in any other way. So many things bothered me, it was like being in intense pain. Now that I've had years of practice – first with signing and then my communication device – I can use my speech and other forms of communication to ask for a break or to move to a quiet space, instead of using aggression. Things are much better for me now."

– DR, a young woman with autism

Before formal interventions are developed, it is important to consider the wide array of possible contributing factors, including the biological ones. Appropriately determining function is then essential to creating a plan that might effectively address the behavior.

For example, if a child is hitting his mom in order to get out of making his bed, putting the child in 'time out' would actually give the child what he wanted (avoiding the task), and therefore support (*reinforce*) the behavior. In this case, he would be inclined to hit again to escape. Instead, if it is determined that the child hits because the task is too difficult, making the task easier to build success might allow him to stay engaged, and eliminate the need to hit. You may want to start by helping him make the bed, but be sure that he has to finish the job correctly by putting on that last pillow.

In considering behavior, it is important to look at the individual as a whole, and to consider productive as well as challenging or *maladaptive* behaviors. It is also important to recognize that what we might consider negative behavior might have positive elements—the individual might be standing up for his wants or desires. Building appropriate self-advocacy and self-determination skills is essential. Visit the *Positive Strategies for Supporting Behavior Improvement* for more information.

People with autism often report that they find the world confusing and anxiety-producing. Many of the successful supports for increasing appropriate behavior involve creating more predictability and safety, while also building self-regulation, communication and self-determination skills. Meet your child where he is now, celebrate the things he does well, and take small, positive steps to build the skills and the trust that will make him more adapted to your family and the world around him.

Two Vital Things to Remember

By applying the principles of behavior, you will teach the individual a more appropriate way to obtain what she wants (i.e., attention, access to leisure materials, or avoiding doing a task, etc.).

- *Consistency is Vital - While function-based behavior intervention can be very effective, for it to be most successful, it must be implemented consistently at all times by the majority of people who interact with the individual.*
- *Continuation is Vital - More importantly, the behavior intervention should continue even if the challenging behavior begins to decrease, much like the way medication or diet works. Hoping for a lasting effect without continuing the changing agent (i.e., behavior treatment, medication, and diet) will only lead to frustration and failure. With consistency and adherence to the behavioral guidelines, you will see gradual change in the individual's challenging behavior.*

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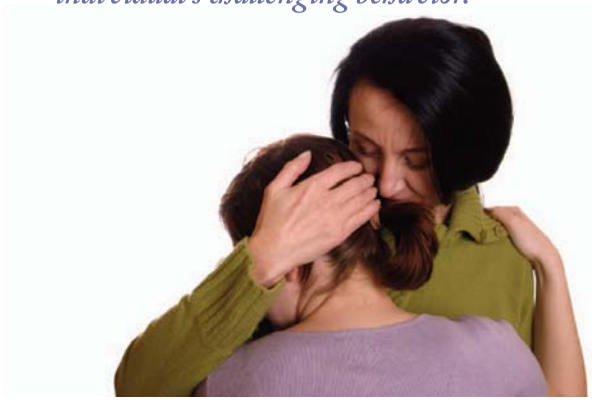

Why is it Important to Do Something about Challenging Behaviors?

Easily seeing what the problem is and adjusting the situation may be simple enough to change challenging behaviors. But sometimes this is unsuccessful, in which case continued challenging behaviors may be a sign that an individual needs help. This may be a medical evaluation or a particular treatment if something is affecting his health. Or it may require some changes in the supports, skills or tools that will allow him to feel comfortable, safe, heard and validated.

Challenging behavior might reflect an individual's only way to cope with a certain difficulty at any given time. Without proper intervention, these behaviors tend to continue and may get worse, creating an increasingly challenging cycle for you and your loved one. Promoting and teaching adaptive behavior as early as possible is essential for long term growth.

"Before Lindsay had speech, we could only guess at what was causing her so much pain. It was truly awful to feel so powerless to help your own child. And when she was aggressive or hurting herself, there was no way I was going to sit back and take my time to figure out what was causing it. I had to intervene right away either by moving away from her or restraining her arms. Once we learned to see her behaviors as her form of communication, we could begin to understand the purpose behind them. Then we could really focus on strengthening the few communication skills she had. Eventually, her problem behaviors became less and less frequent as they were replaced by language."

- BK, a father

Your ability to learn the tools to address and reshape challenging behaviors as early as possible is important for the day to day quality of life for your loved one, as well as your family. Many parents make subtle adjustments to adapt to their child's behavior, but over time, they can drift into patterns that become a "new normal." This may mean they no longer take their child shopping because of his aggression in the community. They may no longer bring him to visits with family or friends because he is disruptive, and so they lose their supports and relationships. They may accept that a child is an early riser, but then 6 AM becomes 5 AM, then 4 AM, and everyone is exhausted and no one is functioning well. Over time, these subtle adjustments (sometimes called *behavioral drift*) can become difficult to change, and can accumulate to limit the child's and his family's access to many important things in life.

Challenging behaviors can have a significant impact on the individual in many ways. They can:

- Interrupt academic learning and as a result limit long term growth and development
- Limit experiences and keep a person out of many opportunities for growth over his lifespan, including play dates, mainstream classrooms, recreational options, and eventually his work options, living conditions and ability to be integrated into the community
- Cause physical decline, pain, injury, especially when aggression and self-injury are involved
- Compromise an individual's psychological state, resulting in depression, stress, anxiety, and reduced self-confidence and self-respect
- Impair social relationships, as well as long term interactions with siblings, parents and other family members
- Affect finances as a result of employability, medical and supervision expenses
- Reduce independence and choice

Challenging behaviors can have a significant impact on the family and caregivers in many ways. Effects include:

- Added stress and worry
- Social isolation as a result of the embarrassment or stigma that accompanies the maladaptive behavior
- Anxiety and/or depression for parents and siblings
- Less time and attention for other children, responsibilities or interests
- Physical danger
- Fear of harm to themselves, other family members, others or the individual himself
- Less support from other caregivers, extended family or friends due to added complexities
- Financial concerns that result from the costs of constant care and supports, damage to property, medical bills, or the necessity of a parent to stop working
- Faster staff burnout and increased turnover
- Problem behaviors that might overwhelm the family's ability to cope or intervene

It is important to address challenging behaviors for many reasons, and the sooner the better. A 25 pound toddler with reactive behavior and a fist is a challenge, but that same behavior in a teenager who weighs 175 pounds is a threat. If your child has challenging behaviors that you are not able to change, it is important to seek out professional help.

What are some Challenging Behaviors Commonly Displayed by Individuals with Autism?

Sometimes knowing more about a behavior itself, or learning the language to describe the behaviors you see to a professional, can help others to recognize the seriousness of the problem or find the right team members or approaches to understanding your concerns. The intensity, frequency and severity of behaviors will vary considerably across individuals and settings, and may change over time. For many families, the list below may seem overwhelming and well beyond the concerns you have about your child. Some of these behaviors occur only rarely and many will not describe what you see in your child. However, any of these may require you to learn new skills or perspective and can be addressed with assistance from professionals when they do occur.

Disruption occurs when an individual exhibits inappropriate behaviors that interfere with the function and flow of his surroundings. Examples include interrupting a classroom lesson, the operation of a work environment, or a parent's ability to make a meal. Behaviors might include banging, kicking or throwing objects, knocking things over, tearing things, yelling, crying, or swearing.

Elopement refers to running away and not returning to the place where a person started. In autism, elopement is often used to describe behaviors in which a person leaves a safe place, a caretaker, or supervised situation, either by 'bolting,' wandering or sneaking away.

"There was a young man who was always eloping, He would run and we could not figure out why. Unfortunately this running was both scary and dangerous. We worked to try and figure out why he was running and when we couldn't we decided to try and teach him how to ask to run. Once we opened this door up he would ask before he would run and the parent was able to tell him where he could run and sometimes she would run with him. It wasn't the perfect solution but it worked to keep him safe and that was the best we could do at the time and it worked".

– Behavioral Consultant

Incontinence is the (usually) involuntary passing of feces or urine, generally not into a toilet or diaper. Sometimes there is an underlying physical concern that might need treatment or incomplete toilet training that may need additional teaching. For some individuals, it may be a sign that there is difficulty recognizing body signals before it is too late. Sometimes an individual learns to use 'peeing his pants' or urinating on the floor as a means of gaining attention or escaping an undesirable task or situation.

Non-compliance is used to describe when an individual does not or refuses to follow the directions, rules or wishes of someone else. Non-compliance can be passive, such as not following a direction, or active, such as whining/crying, becoming aggressive or self-injurious. It is helpful to remember that non-compliance can be purposeful, but at times can also result from lack of understanding, lack of motivation, fatigue, or poor organizational or motor planning issues.

Obsessions, compulsions, and rituals are often strong, irresistible urges that can result in difficulty with a person's ability to cooperate, to manage change or to be flexible and adjust. The compulsion involved in obsessions and rituals can often lead to additional challenging behaviors if they are interrupted or forbidden.

- An *obsession* is when a person's thoughts or feelings are dominated by a particular idea, image or desire, such as a person who only wants to talk about elevators.
- A *compulsion* is the drive to do something in particular or in a particular way, such as the need to straighten all the forks at the dinner table.
- A *ritual* is used to describe a repetitive behavior that a person appears to use in a systematic way in order to promote calm or prevent anxiety, such as arranging all the pillows in a certain way before being able to settle in to sleep.

Physical aggression is an act of force that may cause harm to another person, and might include hitting, biting, grabbing, hair pulling, slapping, kicking, pinching, scratching, pulling, pushing, head butting, or throwing things.

Property destruction includes behavior in which belongings or property are harmed, ruined or destroyed and might include breaking, throwing, scratching, tearing, defacing, etc. belongings (his or those belonging to others).

Self-injury is the attempt or act of causing harm to a person's own body severe enough to cause damage. Self injury can present in a wide range of behaviors including head banging, hand-to-head banging, body slamming, hitting or punching oneself, eyeball pressing, biting oneself, wound picking, and hair pulling. Self mutilation such as cutting one's skin, burning, or bone breaking, is less common in autism unless other psychiatric conditions co-occur.

Sexual inappropriateness can take many forms in autism, and might be described as a lack of sexual inhibition or 'acting out' behavior. Lack of impulse control and poor social understanding might result in acting on sexual impulses that others know to keep private, such as sexual advances (propositions), sexual touching, promiscuity, exposing one's genitals, masturbating in public, sexual talk, obscene phones calls or voyeurism (watching others in private situations). Depending on the severity and the circumstances, sexual inappropriateness may lead to, or be considered, sexual aggression.

Threatening behavior includes physical actions that do not involve injury or actual contact with another person (such as holding up a knife), or stated or written threats to people or property.

Tantrum or meltdown describes an emotional outburst that might involve crying, screaming, yelling and stubborn or defiant behavior. The person might lose control of his physical state, and may have difficulty calming down even if the desired outcome has been achieved.

Verbal aggression generally involves the use of threats, bullying tactics, negative language, ultimatums and other destructive forms of communication.

Less Common Challenging Behaviors

Fecal digging occurs when an individual puts his fingers into his rectum (backside). Fecal smearing and handling of feces (poop) occurs when feces are spread on property or the individual himself. Each of these might be rooted in medical causes such as skin or digestive tract concerns, or may be learned behaviors that serve a purpose such as access to attention or escape from unpleasant situations.

Food refusal occurs when a person refuses to eat anything at all.

Pica is an eating disorder that involves eating things that are not food. Some individuals with autism and other developmental disabilities eat items such as dirt, clay, chalk or paint chips. Pica can also occur when a body craves certain nutrients or minerals that are lacking in the diet/body, as sometimes occurs in women during pregnancy.

Rumination describes the practice of (voluntarily or involuntarily) spitting up partially digested food and re-chewing it, then swallowing again or spitting it out. Rumination often seems to be triggered by reflux or other gastrointestinal concerns.

Purposeful or self-induced vomiting is throwing up on purpose. Contributing factors such as reflux, hyper gag reflexes and eating disorders (*bulimia*) should be considered.

It is important to repeat that while these behaviors might all be challenging, they should not be assumed to be purely behavioral, or purposeful. As discussed earlier, they are often learned responses. Sometimes there is a biological root or trigger that might require investigation or treatment in order to help the individual get to a more comfortable place where he might be able to learn adaptive skills. Even if treatment is not immediately effective, sometimes just knowing of a medical or neurological cause of a behavior can change how you think about it and how you respond.

Resources:

- *Asperger's Syndrome: Meltdowns;* IAN Community,
  http://www.iancommunity.org/cs/about_asds/aspergers_syndrome_meltdowns
- *Autism Solutions, How To Create a Healthy And Meaningful Life For Your Child*,
  Ricki Robinson, MD, MPH
  http://www.drrickirobinson.com/
- *Targeting the Big Three: Challenging Behaviors, Mealtime Behaviors, and Toileting*
  by Helen Yoo, Ph.D, New York State Institute for Basic Research
  Autism Speaks Family Services Community Grant recipient
  http://www.autismspeaks.org/sites/default/files/challenging_behaviors_caregiver_manual.pdf
- *The Autism Revolution*, Martha Herbert
  http://www.marthaherbert.org/

Who Can Help? What is this Idea of a Team?

Individuals with autism are often quite complex, so it is helpful to take a broad approach when evaluating concerns, and deciding how to provide appropriate support. In order to meet their various needs, many individuals with autism, especially those with challenging behaviors, need a team to develop specialized and individualized care.

Team Members to Consider

Depending on the placement, circumstances, services, supports and concerns surrounding your loved one with challenging behaviors, the team might include the individuals and professionals from the disciplines outlined below. The actual mix of professionals and titles will vary across situations, but for most people it will be important to have someone in each of the roles described, either as an ongoing advisor, or as a consultant at some point.

- *Individual with Autism:* To maintain a person-centered approach and treat your loved one with dignity and respect, it is essential to include his voice at the table. Keep his wellbeing in the forefront of your mind as you plan and program as a team. Seek his perspective on the behaviors that are concerning, and why they take place. With some kids, it might help to ask, *'Why do you need to do this? How can we help?'* Wherever possible, involve him in the decision-making. Some individuals will have strong preferences that can greatly affect outcomes.

  Even if it seems that your child is not able to understand what you are saying, let alone make decisions about his care, talking to him directly might deliver more information and generate more understanding than you might expect. In addition, a person who does not respond verbally can deliver a great deal of information about his comfort, preferences and dislikes through his behavior. Involving him in the treatment process can help to build his social skills, self-advocacy skills, and independence. Remember to be sensitive to talking about him in his presence, as it is possible that he understands more than he can show.

Below is an excerpt from A Full Life with Autism, from the perspective of Jeremy, a young man with autism who learned to type to communicate:

"I have often times been the victim of ignorance. I think you have to be brave to get over the horrible times people hurt you by talking like you don't understand the comments they are making about you within earshot. I don't think people realize the kind of effect they have on nonverbal people. You know that intentional abuse is unforgiveable, but in some cases ignorance is just as painful. I remember when I was in junior high the occupational therapist told the teacher I would never learn and she did not understand why I was in mainstream classes ….. I was so upset because even though I could not talk or type, I could listen and learn. I wanted to die."

- *Parent(s):* You are the key informant and advocate and an absolutely essential member of the treatment team. Outcomes are better with family involvement. No one knows your loved one, his history or the dynamics of your beliefs and your household the way you do. You might need to tell a story or give an example to fully describe the situations you find difficult or the needs you might see in your child.

  Be prepared to ask questions, raise your concerns and preferences, and ask for help. Effective communication across the team is essential, and in many cases you may be the one facilitating the sharing of information. Take notes, but also request information, suggestions and treatment plans in writing, since afterwards it may be hard to recall what was said. Ask for referrals to additional resources and share concerns about time and financial abilities. Ask for training and where else you might find help.

  If you are asked to do something you cannot do because it is too expensive, too difficult, or you don't understand the objective, speak up and ask for other ideas.

  You are likely to fall into a role as the team leader or coordinator, but if this is too much for you to take on, there might be help. Look into finding a case manager (see below), *special needs parent advocate*, family member or friend. Ask for suggestions from a primary care provider. Ask someone to accompany you to medical or specialist appointments to take notes and help you understand the choices and information being presented. You do not need to do this alone, but you may need to seek out and advocate for the level of supports that your family needs.

"When my daughter was moving from 1st grade to a new school, I created a 3-ring binder notebook with plastic inserts and dividers. In each plastic insert, I placed sheets of her school work both good and bad to show her growth. I included artwork, certificates and added a picture to the front. Almost just as important, I included information from her Medical Home and all of the other care providers on her team. This gave each team member and everyone who saw it, the full scope of who my daughter was. That notebook gave me the tools I needed to be the best Team Leader for my daughter. Not to mention, it helped me effectively communicate with our entire team. I still update and use this notebook method for everything from IEPs to Summer Camps...it works!!" - KD, parent

- *Case Manager:* Depending on the age or placement of your loved one, this might be a school case manager, or a representative from a service agency, such as a regional center (in California) or your state's Division of Developmental Disabilities or Department of Child and Family Services. Ideally, this person should be your direct contact, and should be helping to gather resources, team members and ideas. The effectiveness, skill set and time availability of a case manager will vary considerably due to many factors, and in some circumstances, you may not have one. You may have to advocate strongly in order for the case manager to understand the level of your concerns. If you do not have a case manager, sometimes a friend or family member can help you to research, track and organize the body of information that comes with the challenges of your loved one.

- *Medical Professional:* If you do not yet have one, try to build a 'medical home'—a relationship with a doctor who knows your child, and who you know and trust. Involve your primary doctor in evaluations, as he should be able to help when considering medical triggers for behavioral concerns. If your provider does not have a lot of experience in autism, it might help to share the list of Things to Consider in the next section and work through the possibilities together. Your doctor might refer you to specialists in areas of concern, and may be helpful in finding some of the other team members or therapists in the roles described below.

- Among others, referrals to specialists might include:
- hearing assessments (*audiologist*)
- vision evaluation (*ophthalmologist or optometrist*)
- stomach or digestive tract concerns (*gastroenterologist*)
- diet or nutrition issues (*nutritionist*)
- allergies (*allergist*)
- immune concerns (*immunologist*)

Just because an individual has autism, it does not mean that he is exempt from any of the other health concerns that affect any of us.

Sometimes doctors try to consider symptoms and signs, relate them back to what they know about autism and write off anything difficult to interpret as behavior. This is especially difficult if your loved one has limited language and cannot describe pain or perception issues. You might have to advocate in order to keep the focus on the individual and your concerns. Just because a broken leg is not associated with autism in the research literature, doesn't mean your child who just fell out of a tree does not have one!

In some states, you might have access to an Autism Treatment Network site, where the medical concerns associated with autism are being researched and treated according to collaboratively developed protocols with teams who specialize in autism treatment.

Is your loved one an adult or approaching adulthood?

It is important to note that while pediatricians are becoming increasingly aware of some of the issues related to autism, individuals on the spectrum are still relatively rare and novel in the world of adult medicine. Sometimes individuals with developmental disabilities stay in pediatric care far beyond childhood. If a switch to an adult provider is necessary, try to facilitate a transition of medical records as well as conversations with the pediatric caregiver. You may want to pass along this introduction for internists: 'Gently does it,' caring for adults with autism, from the American College of Physicians.

If you find your loved one in the care of an adult doctor new to autism, you may need to share the information and resources provided in this tool kit, or additional general background information such as Your Next Patient Has Autism….

- *Behavioral Health Provider* or *Behavior Analyst:* A team member who is trained in behaviorally based evaluations and interventions is often instrumental in understanding your child's challenging behaviors and developing supports and strategies. This might be a school *psychologist*, general psychologist, *Board Certified Behavior Analyst* (BCBA) or other behaviorally trained provider. These providers will use the elements of *Applied Behavior Analysis* (ABA) in supporting your loved one.

  ABA techniques involve controlling factors in the environment and monitoring interactions prior to a behavior (antecedents) and responses after a behavior (consequences). These techniques, including using positive reinforcement, are powerful in shaping behavior in individuals with autism. For more information, see the ATN Applied Behavior Analysis: A Parent's Guide and tips on Partnering with your Child's ABA Instructor.

"I honestly do not know where my son, Tyson, would be today without ABA. I am a true believer, although it was definitely not easy in the beginning. I hadn't realized how much work it was going to be for me and my wife, not to mention for our BCBA, but it was well worth it in the end. We basically started breaking down every task in Tyson's life into very small, manageable steps, and we rewarded him for even his 'smallest' successes. Then the BCBA would have us systematically raise the bar as he did more and more independently. I can say that Tyson is in an inclusive middle school today (with lots of accommodations) because ABA therapy helped him learn how to do almost everything from looking, listening, and sitting in his chair."

– HK, a father

- *Educator/Job Coach/Habilitator:* If your child is under the age of 21, it is likely that he is in a school based program with a teacher. Once he reaches adulthood, instruction is more likely to come through a habilitator or staff member at a day program, or a job coach. In both instances, finding a lead educator with autism experience and background in behavioral interventions will likely be helpful. Schools will require credentials on a state-by-state basis, but there is very little licensing or required training for adult service providers in most states.

- *Mental Health Provider:* Consideration of emotional and mental health concerns, as well as training and supports for the individual and the family, can come from a psychologist, school psychologist, psychiatrist, social worker, or community mental health worker.

- *Speech Pathologist or Speech Language Pathologist (SLP):* A trained speech specialist can evaluate an individual's ability to understand language as well as produce speech. These specialists are trained to see subtle concerns that might reflect communication deficits that an individual might find frustrating., A speech professional can also be invaluable in developing *functional communication* skills.

  Sometimes schools or agencies will resist providing speech services for a person who is non-verbal. But it is the development of communication systems (e.g. use of gestures and visuals, *picture exchange systems (PECS)*, sign language, *voice output technology*), not the pronunciation of sounds, that is the target for many speech therapy interventions in autism. Be persistent!

- *Occupational Therapist (OT):* An occupational therapist can help to evaluate concerns with fine motor issues, as well as the sensory and stimulation differences. Many OTs have also been trained in interventions and coping strategies to help make individuals feel more comfortable in their surroundings.

Physical therapists (PT), who generally work on large motor tasks and functions, may also be trained in related techniques. Both OTs and PTs can be instrumental in developing effective exercise programming.

Each of these team members might bring a different view of the same person to the table, providing perspective and expertise in understanding and creating systems of support. It is up to the parent, hopefully with the support of another key team member such as the case manager or doctor, to weigh and prioritize the input from these team members. A combined approach from the team should help to address physical, mental and learning concerns, and create a positive support plan for addressing challenging behaviors and helping you help your loved one with autism to grow and adapt.

Things to Look For in Your Child's Team (and Questions You Might Ask)

It might be helpful if you first go through the list of questions included below so that you have a sense of your own expectations and perspectives and can find a good match. Also keep it mind that certain personalities and styles will fit you or your child better than others.

- *Person-centered approach:* Professionals who think of your child as a person first—not the disability or the behaviors—will be the most helpful in discovering his strengths and his challenges. A person-centered approach will allow your team to find the tools and strategies that will be most helpful to him as an individual and to you as a family. A family-centered approach is also important, so it is essential to consider the values, priorities and specific needs of your family.
  - *What do you see about my child that you think is meaningful? Helpful? Different?*
  - *What are his strengths? What can you see of his preferences and fears?*
  - *This concern is as much about the questions the provider asks you, as it is about how he answers your questions. Does he try to understand your loved one, family dynamics, priorities, strengths, confounding factors, etc?*
- *Collaborative:* The challenging behaviors that might develop from a variety of factors will require many points of view. There may be a need for multiple providers or even multiple agencies, and the team will need to work together on the person's behalf. Collaboration also requires good communication between the members of the team. Some parents carry a notebook, an informational sheet and even makeshift brochures regarding their child to share with other team members.
  - *How do we communicate as a team?*
  - *What information can you give me to share with other team members?*
  - *How have you worked collaboratively in the past?*

"I have to say, we were lucky enough from the beginning to have assembled a group of fine people who had the very best intentions of helping my son Eli. But a few months into his preschool year, after Eli's progress seemed to have stalled, the school psychologist realized that we were not communicating well enough with each other. We were a patchwork team in which one hand hardly knew what the other one was doing. Once we started holding monthly

team meetings at the school where we could coordinate what each person found helpful, Eli really started to make a lot of progress. Keeping a daily communication book in his backpack (and now an email chain) was terrific because it kept us all in the loop and it was a way to document everyone's ideas." – SW, a mother

- *Broad thinking approach:* Given the complexities and variability associated with autism, it is critical that team members think about all of the possible driving and complicating factors that might influence an individual's behavior. (See Things to Consider) Especially when a challenging behavior is new or has dramatically increased, medical issues should be considered early in the evaluation process.
  - *What do you know about other interventions?*
  - *Do you have any suggestions for other team members with ____ expertise who might be helpful?*
  - *Do you think _____ might reflect something physical or emotional? Is there something else we should be considering?*
- *Experience with Autism:* Especially when it comes to challenging behaviors, it is important to try to connect with providers who are experienced with autism. For example, a doctor who understands that a minimally verbal child cannot report pain may have developed other ways of gathering information about possible concerns. A psychologist who understands that sensory issues may cause a child to be more anxious in certain situations may utilize a different approach to evaluation. You can learn about the provider's experience by asking at his office, or by connecting with school or agency staff, other parents, or local support groups for suggestions and recommendations.
  - *What is your experience in working with individuals with autism? This age group? This type of challenging behavior? This intervention plan?*
- *Commitment to evidence-based interventions:* Team members should focus on medications, interventions and programming that research has shown to be effective. However, it is important to remember that each individual should be treated as such. An intervention that has been validated in a diagnosed co-occurring condition, such as depression, should not be tossed aside just because it has not been established as a treatment in autism.

  The team should treat the person and the presenting symptoms, not the 'autism.'

  In addition, the field of autism is evolving, and for many interventions the research has not been done. A lack of research may not mean a lack of effect or relevance to your child's situation. Consult other team members to help you assess suggestions, but also know that you might not all agree. You should work within your team to weigh risks and benefits. For more on autism best practices, see the National Autism Center's A Parent's Guide to Evidence-Based Practice and Autism and the National Professional Development Center on Autism Spectrum Disorders.
  - *What does the research say about the use of this intervention for ____? What other information is available?*

- *Professional judgment:* While research studies show the general effects of an intervention across a population, an evaluation of effectiveness should take place for interventions used with any specific person. Assessing effects requires set targets, goals and protocols, as well as a plan for collecting and analyzing data. Data analysis is important so that you know what is working, and when and if alternate treatment choices should be considered.
  - *What is the target behavior of this intervention?*
  - *How will we know if it is working? What are we tracking?*
  - *What are the side effects?*
  - *What is our role in the intervention?*
- *Responsiveness:* Providers should give you as much information as you need to understand the intervention and your role in it. They should listen to your concerns and priorities—cultural, familial, financial, etc.—and be able to adjust interventions to make them work for your family, the team, and the individual's needs. Voice your concerns and challenges so the providers can best support you and your loved one.
  - *What is my role in this plan or intervention?*
  - *How can we adjust _____ to take into consideration our family's needs? My travel schedule? Our insurance plan?*
  - *This is too hard. Data reflects that it is not working. This medication is making him worse. What do we do now?*
- *Licensing, board certification or other credentials:* It might be helpful to request references and talk to others who have used a provider you are considering. A list of certification and credentials required for the team members above is listed below:
  - *Occupation Therapist/Physical/Speech Therapists:*
    OT/PT/SLT State Certification Required (available online)
    National Board for Certifying Occupational Therapy (voluntary certification)
    American Speech-Language-Hearing Association (voluntary certification)
  - *Mental Health Provider:*
    Psychologist License: State Licensing Board (available online)
    Psychologist Certification: American Board of Professional Psychology or
    National Association of School Psychologists
    Clinical Social Worker: State license or certification (available online)
  - *Behavioral Health Provider:*
    Certification, required for BCBA designation, but not required to use ABA:
    Behavior Analyst Certification Board
  - *Medical Professional:*
    License: United States Medical Licensing Examination
    Certification required: American Board of Medical Specialties or American Osteopathic Association

How and Where to Find a Team

For school age children, many of these providers will be available through your school (ask your child's teacher or *Individualized Education Plan (IEP)* team case manager), or by referral from your school team or your doctor. Schools are required under the *Individuals with Disabilities Employment Act (IDEA)* to use *Functional Behavior Assessment (FBA)*, and then to support the learning of a child in school using a *Behavior Improvement Plan (BIP)* when necessary. Further information is available here and here.

Additional case management and referral ideas might come through your state disability agency, county offices, or social services agencies. Often there are printed resource directories or you might search online for your state's agency for developmental disabilities. Check phone books and county websites for government offices that might lead to the right agency. You may need to call several numbers to find out how to get to the right place for what you need. This may be quite frustrating, but be persistent! Public health departments, offices of children and family services, disability services or developmental disabilities may be helpful; sometimes their work is subcontracted to other organizations such as Easter Seals or United Cerebral Palsy, or groups that only exist in your state or city. The Autism Speaks Resource Guide also contains state information by age.

"Each time we saw a new doctor or therapist, or my daughter joined a new group or activity, I became increasingly overwhelmed. I oftentimes found myself just staring at papers and numbers and not knowing where to start. A friend of mine, whose child is also on the spectrum, suggested I reach out to a case manager to help me sort through everything. I wanted to think I could do this all on my own but decided to call. After an hour-long meeting with a case manager at a local organization I felt much better. There's still so much to do but I feel like I have a clear path to get there now."

– MM, a parent

Some states have *wraparound* programs, designed to build teams of providers, family members and natural supports to help keep complex youth in their homes and communities. In autism, wraparound services can sometimes fund behavioral programming. You can find a Board Certified Behavior Analyst (BCBA) here.

For adults, referrals might come through an existing service provider, medical home or *Medicaid* case manager. Contacting the county or state agencies will be similar to what is described above, but different agencies may be involved in care for adults.

It is important to note that your primary or initial contacts may not have the necessary time or specific skills necessary to fulfill the needs of your child, his evaluation, or ongoing supports and interventions. You may need to ask for additional referrals and supports. Keep asking.

Contacting other parents, often through your child's school, program or local autism support groups, might reveal additional suggestions and resources, especially for providers who are already working in the field of autism. Attend conferences, lectures, or fundraising events such as Walk Now for Autism Speaks. Even if you don't have time for the lectures or the event itself, take a pass through the vendor tables that are often set up just outside to meet area providers who might be able to help.

To access supports or resources specific to your state, please consult the Autism Speaks Resource Guide. If you have found providers that have been helpful, please submit them to the database here.

Funding Sources

Even if you have an experienced professional team assembled, paying for the additional services and supports can be yet another hurdle. Services provided by the school under the stipulations of IDEA are required to be free and appropriate. That means you do not need to pay, and if the school does not have the necessary skills or staff to meet your child's needs, it is their responsibility to pay for the services required to do so. It may require significant advocacy to get them to do what the law requires. More information on your rights under IDEA can be found here.

Ask your Human Resources officer about benefits, or check with your insurance company. Contact the public health department to learn about community plans such as those for mental health or those targeted to children. Funding for medical needs is often covered through health insurance and/or Medicaid. Speech and occupational therapists, as well as medical specialists, are often covered under medical plans. Historically, some of these benefits were specifically denied for autism and developmental disabilities, but as autism has become more common and research and advocacy efforts have increased, coverage for these items is improving.

Some states have mental health parity laws, which indicate that mental health care has to be covered to the same degree as physical health issues. Some insurance plans also have stipulations for behavioral health supports and interventions, and Medicaid programs provide *wrap around* services for behavioral interventions. It may take some significant investigation through your Human Resources department, your insurance company or the Medicaid office to find out the details of the mental or behavioral health coverage available. You may find assistance through your primary care provider or a case manager.

Military families are covered by *TRICARE*, the military healthcare program, which provides for limited ABA coverage for certain beneficiaries under the TRICARE Extended Care Health Option (commonly referred to as the ECHO program). Learn more about TRICARE eligibility criteria here.

Autism insurance legislation is in the process of being enacted state by state, with various terms regarding implementation and coverage. More than 30 states have passed autism insurance laws; they are listed on the National Conference of State Legislatures website. It is advisable to investigate and understand your coverage so that you know what to expect before beginning services. To find out the status of specific laws for insurance coverage for autism services in your state, visit the Autism Speaks Autism Votes website and select your state.

Certain state agencies can also provide funding for *respite*, which is helpful in giving you a chance to catch your breath. These agencies, such as Departments or Divisions of Developmental Disabilities or Children and Family Services may have programs, supports or suggestions of resources.

Sources/Resources:

Behavior Analyst Certification Board, Inc. (BACB)
http://www.bacb.com/

'Gently does it,' caring for adults with autism
http://www.acpinternist.org/archives/2008/11/autism.htm#sb3

National Autism Center's *A Parent's Guide to Evidence-Based Practice and Autism*
http://www.nationalautismcenter.org/learning/parent_manual.php

National Conference of State Legislatures (autism insurance information)
http://www.ncsl.org/issues-research/health/autism-and-insurance-coverage-state-laws.aspx

National Professional Development Center on Autism Spectrum Disorders
http://autismpdc.fpg.unc.edu/

Special Needs Parent Advocate
www.specialneedsadvocate.com

Wrightslaw (special education and disabilities legal information)
www.Wrightslaw.com

US Bureau of Labor Statistics *Occupational Outlook Handbook*
(Information on practitioner training and qualifications)
www.bls.gov/OCO/

Your Next Patient Has Autism…
http://www.northshorelij.com/cs/Satellite?blobcol=urldata&blobheader=application%2Fpdf&blobkey=id&blobtable=MungoBlobs&blobwhere=1247088820137&ssbinary=true

What are the Things to Consider?

When trying to understand what might be contributing to challenging behaviors in any person at a certain point in time, the team needs to utilize a broad approach. Thoughtful consideration must be given to the various issues that might be resulting in the individual's actions. You may want to have your providers explore possible medical and mental health factors (also referred to as applying the principles of *differential diagnosis*). In this way, they can better evaluate what might set up, trigger, or maintain the behavior.

Some of these concerns might be quite obvious. For example, you would expect pain if a child has a visibly broken arm. However, other issues might require the skills of an expert who knows what subtle signs to look for, such as staring spells that might suggest seizure activity, certain behaviors that might suggest belly discomfort, or patterns that suggest an additional mental health concern.

"Until age 9, generally I lived in my own world relating to things, shiny coins, marbles and sparkly objects that I collected and hid in a secret place. I focused intently on these objects, lining them up over and over in patterns only I understood. If anyone disturbed them I had a tantrum, a meltdown, banging my head against the floor or wall for fifteen minutes. Nothing seemed to assuage my rage, it seemed to run a predictable course. I pulled my hair, picked at my skin and bit my arms. When it was over I was very thirsty and tired. Often, I returned to my activity to repair the interruption. My world was a house of cards, any breeze could collapse it.

I was an escape artist. I ran wildly, arms flailing until I became too winded to continue. Then I fell down, rolled onto my back and stared at the sky. I usually fell asleep. I believe that I had seizures.

I played with others if I could lead, and control the activities. If not, I left without a word. I seldom fought with other kids, except my bossy older sister who felt responsible for me. I didn't have a connection to people until I was in grade school.

High School and College I succeeded academically and socially pursuing artistic interests. I had many casual friends, none were close."

– Ruth Elaine Hane,*
a married woman with High Functioning Autism

**To read more about Mrs. Hane, please refer to Appendix 1 at the end of this section.*

It might be helpful to know that in general, people with developmental disabilities (including autism) are more likely to receive inadequate or inappropriate medical treatment. They receive fewer routine physical examinations, less preventative dental care and less mental health care than other Americans. People with communication issues are at greater risk of poor nutrition, overmedication, injury, neglect and abuse. There are likely multiple factors involved in these statistics, but certainly it is harder to care for someone who does not reliably say 'This hurts,' or 'Hey mom, why can't I see the blackboard at school?' Often, it is the parent's ability to be a watchful observer and careful reporter, combined with the skilled listening and evaluation of an experienced provider, that brings the necessary factors of a person with autism's health and other factors into consideration.

The following chart lists areas of potential consideration for the professionals on your team, and the types of questions you might ask in each area. This list is not complete, but hopefully it will support you and your team in considering topics that might be relevant with respect to your loved one and his concerns. If this list suggests an area that a provider is not investigating, be sure to bring it up. Know that you may have to be persistent or consult with other team members for each of your concerns to get the attention your loved one deserves.

Things to Consider

Possible Cause	Potential Areas of Focus	Questions to ask
Medical	Pain e.g. ear infection? Toothache?	Could this person be in pain?
	Seizure	Could this be seizure related?
	Sedation / Poly pharmacy (multiple medications)	Is this individual sedated? Is he on too many medications? Is he on the wrong medications or dose?
	Insomnia/Inadequate sleep	Does the person get enough sleep?
	Allergies	Are there seasonal, food or environmental allergies involved?
	GI Issues/Nutrition	Is behavior related to meal times or food? Has there been a change or concern about bowel habits?
	Dental concerns	When was the last dental exam? Is there tooth pain?
	Vision/Hearing	Is there a change in or problem with perception?
Genetic	Fragile X, Down Syndrome, etc.	Could this behavior be related to an undiagnosed genetic syndrome?
Mental health	Co-occurring mental illness	Could he be experiencing anxiety, depression, ADHD? OCD?
Cognitive	Intellectual ability/ Processing abilities	Are the demands on the individual too high or low for his cognitive level?
Communication	Adequacy of communication system	Does this person have a functional communication system? Does he use it spontaneously (without prompt)?
Sensory Dys-regulation	Unmet or overwhelming sensory factors	Is the behavior supplying sensory input/ attempting to meet sensory needs?
	Sensory defensiveness	Is the behavior in response to sensory overload? Are there big responses to things in the environment? (Loud noises, etc.)
Environmental factors	Location, time of day, setting, activity	Is he too exhausted at the end of the day to handle this demand? Why is he okay at other doctors' offices, but not here? Is this task beyond his motor ability?
Environmental reinforcement of behavior	Family/ Staff / Educator / Caregiver responses to behavior	Is the behavior responded to with attention? Removal of a request? Other?
Family / Staff dynamics	Changes in family environment	Have we had losses/changes in our family?
	Changes in staffing	Has a favored staff member left? Are new staff members adequately trained? Is there a shift in schedules/patterns?

Adapted from: *"Psychopharmacology of Autism Spectrum Disorders: Evidence and Practice,"* in press, Child and Adolescent Psychiatry Clinics of North America, 2012, Matthew Siegel, M.D.

Physical Concerns

As the previous chart outlines, there are many potential physical causes of and medical contributors to behavior. Gathering information about pain and symptoms can be especially difficult in individuals with autism due to communication difficulties, variable responses to sensory input and pain and even in those with good verbal ability, a lack of self-awareness.

It is also important for the team to know about medical concerns that often accompany autism, or more specifically, challenging behaviors. Addressing these less obvious concerns can often change behaviors. The most recognized of these include the following:

- *Seizure disorder* or epilepsy occurs in as many as a quarter of individuals with autism. Spotting seizures is sometimes tricky, since some seizures might occur at night but leave daytime effects, and others can appear in milder forms such as *staring spells* or times of 'spacing out.' Sometimes the after effects of a seizure can leave the person lethargic or reactive. You can find resources related to epilepsy here.
- *Gastrointestinal complaints or digestive disorders* such as reflux, stomachache, constipation, bowel pain, and diarrhea are often reported in autism. Investigation can be difficult in light of language challenges, but treatment has been shown to improve comfort and increase access to learning environments. See Recommendations for evaluation and treatment of common gastrointestinal problems in children with ASDs.
- *Sleep disorders or disturbances* such as difficulty falling asleep, insomnia, *sleep apnea* (disrupted breathing), and night waking are often reported in autism. Sleep is always an important consideration, both for the individual and the caregiver. Sleep is essential for physical as well as psychological restoration. It is hard to remain calm and keep perspective when you are exhausted, so evaluating and treating sleep concerns is essential. See the ATN Sleep Strategies Guide.
- *Sensory issues* are important to consider, since many individuals with autism respond to sensory input in an altered way. Sounds are louder, lights are brighter, words and visuals cannot be taken in at the same time, and the world is hurtful or confusing. It is also important to remember to assess sensory input. Have your child's eye sight and hearing checked? Make sure the doctor uses the right tests, since these concerns can be a challenge to evaluate in people with autism. In addition, these issues can change over time. Any of these factors might change a person's reactivity and promote a behavioral response.
- *Allergies, immune dysfunction, or autoimmune conditions* may show behavioral features that vary with exposure. Seasonal or *food allergies* or *intolerances* only occur at certain times of year, or when a particular food is eaten. Some food intolerances cause discomfort but not obvious rashes or breathing concerns, and may be difficult to identify. Immune activation such as eczema, joint pain or other conditions can cause a chronic discomfort that goes unnoticed.
- *Headaches or migraines* can result in a person with autism walking around with pain that you or I might readily fix with an over the counter pain killer. The inability to report pain—or even in more verbal individuals to identify pain in a certain place—can lead to discomfort that results in challenging behavior.
- *Genetic disorders* are associated with autism, and some can be accompanied by additional challenges that are worthy of medical consideration. Sometimes knowing about genetic differences can help you be more aware of other associated conditions, such as seizures.

Reflections on my childhood:

"I had terrible belly pain, and I did not know what to do about it. So I would run. I ran for miles just to try to get away from the pain. Of course, it was a small town and everyone knew me, so eventually I would end up back at home."
- RT, adult with autism

Other medical conditions have been noted in individuals with autism that may cause significant changes in behavior. These concerns may not immediately come to mind for your medical provider. But there is growing awareness of and investigation into the role they may play in autism, and sometimes in the appearance of challenging behaviors.

- *Whole body condition* is important to consider as autism is being increasingly recognized as a condition of the body, not just the brain. Many of the associations discussed above highlight the idea that there is likely more going on physically than was once thought. Insights into **nutrition** and **various body processes** might be worth considering.
- *Missed infections*, such as **Lyme's Disease**, **PANDAS**, an ear infection, an ongoing upper respiratory infection that harbors strep, or other low grade infections might cause immune activation but perhaps not obvious signs like a fever. Sometimes, there are effects on the nervous system as well as physical results of these infections. A doctor might check blood samples to look for titers (evidence of infection in the immune system) if behavior changes, such as extreme lethargy, tics, or a sudden onset of obsessions take place.
- *Catatonia* might be worth investigation if there is behavioral regression and significant changes in *motor* function (the ability to move, or to control one's movements). With catatonia, an individual may appear to hesitate, develop strange body postures, limit eating, and develop odd movements and tremors. Behaviors can appear such as self injury and aggression as a result of the individual's lack of motor control. Though it is not well recognized in the U.S., catatonia has been shown to develop in a significant number of teenagers and young adults with autism in studies in the UK as discussed in *Catatonia in autism* and may be worthy of consideration if these symptoms sound familiar.
- *Changing hormones* and the onset of *puberty* can make a typical child seem like a stranger, and these same effects can occur in people with autism. However, in autism, additional considerations come into play because of the language and social deficits. It is important to consider whether some of the behavioral features you are seeing are a natural, developmentally appropriate strive towards greater independence. If so, you should consider allowing additional choices and other proactive strategies (described in the next section) that will address this need. In addition, statistics show that individuals with developmental disabilities are at greater risk of abuse, including sexual abuse. The team should give consideration to this as a potential factor in sudden challenging behaviors. You can learn more by visiting the **Autism Speaks Safety Project** website.

Although it is not specific to autism, the chart of *"Common" behavior problems and speculations about their causes* might trigger some thoughts of additional considerations in your child (please see Appendices 2 & 3).

For some children, evaluations may have been skipped or avoided because of difficulty or fear of the procedures themselves. If anxiety about procedures affects the ability of your medical or dental team to evaluate your child, these tool kits, which were created by the *Autism Treatment Network (ATN)* might be helpful to you or your providers:

- Blood Draw Tool Kit
- Dental Tool Kit for Families
- Dental Tool Kit for Professionals

Mental Health Considerations

Studies of individuals on the autism spectrum show frequent overlap with symptoms that meet diagnostic criteria for other mental health conditions. This is a difficult area and interpretation often varies by provider, since many of the features of autism also occur in other named disorders and there is no distinct line. For instance, various providers might use different criteria in distinguishing between the repetitive behaviors of autism and a diagnosis of obsessive-compulsive disorder.

Sometimes the features of *depression*, *anxiety*, *ADHD*, *obsessive compulsive disorder*, *Tourette's Syndrome*, *bipolar disorder* or *schizophrenia* are significant enough that they stand on their own as worthy of specific diagnosis and treatment. When a person has two or more diagnosed conditions, this is called a *co-morbid condition* or *dual diagnosis*. Challenging behaviors are common in individuals with dual diagnoses, and it may be that another mental health concern has not yet been diagnosed or considered.

Statistics for dual diagnosis in individuals on the 'higher functioning' end of the spectrum or with Asperger's Syndrome are high. This might be because they are better able to report concerns. It may be that the combination of the social aspects of autism and the effects of the co-morbid condition combine to cause challenges that drive them to evaluation, services and hopefully, treatment. More information is available through the National Association of Dual Diagnosis (NADD).

The role of the mental health provider might include differential diagnosis, medications, therapy and/or *cognitive behavior* interventions, as well as partnership with other team members. It might be important for a mental health provider to educate the team about the features of a dual diagnosis, so that, for example, the uncontrollable tics of *Tourette's* might be considered and treated as something different from *behavioral stereotypy*. A mental health provider might ask questions about the behavior, as well as changes in behavior that might reveal new circumstances or areas of concern such as depression, anxiety, *post-traumatic stress*, or *psychosis*.

It is important to note that mental health disorders and symptoms should not be considered purely psychological. There are biological factors that can drive anxiety, anger, tics and other behaviors. Just as it may be impossible to know when a seizure is coming, the biological triggers for some of these symptoms in some individuals, and the resulting behaviors, can be unpredictable. If this is the case, your mental health provider should help you understand this situation better and may be able to help. Together with your behavioral/educational team, you may be able to determine subtle signs that your child is headed towards a surge and then develop approaches that will minimize its effects.

Recent research has shown preliminary evidence of *biomarkers* of depression in teenagers. A biomarker is a sign of an objective, measurable biological state. For many, the presence of a biomarker makes something 'real', like high cholesterol or an infection with a specific virus. In contrast, autism and most mental health concerns are diagnosed based on observed behaviors, and therefore more subjective and likely to be thought of as psychological in nature. Identification of biomarkers in autism is an objective of the research field, but even if only potential co-morbid conditions can be assessed this way, it could be helpful in defining concerns, and tailoring treatments for many individuals.

Another potential factor is the role of adolescence in changing behaviors. Puberty is often a time when conditions such as depression and anxiety appear. The physiological changes, as well as the developmentally programmed need for greater independence and breaking away from parental control, are just as real in an individual with autism as they are in a typical teen. For those who have academic and functional skills closer to their peers, such as young people with Asperger's Syndrome, teenage years can be a sensitive time when a growing awareness of their differences or difficulties making friends and fitting in becomes increasingly frustrating. A mental health provider might be able to help your child, and also aid in your understanding of these changes and how you might adapt to grow with your child as he strives for more autonomy and self-advocacy.

Post-traumatic stress (PTSD is another condition worthy of consideration, especially for someone who cannot describe what he has experienced. Some individuals may have been in situations that have caused significant stress, such as medical concerns/pain/procedures, changes in surroundings/staff/family, neglect, or abuse. *It is important to be aware that research also shows a higher likelihood of sexual abuse in the developmentally disabled population.* The possibility of abuse or trauma should be considered when challenging behaviors develop suddenly.

Other individuals may feel additional stress in response to interventions that have targeted challenging behaviors using approaches such as *seclusion* (putting a person in a place alone), *restraints* (tying, wrapping or otherwise restricting a person's ability to move), *over correction*, *'aversives'* (interventions that are painful or disliked), or other punishments. In these instances, caregiver/staff responses to challenging behavior may be instrumental in creating a disturbing cycle that raises stress and increases the likelihood of more difficult behaviors. In other words, how the people around your child are responding to his behavior might be making his situation even more stressful and challenging. More discussion of the effects of intervention is included in the behavioral section that comes later in this tool kit.

Medication

If your loved one takes medicine, it might also be worthwhile to talk to your doctor about the possible effects on behavior. Many of the medications we use affect more than just the intended outcome. These side effects can sometimes be quite significant and can change an individual's sensitivity or ability to regulate. For example, some medications can be *ototoxic*—which means they might be damaging to the ears, causing sound sensitivities, dizziness or balance issues. Other medications might cause stomach pain in a person who never had digestive issues before. It is not just traditional *psychotropic* (acting on the brain) medications that need to be considered. It is possible that a prescription for acne medication might be having an effect that might trigger new behavior. Carefully review side effect lists and discuss the side effect profiles of each medicine with your doctor, especially in someone who might not be able to report on his symptoms.

In considering medication, note that proper dosage can be very sensitive, particularly in individuals with autism. Sometimes too much medication can be *over-stimulating* or *sedating* (tiring), perhaps even causing the person to find other ways (through new or difficult behaviors) to try to get back to a sense of stability or normality. Some medications can have unexpected or rebound effects. Layering on multiple medications at one time, called *poly pharmacy*, can also have unintended effects. Some doctors have reported success in slowly taking a person off all medications to re-establish 'baseline' in an effort to sort out 'what is the autism?' from 'what is the medication?'

"I recall that when Jack was little our doctor suggested that we try a stimulant. This was meant to calm and focus him. As time went on, Jack didn't sleep for 48 hours sometimes, and we were all a mess as he was bouncing off the walls. We couldn't imagine what he would be like without the benefit of those calming meds. Eventually we tried a weekend drug holiday as they often suggest for stimulants, and he was lethargic the whole weekend. Aha! We realized it was the drugs, not the autism, that was causing the behavior. In hindsight it seems obvious, but in the moment, it was hard to see the relationship."

– SG, parent

As an individual grows and changes, medication may need to do so as well. For example, a larger teen might need more medication to achieve the same effect on attention or anxiety. Medical expertise specific to autism is often quite helpful in carefully determining the right pharmacological interventions for an individual at any point in time.

Families often struggle with decisions about the role of medication in addressing challenging behaviors, and when and what kinds of medication might be useful. This Medication Guide is designed to help in defining your values and goals surrounding medication use. It also provides perspective and talking points to assist in speaking with your doctor and making decisions. It can be used for new medication decisions, or in re-evaluating current medications.

If medication is started, it is important to track side effects and look for other concerns to ensure that the medication is helping where it is supposed to help, and not causing other problems. Sometimes a provider might use a measurement tool that involves asking the family or staff questions prior to starting a medication or other intervention. One often-used tool is the Aberrant Behavior Checklist. The provider might repeat this test after a few weeks or months as a way of measuring the effects of the medication. It is wise to have multiple responders, as well as to compare baseline and follow-up responses from the same person.

The use of simple *tracking scales* for both target behaviors and side effects is another way to assess the effects of a medication. This might be undertaken in cooperation with a behavioral provider or team using their data collection systems, or you could create or modify something like this tracking scale:

Date: _____

Medication Name: _____

Medication Dose: _____

Behavior/Symptom Occurred	Morning	Midday	Evening
Burping			
Sleepiness			
Uses iPad to make request			
Hitting			
Kicking			
Other			

"We did not like the weight gain associated with the meds that Sammy was on, and we weren't even sure it was helping. So, every few months, I would decrease his dose just as the doctor instructed, and I would start on a Friday so that we would be able to see changes that we wouldn't see while he was off at school. I would not tell my husband, so that at least one of us was getting a 'blinded' view of any changes. By Sunday afternoon, in the midst of some frustrating situation, he would say, 'are you doing that meds withdrawal experiment with Sammy again?' And we knew the meds were still working."

– BW, parent

Sometimes it is helpful to keep some team members or family members *'blinded'* to a new intervention. Often, if we know something is supposed to help in a certain way, we are more likely to see it, even if it is not really there. For example, if you tell the lead teacher about a new medication but not the classroom aides, you might get better information from the team about the true effects of a medication on your child's behavior.

Consideration of changes in the effects of medications should be ongoing. Sometimes adjusting dosage, form (some medications come in time-release forms for more even delivery), time of delivery (before vs. after meals, at bedtime instead of morning, etc.), or other factors can help to increase the benefits and reduce the side effects of a medication.

Being a careful observer and a good reporter to your doctor, and discussing both the benefits and downsides of a medication in advance and as the intervention progresses, can often help to manage a medication so that it is most helpful. Using a chart such as the one above can help you to see if the medication is effective. If medical concerns are a feature of your loved one's profile, it is important to maintain good records and share information among team members.

Behavioral Considerations

When a person behaves in a way we find difficult or offensive, we often reflect on the impact of that person's actions on us—how we feel threatened or embarrassed or hurt. This is absolutely normal, but not always helpful. Instead, it is important to think about the behavior from the individual's perspective.

What is so scary about entering this place that my child is so panicked that he has to bite me? What pain is occurring in his body that he might be trying to over ride it by hitting himself in the head? Is this something biological over which he does not have control? If so, can we help him to learn how to adapt?

Shifting our thinking from how a particular behavior affects us (and the siblings, the classmates, the furniture, etc.) to what might be happening from the individual's perspective is an important step in finding ways to understand behavior. Understanding the behavior will allow you to support the replacement of disturbing or *maladaptive* behaviors with functional skills.

Going back to the basics of behavior, it is important to consider the possible purpose or function. *How does this behavior serve the person? Does he get something out of it? Does he get to escape something boring or difficult? Does he get attention? Does it allow him to assert a little bit of control over his life or surroundings? Does it help to block out pain? What is good about the behavior? Is he trying to tell me something?*

Taking the time to understand the function can often give a window into the motivation behind the behavior. Proper evaluation of function is usually essential to crafting an appropriate response.

For example, suppose a child kicks when it is time to go to gym class and the response to his kicking is to put him in a 'time out.' This is likely to be an ineffective intervention if the whole reason for kicking was to avoid going to gym. He just got what he wanted, and he learned that kicking is an effective way of making his argument. Next time he doesn't want to go to gym class, what is he likely to do? But if kicking keeps him out of the loud, echoing chaos of gym that he finds hurtful or disturbing, he is likely to use the communication he has learned *unless and until* he is taught a better way of coping with gym class (e.g. asking for a different activity) or advocating for avoiding the unpleasant situation.

In the field of Applied Behavior Analysis, the three components that are documented and considered in looking at a specific behavioral episode are called *A-B-C (antecedent-behavior-consequence) analysis*, and include the following components:

- a clear description of the behavior (behavior)
- the situation, events and conditions that occurred before the behavior began (antecedent)
- the situation and events that immediately followed the behavior (consequence)

These behaviors may be tracked using a sheet such as this:

ABC SHEET

Student: _____ **Observer:** _____

Target Behavior: _____

Antecedent: The event that occurs immediately before the behavior

Behavior: The occurence of the target problem behavior (reecord frequency)

Consequence: The event that immediately follows the occurence of the behavior

Date	Time	Antecedent	Behavior	Consequence	Comments

A professional with expertise in behavioral assessment and intervention (e.g. a BCBA) will use a variety of tools to help understand the function of a behavior at any given point in time. It is important to remember that the scales are tools, not answers. A good *functional behavior assessment (FBA)* will use several measures—questionnaires as listed below, observational assessments, active listening, and the professional's experience and background.

An FBA should be broad based and should take into account the observations of behaviors and how and when they occur. They should also seek to be empathetic and to understand why the person might feel the need to behave in a certain way. Make sure your provider is using a broad approach, since this is essential to getting a good handle on the concerns, potential causes of the behavior, and possible interventions and solutions for replacing this behavior with skills.

The following resources will help you learn more about how behavior is often evaluated and considered by professionals:

- **Parents' Guide to Functional Assessment**
- **Functional Behavioral Assessment and Positive Interventions: What Parents Need to Know**
- **Targeting the Big Three parent training manual**

For a school-aged child, the school district is responsible (under the laws of *IDEA*) to perform a FBA and create positive interventions for a child whose behavior inhibits his learning, or the learning of those around him. If they do not have this expertise on staff, they need to secure these services through other agencies or consultants. Some schools will provide additional training and instruction in the home, or through other community providers such as *wraparound* supports. Behavioral interventions through your health insurance provider may also be able to provide this support.

If you do not have access to a behavioral support provider or team, you can begin to become a more advanced observer of the elements of behavior yourself. Tools such as Barbara Doyle's **data collection** and **communication dictionary** might be helpful.

After defining and evaluating the behaviors, the behavioral team, teaching staff or other providers should explain the results to you and develop instructional strategies using *Positive Behavior Supports (PBS)* and *Reinforcement Strategies*. Using Positive Behavior Supports is a way to promote functional skill development and motivation and can be used at home, school, work, and in the community. These supports often need to be individualized to the needs of the child, and the functions of his behaviors, to be effective. Classroom based supports are often not sufficient for challenging behaviors, so you may have to advocate for these to be individualized. More on positive behavior supports, training and resources for families, schools and staff, and strategies for building positive behavior are included in the next chapter.

If the function of the behavior is to gain attention, challenging behavior can be reduced if attention and interaction are no longer given when the individual engages in the problem behavior. This means not giving direct eye contact or calling the individual's name, no reprimands, no reasoning and lecturing, or showing that you're upset. Attempts to redirect the behavior by giving attention may inadvertently increase the problem behavior.

Note: Ignoring challenging behavior may initially increase the challenging behavior because that is how he communicated what he wanted and how he got his way until now. Keep the faith. Ignoring will ultimately decrease the likelihood that the individual will engage in challenging behavior to gain attention.

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Other Concerns to Consider

Communication Issues

Teachers, behavioral providers and/or speech pathologists should also evaluate the *functional communication* skills available to an individual, as this can be a critical factor. After all, behavior is often a form of communication—sometimes the only form available to an individual who has not learned other skills.

It will be helpful to consider: *Did he understand what I said? Can he independently use speech or other forms of communication to raise concerns? Report pain? Make requests? Ask to get away? If not verbally, does he have cards or a device that he uses independently for this? Even if he can speak well, does he have the language or the confidence to make his needs and concerns known verbally?* If not, it is likely he is finding other ways to express wants, frustration, fear or other information.

Many individuals with autism have difficulty processing information—hearing all the parts of what someone said, matching what they see to what they hear, or being able to decide what information is important and relevant in light of all the possible sights, sounds, smells, etc. Many people with autism are visual learners, or otherwise benefit from information presented in pictures, words or video. Verbal information (speech) disappears as soon as it is said, but visuals have staying power—they can be available and accessed as long or as often as the individual needs.

It is essential that the functional communication system is something that your child can initiate and use independently. Often a speech pathologist can perform an evaluation and design appropriate interventions. Many skilled autism intervention teams have also developed expertise in communication supports and development. If supports and training in functional communication are needed, there are a variety of systems that the team should explore, such as PECS and voice output devices, to find a fit for the individual and his specific needs and preferences.

"I remember how he would throw himself to the floor when he was thirsty. The speech pathologist taught me how to take his little hand and shape his fingers into a point, then lead his hand to touch the cup. We did this hundreds of times, moving from the cup to toys and movies he wanted to watch. When he pointed, he got what he wanted. He started pointing. He was learning to ask!"

- TO, parent

Sometimes even highly functional individuals with autism can have difficulty communicating certain concerns. For example, many individuals with Asperger's Syndrome lack self-awareness. So as a result, isolating pain, describing emotions or identifying what is causing a negative feeling can be very difficult. Expectations that a 'straight A student' should be able to navigate social situations or other challenging experiences can often leave an individual unsupported, and as a result, increasingly anxious and reactive. Specific instruction in social and self-awareness can be hugely beneficial for someone who might have an incredible vocabulary but difficulty communicating about socially relevant concerns.

Sensory Concerns

Individuals with autism often report on their different ways of experiencing the world, and it is helpful to keep these issues in mind when considering a person's specific behaviors. A child may scream or run out of the singing of the Happy Birthday song not to be difficult, but because the singing and/or the cheering that follows is truly painful for him. Often these responses are more like reflexes than behavioral choices. When a person stays away from certain experiences—sounds, touch, smells, food tastes/textures, certain types of movement, etc., it is often called *sensory avoidance* or *sensory defensiveness*. Even in these same individuals, there is often a contrasting need for additional stimulation of certain senses as a way of maintaining attention or achieving a calmer state. This is called *sensory-seeking behavior*.

It is important to consider whether the individual has some sensory need that is otherwise not being met. Is he jumping up and down because it feels good? Alternatively, is there sensory defensiveness? Is there something about this tag in his shirt, this lighting, this sound, this crowd, these odors that he finds painful or overwhelming?

"He had a fascination with birthday parties and blowing out candles, and at one point we would have to re-light, re-sing, and re-blow – 20 times or more each birthday. We developed a program to teach Joey how to end Birthday Parties. Of course all of this was after at age 5, because until then he couldn't tolerate listening to the song 'Happy Birthday' at all."

– BH, Parent

To investigate whether sensory factors might be a consideration with your loved one, an Occupational Therapist or other provider might use an age-appropriate form of the Sensory Profile or the Sensory Processing Measure (SPM). A sensory checklist and additional information are available at the Sensory Processing Disorder Foundation website. More information can be found here.

Support Systems and Environment—Family, Staff, Supports Dynamics

Change is difficult for any of us, but it may be more so for those who do not understand what changes are taking place and why. Consider potential contributing factors that might be leaving your loved one with autism feeling confused or anxious.

If challenging behaviors come on suddenly or intensify, it is important to ask what changes have occurred in his life. *Have there been changes in schedules? School, work or residential placement? Changes in the family environment? A sibling heading off to college? Loss of a family member? Have there been changes in staff? Loss of a preferred staff member? If there is a behavior plan, is it being followed consistently? Perhaps new staff who need additional training or who employ methods that are stressful? Is there any concerning behavior in caregivers? What is their stress level?*

Resources:

General:

Ask and Tell, Self-Advocacy and Disclosure for People on the Autism Spectrum

Autism Solutions; How to Create a Healthy and Meaningful Life for Your Child,
Ricki G. Robinson, MD, MPH

National Autism Center's A Parent's Guide to Evidence-Based Practice and Autism
http://www.nationalautismcenter.org/learning/parent_manual.php

Behavior Function and Evaluation:

Functional Behavioral Assessment and Positive Interventions: What Parents Need to Know
http://www.wrightslaw.com/info/discipl.fba.jordan.pdf

How to Think Like a Behavior Analyst, Jon Bailey and Mary Burch
Parents' Guide to Functional Assessment
http://pages.uoregon.edu/ttobin/Tobin-par-3.pdf.

To Walk in Troubling Shoes: Another Way to Think About the Challenging Behavior of Children and Adolescents,
Bernie Fabry PhD, 2000
http://www.parecovery.org/documents/Troubling_Shoes_2000.pdf

Targeting the Big Three: Challenging Behaviors, Mealtime Behaviors, and Toileting
IBR Autism Speaks Family Services Grant Challenging Behaviors Curriculum
http://www.autismspeaks.org/sites/default/files/challenging_behaviors_caregiver_manual.pdf

Skill Evaluation/Development:

The ABLLS-R; The Assessment of Basic Language and Learning Skills,
James Partington and the AFLS too!

Severe Behavior Problems: A Functional Communication Training Approach (Treatment Manuals for Practitioners),
V. Mark Durand

Sensory Profile
http://www.pearsonassessments.com/HAIWEB/Cultures/en-us/Productdetail.htm?Pid=076-1638-008

Sensory Processing Measure (SPM)
http://portal.wpspublish.com/portal/page?_pageid=53,122938&_dad=portal&_schema=PORTAL

Medical/Medication:

Buie T, Campbell DB, Fuchs GJ, et al.,
Evaluation, diagnosis, and treatment of gastrointestinal disorders in individuals with ASDs: a consensus report.
[Consensus Development Conference, Journal Article, Research Support, Non-U.S. Gov't]
Pediatrics 2010 Jan.:S1-18.
http://pediatrics.aappublications.org/content/125/Supplement_1/S1.long

Buie, et al.
Recommendations for evaluation and treatment of common gastrointestinal problems in children with ASDs.
http://pediatrics.aappublications.org/content/125/Supplement_1/S19.long

Herbert, Martha,
The Autism Revolution
www.marthaherbert.org

Loschen, EL and Doyle, B,
Considerations in the Use of Medication to Change the Behavior of People with Autism Spectrum Disorders
http://www.asdatoz.com/Documents/WebsiteCONSIDERATIONS%20IN%20THE%20USE%20OF%20MEDs%20ltrd.pdf

Siegel M & Beaulier A, Journal of Autism and Developmental Disorders, November, 2011
Psychotropic Medications in Children with Autism Spectrum Disorders: A Systematic Review and Synthesis for Evidence-Based Practice.
http://www.ncbi.nlm.nih.gov/pubmed/22068820

Siegel, M,
Psychopharmacology of Autism Spectrum Disorder: Evidence and Practice,
Child and Adolescent Psychiatry Clinics of North America, 2012, in press,
http://www.ncbi.nlm.nih.gov/pubmed/22068820

Appendix 1

Ruth Elaine Hane, who was diagnosed with High Functioning Autism in 1995, lives in Minneapolis, with her husband and their two cats. Contributing author to *Ask and Tell, Self-Advocacy and Disclosure for People on the Autism Spectrum* and *Sharing Our Stories* and numerous other publications, Ruth Elaine mesmerizes audiences with her vivid memories of growing up in a large family without knowing the characteristics of autism. Born as a Rubella measles baby; unable to swallow or tolerate touch, Ruth Elaine did not talk until nearly five years old, when she began using full sentences with reciprocal language. Her strength lies in her unique view of how things are, and an insatiable desire to improve her life by learning to read faces and understanding complex nonverbal messages. Ruth Elaine mentors and coaches others, effectively teaching the skills she has learned, and serves on boards and task forces for many autism organizations. Presently she is focusing on developing her Face Window idea to work to overcome face blindness , by assisting in Child Psychology research at the Fraser Family Services and the University of Minnesota. Ruth Elaine is a gifted healer, utilizing Reiki Energy to balance the whole body system, believing that an underlying deficit in autism is an unbalanced whole- body system.

Appendix 2

Common "problem" behaviors and speculations about their causes

Ruth Myers, MD, James Salbenblatt, MD, Melodie Blackridge, MD

"High pain tolerance"
- A lot of experience with pain.
- Fear of expressing opinion.
- Delerium
- Neuropathy (disease of the nerves)/many causes

Fist jammed in mouth/down throat
- Gastroesophageal reflux
- Eruption of teeth
- Asthma
- Rumination
- Nausea

Biting side of hand/whole mouth
- Sinus problems
- Eustachian tube/ear problems
- Eruption of wisdom teeth
- Dental problems
- Paresthesias/painful sensation (e.g., pins and needles) in the hand

Biting thumb/objects with front teeth
- Sinus problems
- Ears/Eustachian tubes

Biting with back teeth
- Dental
- Otitis (ear)

Uneven seat
- Hip pain
- Genital discomfort
- Rectal discomfort

Odd unpleasurable masturbation
- Prostatitis
- Urinary tract infection
- Candidal vagina
- Pinworms
- Repetition phenomena, PTSD

Waving head side to side
- Declining peripheral vision or reliance on peripheral vision

Walking on toes
- Arthritis in ankles, feet, hips or knees
- Tight heel cords

Intense rocking/preoccupied look
- Visceral pain
- Headache
- Depression

Won't sit
- Akathisia (inner feeling of restlessness)
- Back pain
- Rectal problem
- Anxiety disorder

Whipping head forward
- Atlantoaxial dislocation (dislocation between vertebrae in the neck)
- Dental problems

Left handed or fingertip handshake
- Frightening previous setting
- Pain in hands/arthritis

Sudden sitting down
- Altlantoaxial dislocation (dislocation between vertebrae in the neck)
- Cardiac problems
- Seizures
- Syncope/orthostasis (fainting or light-headedness caused by medication or other physical conditions)
- Vertigo
- Otitis (thrown off balance by problems in the ear)

Waving fingers in front of eyes
- Migraine
- Cataract
- Seizure
- Rubbing caused by blepharitis (inflamation of the eyelid) or corneal abrasion.

Pica
- General: OCD, hypothalamic problems, history of under-stimulating environments
- Cigarette butts: nicotine addiction, generalized anxiety disorder
- Glass: suicidality
- Paint chips: lead intoxication
- Sticks, rocks, other jagged objects: endogenous opiate addiction.
- Dirt: iron or other deficiency state
- Feces: PTSD, psychosis

Common "problem" behaviors and speculations about their causes continued

Ruth Myers, MD, James Salbenblatt, MD, Melodie Blackridge, MD

General scratching

- Eczema
- Drug effects
- Liver/renal disorders
- Scabies

Self-restraint/binding

- Pain
- Tic or other movement disorder
- Seizures
- Severe sensory integration deficits
- PTSD
- Parasthesias

Scratching stomach

- Gastritis
- Ulcer
- Pancreatitis (also pulling at back)
- Porphyria (bile pigment that causes, among other things, skin disorders)
- Gall bladder disease

Scratching/hugging chest

- Asthma
- Pneumonia
- Gastroesophageal reflux
- Costochondritis/"slipped rib syndrome"
- Angina

Head banging

- Pain
- Depression
- Migraine
- Dental
- Seizure
- Otitis (ear ache)
- Mastoiditis (inflammation of bone behind the ear)
- Sinus problems
- Tinea capitis (fungal infection in the head).

Stretched forward

- Gastroesphageal reflux
- Hip pain
- Back pain

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Ruth Myers, MD

What are the Positive Strategies for Supporting Behavior Improvement?

As highlighted in the previous section, there are many possible contributors to the development of challenging behaviors. It is important to investigate and evaluate these, but also to take action sooner rather than later, since many behaviors can become increasingly intense and harder to change as time goes on.

Often a necessary approach to managing behavior involves a combination of addressing underlying physical or mental health concerns, and using the behavioral and educational supports to teach replacement skills and self-regulation. There is no magic pill, but there are a number of strategies that can often be helpful.

The use of *Positive Behavior Supports* is more than just a politically correct approach to behavior management. Research shows that it is effective. The alternative is usually *punishment*, which decreases the likelihood of a behavior by taking something away (such as removing a favorite toy) or doing something unpleasant (yelling, spanking.) While punishment might work immediately, it has been shown to be ineffective in the long run and can increase aggressive behavior, provide a model for additional undesirable behaviors, and strain the relationship with the caregiver (you). It is worth noting that to continue to be effective and maintain improvements, positive supports and feedback need to be ongoing as well.

"Withholding reinforcement for problem behavior (i.e., extinction) is technically an example of punishment. Proponents of Positive Behavior Support (PBS) acknowledge that controlling access to reinforcement is necessary when trying to change behavior. What PBS does not condone is the use of aversive (e.g., demeaning, painful) procedures to suppress behavior. Such approaches have been demonstrated to be ineffective in producing durable changes in people's behavior and do not improve to quality of their lives." –Association for Positive Behavior Support

If you have made changes to improve your child's health or happiness, and these have not helped to improve his behavior in a reasonable time frame (a couple of weeks), or you are concerned about safety, help may be needed. Positive strategies and an intervention plan can be developed by a behavioral or educational team, usually in response to what is learned in a *functional behavior assessment* (FBA) as described in the previous section.

When several challenging behaviors exist, it is important to establish priorities. You may want to first target behaviors that are particularly dangerous, or skills that would help to improve situations across several behavioral scenarios. Remember to set goals that are realistic and meaningful. Start with small steps that can build over time. A non-verbal child is not likely to speak in full sentences overnight, but if learning to hold up a 'take a break' card when he needs to leave the table allows him to exit, and keeps him from throwing his plate, that is a huge success.

A plan for you and your team should meet four essential elements:

- *Clarity:* Information about the plan, expectations and procedures are clear to the individual, family, staff and any other team members.
- *Consistency:* Team and family members are on the same page with interventions and approaches, and strive to apply the same expectations and rewards.

- *Simplicity:* Supports are simple, practical and accessible so that everyone on the team, including the family, can be successful in making it happen. If you don't understand or cannot manage a complicated proposed behavior intervention plan, speak up!
- *Continuation:* Even as behavior improves, it is important to keep the teaching and the positive supports in place to continue to help your loved one develop good habits and more adaptive skills.

Please recognize that many skills take time to develop, and that changes in behavior require ongoing supports to be successful. In some cases, especially when you are ignoring a behavior that used to 'work' for your child, behavior may get more intense or more frequent before it gets better. Your team should keep good records and track progress and responses to intervention to know if the plan is effective.

There are increasing numbers of tools and apps for behavioral intervention tracking that are portable and simple to use.
Links can be found here.

Being realistic at the outset is crucial. It can help parents and caregivers appreciate that they are making small yet meaningful changes in their lives and the lives of the individual they care for. Making goals realistic means they are achievable. Being realistic keeps the picture positive. It focuses attention on progress towards a goal, rather than perfection.

Setting Realistic Behavioral Goals:

Setting goals allows us to objectively measure progress toward an identified desired outcome. It also allows caregivers and parents to ask themselves, "What behavioral changes would really make the greatest improvements in our lives together?" It allows them to identify what really matters. For instance, it may be more important to address a behavior such as throwing things during a classroom activity than to address that person's tendency to stand up during meals.

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For example, it is possible that you or your team may have misinterpreted the function of a behavior, or that the function has changed over time. A-B-C data often indicates that screaming has the function of attention, because attention from others is a common (and usually natural) consequence. But it may be that screaming is triggered by painful reflux and attention is not the true function. Tracking and interpreting the data is important since it may help to show that more investigation is needed, and the plan may need to be adjusted to be effective.

Information on supports for teaching behavior management can be found in the Autism Treatment Network's An Introduction to *Behavioral Health Treatments* and *Applied Behavior Analysis;* A Parent's Guide.

In the end, you are trying to teach your child that life is better, and that he can get what he needs, without having to resort to challenging behaviors. The suggestions below are strategies to help make individuals with autism feel more comfortable and more empowered.

Adapt the Environment

As you learn to think like a detective about your child's behavior, your observations (or the FBA) are likely to show that behavior occurs at specific times, with certain people or in particular environments. You and your team will need to tune in, learning to recognize the signs of increasing tension, anxiety or frustration that eventually lead to challenging behaviors. Often there is a ramping up, or escalation period, and learning to recognize that early and using many of the approaches here can help to calm a situation and prevent behavioral outbursts. Sometimes these signs may be very subtle—red ears, a tapping foot, heavier breathing, higher pitched speech—but it is essential that everyone on the team responds to the importance of tuning in and working towards *de-escalation*.

Changing the environment can often reduce behavioral episodes. Expand situations, relationships, places and opportunities that are successful. If possible, try to adjust or avoid situations that are triggers for challenging behavior. Incorporate ways to reduce frustration and anxiety and increase understanding. Below are some things to consider when working to create a more successful environment:

- *Organize and provide structure:* Provide clear and consistent visual schedules, calendars, consistent routines, etc. so that the person knows what is coming next.
- *Inform transitions and changes:* Recognize that changes can be extremely unsettling, especially when they are unexpected. Refer to a schedule, use countdown timers, give warnings about upcoming changes, etc.
- *Use Visual Supports:* Pictures, text, video modeling and other visuals are best for visual learners, but they are also critical because they provide information that stays. The ATN Visual Supports Tool Kit provides a step-by-step, easy-to-understand introduction to visual supports.
- *Provide a safe place and teach when to use it:* A calming room or corner, and/or objects or activities that help to calm (e.g. bean bag) provide opportunities to regroup and can be helpful in teaching self-control.
- *Remove or dampen distracting or disturbing stimuli:* Replace flickering fluorescent lights, use headphones to help block noise, avoid high traffic times, etc.
- *Pair companions or staff appropriately for challenging activities or times:* Some people are more calming than others in certain situations. If going to the store with dad works better than with mom, focus on that and celebrate successes.
- *Consider structural changes to your home or yard:* These changes might address some of the specifics of your situation to increase independence or reduce the risks when outbursts occur. Making Homes that Work includes a range of potential changes that can be made to reduce property damage, improve safety, and increase choice and independence.

"One of the barriers that we often find for children with autism in toilet training has to do with the condition of the bathroom itself. Often times we find that people with ASD can be very tactfully defensive so the space itself needs to be as neutral as possible. There needs to be enough room around the toilet so people don't feel too confined. It is really helpful if the space is warm and you address other types of sensations around the toileting experience. For example, is it cold, is there a fan running, is the light too bright, or not bright enough? You can sometimes help encourage people to use the toilet if the bathroom is a friendly place for them to be

– George Braddock, President,
Creative Housing Solutions LLC

What else can I do to promote a Safe Environment?

Even the best-laid plans don't always work in every situation or at the necessary speed. Despite proactive strategies, particularly challenging times and stressful situations can get beyond our control. Aggression or self-injury can get to a point where the situation is dangerous. It is good to be prepared if you think this might happen.

Communicate to Others

Many families have found it helpful to communicate to those around them about their child's special needs and some of the behavioral situations that might arise. Sometimes it is helpful to let others know what is going on so that they can also be observers and help provide helpful input about your child. Some families have found it helpful to talk to their neighbors, or to communicate with others in the community using stickers, cards, or other visuals.

I carry a note card stating:

> *"Thank you for your concern. My child has autism. He finds many situations difficult, including this one. Right now, we are doing a treatment plan recommended by our therapist, Dr. BCBA. This includes not giving attention to my child when he is acting out in order to discourage it. If you have any questions, you can contact Dr. BCBA at 123-456-7890."*

I post these cards in the windows of my car, on the front door of my house and at any other environment, like family members houses. My child has Autism printable card
http://card.ufl.edu/handouts/Autism-Card-w-border.pdf

Preparing for an Autism Emergency

Because autism often presents with special considerations, tools have been developed to help families prepare ahead of time for some situations that might arise. The following resources have suggestions for families, as well as information that can be shared with local law enforcement and first responders:.

- Autism Speaks Autism Safety Project
- First Responders Tool Kit
- Community and Professional Training Videos for First Responders
- National Autism Association's Big Red Safety Boxes
- Autism Wandering Awareness Alerts Response and Education Collaboration (AWAARE)
- Making Homes that Work

Use Positive Behavior Supports

Your team should develop strategies for you to use to increase the behaviors you want to see in your child. These will need to be individualized to his particular needs and challenges. They can often be helpful in building a sense of pride in accomplishments and personal responsibility, and a sense of what is expected. This will reduce the anxiety and reactivity that results in aggression or other behaviors. Some helpful strategies:

- *Celebrate and build strengths and successes:* Tell him what he does well and what you like. A sense of competence often fosters interest and motivation. Strive to give positive feedback much more frequently than any correction or negative feedback. 'Great job putting your dishes in the sink!'
- *Respect and listen to him:* You may have to look for the things he is telling you, verbally or through his choices or actions. 'You keep sitting on that side of the table. Is the sun in your eyes over here?'
- *Validate his concerns and emotions:* Do not brush aside his fears or tell him not to worry. His emotions are very real. Help to give language to what he is feeling. 'I know you do not like spiders. I can see that you are very afraid right now.' 'I can see that you are angry that our plans have changed.'

- *Provide clear expectations of behavior:* Show or tell your child what you expect of him using visual aids, photographs or video models. A great way to teach new skills is Tell-Show-Do.
- *Set him up for success:* Provide accommodations. Accept a one word answer instead of demanding a whole sentence. Use a larger plate and offer a spoon to allow him to be neater at the dinner table. Use Velcro shoes or self-tying laces if tying is too frustrating.
- *Ignore the challenging behavior:* Do your best to keep the challenging behavior from serving as his way of communicating or winning. This is hard to do, but in the long run it is effective. Do not allow his screams to get him out of brushing his teeth, or his biting to get him the lollipop that he wants. Behaviors may get worse before you start to see them get better. Stay the course! And make sure all family and team members are consistent in this approach and that you pair this with other positive strategies.
- *Alternate tasks:* Do something that is fun, motivating or that your child is good at. Then try something hard. He will be less inclined to give up or get agitated if he is already in a positive framework.
- *Teach and interact at your child's or loved one's learning level:* Take care to set him up for growth and accomplishment, rather than the anxiety produced by constant failure or boredom.
- *Give choices, but within parameters:* Everyone needs to be in control of something, even if it is as simple as which activity comes first. You can still maintain some control in the choices that you offer. 'Do you want to eat first, or paint first?'
- *Provide access to breaks:* Teach the individual to request a break when he needs to regroup (e.g. use a *PECS* card that represents "break"). Be sure to provide the break when he asks so he learns to trust this option and does not have to resort to challenging behaviors.
- *Promote the use of a safe, calm-down place:* Teach him to recognize when he needs to go there. This is a positive strategy, not a punishment.
- *Set up reinforcement systems:* Use simple, predictable processes that reward your child for desired behavior. Catch him being good and reward that, verbally and with favored activities, objects or 'payment.' *'I love that you stayed with me during our shopping trip. You earned a ride on the airplane toy!'*
- *Allow times and places for him to do what he wants:* Even if it is a 'stim', it is important to provide these options when it is not an intrusion or annoyance to others.
- *Reward flexibility and self control: 'I know you wanted to go to the pool today and we were surprised when it was closed. For staying cool and being so flexible about that change in plans, let's go get some ice cream instead!'*
- *Pick your battles:* Strive for balance. Focus on the behaviors and skills that are most essential. Be sure to include positive feedback and intersperse opportunities for success and enjoyment for you, your family, and your loved one with autism. Be resilient. Celebrate the fun and the good things!
- *Use positive/proactive language:* Use language that describes what you want the individual to do (e.g. *'I love how you used a tissue!'*), and try to avoid saying 'NO', or 'don't' (e.g. *'stop picking your nose.'*).

Teach Skills and Replacement Behaviors

Since behavior often represents communication, it is essential to replace behavior by building more adaptive skills. It is important that you and your team not assume that a child has the skills needed to do something 'the right way' and that you are prepared to use systematic instruction and motivation to build new abilities.

Focus on communication and functional skills to promote greater independence, social skills to promote greater understanding and reduce apprehension, and self-regulation skills. The team should specifically work on skills that will address the behavior's function, and thereby help to replace, the target behavior. Skill building can take some time, so be persistent and celebrate the small steps along the way.

"Communication-based intervention refers to an approach that reduces or eliminates problem behavior by teaching an individual specific forms of communication. Because the communication forms that are taught are more effective ways of influencing others than the problem behavior, they eventually replace the problem behavior itself… By communication training, we mean that individuals are taught specific language forms including, for example, speech, signing, and gestures that can be used to influence other people in order to achieve important goals."

– Ted Carr, Ph.D.,
State University of New York at Stony Brook

When you adjust to give different feedback or to help your child develop a new skill, celebrate yourself as much as you celebrate your child's growth! Reward a sibling for being extra patient or modeling a skill you are teaching. Use the pride in your successes to help you stay focused and dedicated, and to help you reflect on the good things in your child and your family.

It is essential to teach skills in the context of a positive learning situation, which is NOT while a behavior is occurring. These skills need to be part of a comprehensive educational plan. Just like math facts, they may need to be practiced many times during the day when the child or adult is calm and attentive. Label 'calm' and 'ready to learn' states and teach your child what they feel like.

- *Develop and expand functional communication:* Find a way to build effective communication that is appropriate for the person across his daily activities. Use language instruction, *PECS*, sign language, communication devices or other tools. For example, teach an over-stimulated child to ask for quiet time (using his words, PECS, pointing to a picture, or an iPad app), instead of running away. Functional communication should be rewarded with immediate access to the requested item to build the connection. This allows you to use request = item rather than behavior = item. A trained autism specialist or speech therapist will be very helpful in choosing and supporting effective interventions for functional language development. More information and possible resources:
  - The National Professional Development Center's Functional Communication Training
  - Functional Communication Training
    http://www.autismspeaks.org/sites/default/files/challenging_behaviors_caregiver_manual.pdf
  - Severe Behavior Problems: A Functional Communication Training Approach (Treatment Manuals for Practitioners), by V. Mark Durand

- Picture Exchange Communication System (PECS) and Associated Apps
- Other Autism Apps, such as Proloquo

Developing a voice can be life changing, and finding the right supports can help to increase functional communication in a variety of ways. For one dramatic example, watch Carly's story.

- *Teach Social Skills*: Use social stories to explain expectations and build skills and awareness. Recognize that some skills might require a team approach. For example, messy eating or toileting can be the result of a combination of sensory concerns, motor planning and social awareness, so working with an occupational therapist and using social stories as well as behavioral interventions might be needed
- *Create Activity Schedules:* Teach the use of schedules using pictures, written words or videos to help organize a chunk of time (e.g. a day, a class period, etc.) and break tasks into small, manageable steps. These schedules often reduce anxiety, provide skill development, and promote independence. Examples and resources:
  - Picture Activity Schedules, from Do2Learn
  - Activity Schedules for Children With Autism, Second Edition: Teaching Independent Behavior, by Lynn E. McClannahan and Patricia Krantz
  - Other Autism Apps, such as ReDo
- *Teach Self-Regulation and De-escalation Strategies:* Learning to self regulate is essential to a person's ability to remain calm in the face of the assaults that the world will undoubtedly bring his way. Your child is most likely to show problem behaviors when he is in an emotional state of anxiety or agitation. Strategies and programs for building self-regulation relate to both arousal and emotions. Many of us have had to learn these ourselves—counting to ten, taking a deep breath—and the same principles apply to the learning needs of an individual with autism.

"My behavior began to improve when I started to learn about emotions-- how to recognize them not only in others, but in me. This was an essential step to learning self-regulation, and it was then that I started to take more control of my actions."

– RH, adult with autism

- Use The Incredible 5-Point Scale to teach social awareness and emotions
- Teach recognition of arousal levels: The Alert Program: How does your engine run?
- Employ Behavioral Relaxation Training (BRT) which uses motor exercises (posture, breathing, etc) to find a relaxed state, and has been shown to be helpful in individuals who are less able to talk through issues or concerns.
- Teach self control and behavioral targets using Social Stories or Cognitive Picture Rehearsal.
- Teach the individual to recognize the triggers for his behavior, and ways to avoid or cope with these when they occur.
- Find ways to arouse and ways to calm your child, which can vary from person to person, and teach him to do these when he needs to.
- Review additional tips and hundreds of sample behavior charts and targets, including feeling charts.

- *Find providers who use Cognitive Behavior Therapy* or teach cause and effect, self-reflection, and social understanding through tools such as the Social Autopsy. While these techniques lend themselves to more verbal individuals, they can be used with individuals of all verbal abilities with appropriate accommodations such as use of visuals and role-play.

- *Teach Self-Management Skills:* Self-management focuses on becoming aware of one's actions and learning responsibility for behavior and tasks without the support of caregivers. This is especially important in the adolescent years, as young adults with autism often feel the need for greater autonomy and independence just like their peers. Teaching self-management provides your child with a sense of personal responsibility, pride and accomplishment. Some books include:

  1. How to teach self-management to people with severe disabilities: A training manual, by Lynn Koegel
  2. Self-Management for Children With High-Functioning Autism Spectrum Disorders, by Lee A. Wilkinson

- *Promote Exercise:* Exercise can be a powerful factor in overall quality of life, for reasons beyond just physical fitness and weight issues. Research shows that aerobic exercise can influence behavior, decreasing self-stimulatory behaviors such as rocking and spinning, as well as discouraging aggressive and self-injurious behavior. Sometimes the challenges of autism (e.g. sensory input, motor planning, social aspects of team sports, etc.) can require a little extra creativity in terms of designing an approach to physical activity that is beneficial and motivating for a specific person. However, if implemented appropriately, the addition of physical activity to an autism intervention program can address some of these specific challenges, increase self-confidence and social interactions, and improve overall quality of life. The same interventions that are used to teach other skills (ABA, structured teaching, etc.) can be used to build exercise skills and routines.

  - The Benefits of Sports and Exercise in Autism
  - Top 8 Exercises for Autism Fitness *from AutismFitness.com*
  - Autism Fitness Exercise Videos *from AutismFitness.com*

- *Address Hormones and Sexuality Considerations:* The hormone and brain changes of puberty can make a typical child seem like a stranger, and these same effects occur in people with autism. However, in autism, additional considerations come into play because of the language and social deficits. Tell your child, even if you think he may have difficulty understanding, about what is happening to his body. Specific teaching to the skills of appropriate social considerations (personal space, privacy, feelings vs. actions, etc.) can help to keep an individual with autism out of situations that others might find disturbing or inappropriate. Responding to Inappropriate Sexual Behaviors Displayed by Adolescents With Autism Spectrum Disorders by Jenny Tuzikow, Psy.D., BCBA-D has helpful insights.

Editor's Note: This story reflects the need for the team to take into consideration the culture and comfort of those being asked to take part in an intervention. Your family's perspective and concerns need to be considered as you program, as a team, for your child.

"Just like any other teenage boy, my 13 year old son with autism starting having occasional, unexpected erections that seemed outside of his control. He found them funny, but obviously others did not. We explained to him what was taking place, but that it was something that he should keep private. Even if he understood what we were saying, we recognized this would be difficult to do when you don't have the language to let others know you just 'need a few minutes at the desk.' His behavioral team thought the way to address this was to give it an outlet, suggesting some

Victoria's Secret catalogs and some modeling from Dad. I was so relieved that I could not be asked for this duty! But we were also concerned about what else we were teaching him. What if Victoria's Secret became his 'trigger' and we went to the mall??? We reasoned with the team, and instead taught our son to ask for Private Time-- in his room, at home, with a Private Time sign on his door. Eventually he outgrew this phase and it has not been an issue. We can even go to the mall and pass Victoria's Secret without concern!"

– ES, a mother

An Intervention Example: C.O.P.E.S. ™

One school intervention team has had success using strategies for 12 teenage students with long histories of failed interventions and high incidence of aggressive and self-injurious behaviors. C.O.P.E.S. ™ involves consistent implementation of a collection of individualized approaches. This program incorporated several interventions to greatly reduce behaviors and build positive skills and happier students. For a description and accompanying visual examples, please see the Appendix at the end of this section.

Punishment vs. Rewards: What does science tell us?

Punishment is often used in shaping behavior. It works because it reduces the chances that the behavior will happen again. Punishment often takes two forms— *doing something* such as spanking or giving extra chores, or *taking something away* such as TV time or the car keys. We often use punishment in its more subtle forms without even realizing it—raising our voices, removing a favorite toy or withdrawing attention.

The short term consequences of punishment bring focus to a problem and may stop the behavior in the moment. But studies show that punishment is largely ineffective in the long run, especially when it is not used together with positive and preventive approaches. It can promote emotional responses such as crying and fearfulness, and aggressive behavior by providing a model (e.g. hitting). It can also promote a desire for escape and avoidance of the person or the situation that caused the punishment. It often needs to be repeated and often becomes more intense, because punishment may teach what *not to do*, but does not build skills for what *to do*. The negative feelings associated with punishment are often paired with the person delivering the punishment, causing the relationship with the parent or caregiver to be affected as time goes on.

Of course, every child exhibits behavior that needs to be corrected, or shaped, so what else can I do?

Rewards, or using *reinforcement*, are one of the most consistent ways to change behavior and build desired responses. For people with jobs, the reward is a paycheck at the end of the month. Children, especially those with autism, often need their rewards much more immediately, and in connection with the desired behavior. So, as soon as he buckles his seatbelt, he gets a 'high five'.

Sometimes reinforcement is viewed as simple, such as giving an M&M after a correct response, but reinforcement can be much more than that. When a tangible reward (M&M) is paired with a social reward (*'Great job saying Good Morning to your brother!'*), the positive feeling of success gets paired with both the verbal praise, and the person giving the reward. This helps to build the desired behavior, and also often improves the relationship with the parent or teacher using the reward.

Reinforcers can vary considerably from person to person. It is important to observe your child to learn what he finds rewarding so that you can give him what he wants after he has responded in the way that you desire. Watch what he does in his free time, or when he has choices—some children love to be tickled, others do not. Consider edibles (such as a cookie or other favorite food) but also other *tangibles* (a toy, bubbles, etc.) or experiences (listening to music, taking a walk, curling up on the bean bag). Be creative and mix it up. Know that the more opportunities a person has to encounter a reinforcer, the less rewarding it might become—so the 'power' of a reward is often increased if it is saved for certain times when you want to celebrate your child's behavior.

Research shows that positive, reinforcement-based strategies are most effective in creating long-term behavioral change. However, it is also important to have an immediate response to a behavior in order to maintain safety or minimize disruptions. Planning in advance for the type of situation is important, so that caregivers across settings (home, school, etc.) are consistent in their responses and delivery of consequences. Most reactive strategies fall into three areas as listed below.

- *Ignoring the behavior* (*extinction*) is often used when the behavior is used for attention, and is mild or not threatening.
- *Redirection*, often supported with visuals, may involve redirection to an appropriate behavior or response and is often paired with positive strategies.
- *Removal from a situation or reinforcement* through a time out is often used for calming down opportunities.

Ignoring challenging behavior means not giving in to the behavior that you are trying to eliminate, to the best of your ability. If he kicks to get a cookie, ignore the kicking and do not give him a cookie. But, use other strategies here to teach him to request a cookie, and be sure to give the cookie when he asks, so as to build his trust in you. Note that when you first start to ignore a behavior (called *extinction*) it may increase the behavior. This is called an *extinction burst* and is very normal. Stay the course.

- Certain behaviors (those that are dangerous or injurious) are more difficult to ignore and sometimes need to be redirected or blocked (e.g. putting a pillow by his head so that his self-hitting does not do damage), even as you strive to not allow the behavior to 'win.' link to Yoo section on ignoring?

"When Joey was little, every time he spilled his glass of water, he banged his head on the edge of the table. I learned to wipe-up his spilled water quickly, in order to avoid this self-injurious behavior. If I was really fast, he'd attack me on my way to cleaning it up – grabbing my hair and pulling. I also noticed that his aggression didn't stop once I had cleaned up the obvious puddles, but continued as I wiped what I thought was a dry surface.

This behavior continued because, try as we might, we could not completely avoid spilling water. By the time Joey was age 9, the entire family was very alert to the importance of not spilling water and the need to respond quickly trying to reduce the duration of Joey's aggression. Only after we started a home ABA program was it pointed out that my rushing to clean up spilled water followed Joey's becoming self-injurious and aggressive. By wiping up the water, we were reinforcing Joey's inappropriate behaviors. I realized that Joey did not know how to clean up the water himself. He also did not have another way to ask us to clean up the spilled water or to tell us that it bothered him, other than banging his head or pulling our hair.

With the help of our behavior consultant, we learned to clean-up the spilled water only before Joey becomes aggressive or self-injurious. We also learned to prompt appropriate language "clean up" as we cleaned up. If Joey aggressed, we ignored the spilled water and followed our behavior protocol. After practice, Joey learned to say "clean up" instead of banging his head and pulling hair. Eventually, we taught Joey how to ask for a towel or to get a towel and clean up the water himself."
– BH, parent

Redirection can be a very powerful tool, giving you the opportunity to steer your child into a situation that is more positive, or more manageable. It also helps to avoid or calm an escalating situation. The use of a time out can vary considerably, and to be most effective, it is important that it is done correctly. A time out is not just a change in location—it means your child loses access to something he finds rewarding or cool. For more complete discussion on how best to use time out, see the ATN ABA guide or this parent training information.

Other strategies your behavioral team might employ include teaching accountability (if he spilled the milk, he is the one to clean it up), or using positive practice, sometimes known as do-overs. For example, if he let the door slam in someone's face, he might practice in the doorway how to enter the house and hold the door five or ten times. *'Oops, let's practice doing that that the right way.'* In doing this, try to limit the sense of punishment, keeping positive strategies employed (reinforcement, praise) to build the desired behaviors over time. *'I love that you noticed I am right behind you and you held the door open!'*

- When behavior does occur, be careful not to:
- Feed into the behavior, give in or provide what your child wanted to get from the behavior
- Show disappointment or anger
- Lecture or threaten
- Physically intervene (unless necessary for safety, such as keeping a child from running into the street)

A new look at time-out

Contrary to popular belief, time-out is not sitting in a chair for a few minutes. Time out is losing access to cool, fun things as a result of exhibiting problem behavior, usually by removing the individual from the setting that has those cool, fun things. Time-outs can only occur when the individual is in time-in. That is, if nothing enjoyable was happening before time-out, you are simply removing the individual from one non-stimulating, non-engaging room to another.

For example, if the individual is watching her favorite TV show, but hits and screams at her sibling for getting in the way, taking her to a chair located in the same room will not serve as a time-out since she can still see and listen to the TV. Removing her from accessing the TV completely, however, is an example of a time-out. In this case, time-in (watching a favorite show) was in place, allowing for time-out to be effective upon the occurrence of the problem behavior. Once the individual is in time-out, let her know that she must be calm for at least 10 seconds (or a duration of your choosing, usually shortly after he is calm) before she can return to time-in. Do not talk to the individual or explain to her what she did wrong while she is in time-out. You may use a timer to indicate to the individual when the time-out will be over. When the timer goes off, he should be allowed to return to what he was doing, i.e. time-in.

How to use time-out correctly

- *A fun, enjoyable activity should be in place before using time-out (e.g. playing video game, visiting friends).*
- *Time-out should not lead to the individual avoiding or delaying an unpleasant task or work activity*
- *Time-out should take place in a boring and neutral setting.*
- *No attention should be given during time-out. Simply tell the individual, "You hit your brother, no TV. Go to time-out until you are calm".*
- *Time-out should be discontinued shortly after the individual is calm and quiet (approximately 10 seconds of calm behavior).*

– page 74, Targeting the Big Three

Resources:

Behavioral Relaxation Training and Assessment
by Roger Poppen

Behavioral Relaxation Training (BRT): Facilitating acquisition in individuals with developmental disabilities
by Theodosia R. Paclawskyj, Ph.D., BCBA, and J. Helen Yoo, Ph.D.,

The Cycle of Tantrums, Rage, and Meltdowns in Children and Youth with Asperger Syndrome, High-Functioning Autism, and Related Disabilities
by Brenda Smith Myles and Anastasia Hubbard

How to teach self-management to people with severe disabilities: A training manual
by Lynn Koegel

Self-Management for Children With High-Functioning Autism Spectrum Disorders
by Lee A. Wilkinson

Taking Care of Myself: A Hygiene, Puberty and Personal Curriculum for Young People with Autism
by Mary Wrobel

Targeting the Big Three: Challenging Behaviors, Mealtime Behaviors, and Toileting
by Helen Yoo, Ph.D, New York State Institute for Basic Research
Autism Speaks Family Services Community Grant recipient

Autism Fitness.com : Leading Authority in Autism Fitness
Eric Chessen

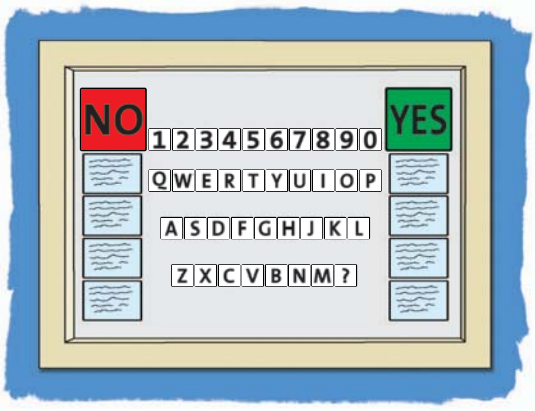
Depression and Anxiety: Exercise Eases Symptoms
Mayo Clinic

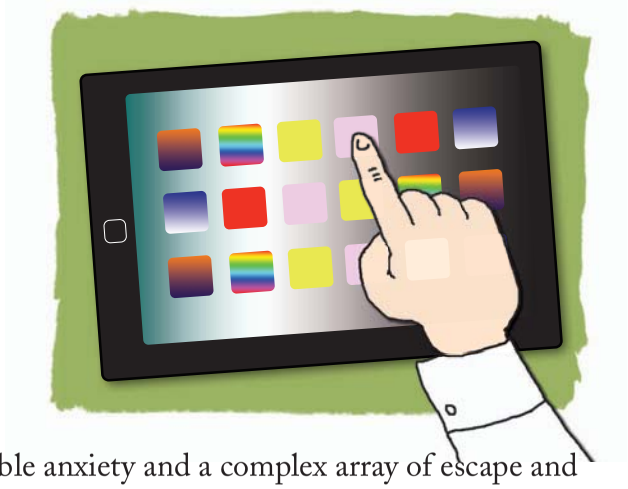
Exercise for Mental Health
Primary Companion to the Journal of Clinical Psychiatry

C.O.P.E.S.™

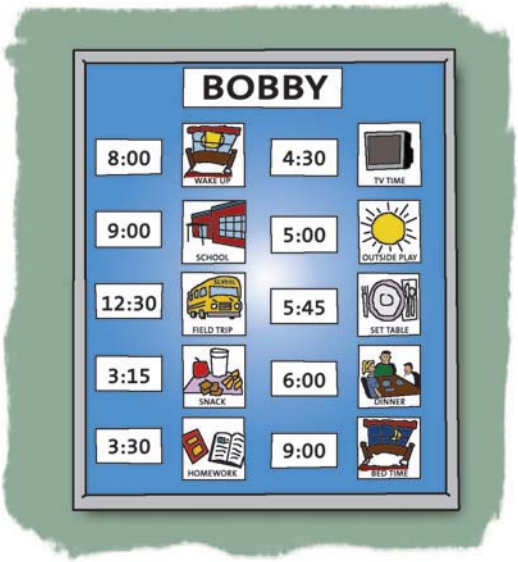
The COPES program uses individualized programs for each of their students that incorporates the following elements:

- *Communication:* students were given immediate access to communication for emotional issues. Multi access approaches were tailored to the student's needs using YES - NO boards, icons, and iPads with augmentative apps. Teach communication at his level and start with what is most essential.





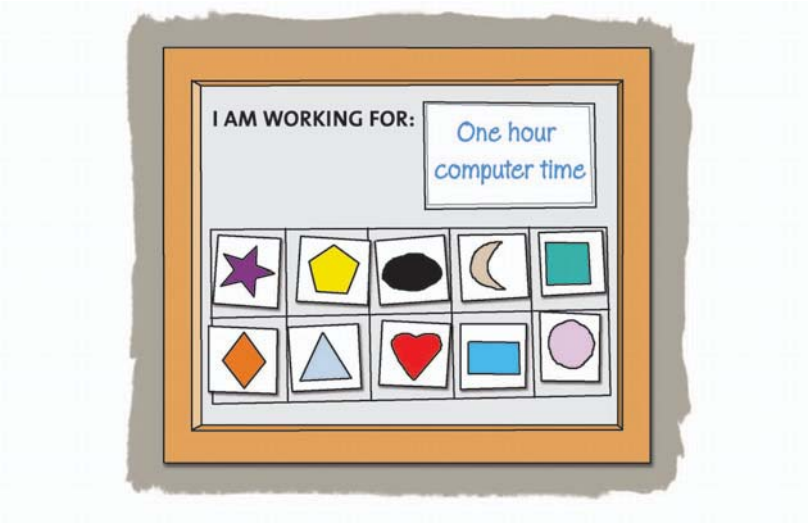
- *Organization:* many of the students showed considerable anxiety and a complex array of escape and avoidance behaviors since they had no systems to help them organize and anticipate events, daily schedules, changes in schedules and or future events. Simple schedules and training on basic contingency management and use of visual supports showed rapid changes in behavior and reduced anxiety.



Tommy's Schedule Monday	All Done
Put Backback in Cubby	
Independent Work	
Morning Meeting	
Reading Time	
Music Class	
Lunch	
Recess	
Special Reading Group	
Pack Up Backback	
Go Home	

- *Postive behavior supports:* Even though all of the students had prior FBAs and complex contingency management systems, the interventions often failed since they were too little, too late. By being reactive instead of addressing why the behavior occurred in the first place, the previous interventions were sending the message that the student's behavior was frustrating, but missing the opportunity to prevent its occurance in the future. Prevention had to be addressed as a primary objective and replacement skills needed to be built using positive behavior supports. Simple token charts were introduced and each student was reinforced for success, as simple as walking into a room nicely to sitting for a minute in a chair. The students responded immediately to being honored and acknowledged for the things they did right, though they were in shock at first since they were accustomed to primarily negative feedback. You could almost see the questions in their faces—What do you mean I'm being given constant feedback? And it's positive!

  Example of reinforcement steps to earning computer time:



- *Emotional regulation:* Starting on day one of the behavior support plan, each student was systematically taught to understand and identify his own regulatory state and escalation cycle. Proactive programming was essential. Empowerment and self-determination was a significant part of the program and the students responded immediately to their involvement in their plans. The plans were based on knowing that the student who understands that stress, anxiety and specific activities or situations often result in tension, frustration, and behaviors, is a student who has a chance of self-regulating.

  The program has been taught successfully to numerous students with limited to no verbal skills. Individuals with limited verbal skills are often assumed to be without a full range of emotions, with limited ability to comprehend what others are saying. As a result they live frustrating lives. These students are often misunderstood and their emotions, feelings and responses are not fully considered. People talk about them as if they are not there and they make judgments and statements that do not take into account for the full depth of their feelings, thoughts and opinions.

  - Teaching the student his escalation cycle does two main things:
  - it allows him to have some say or opinion in his program
  - it teaches him to be aware of the things that cause him anxiety or frustration that often leads to disruptive behaviors, and teaches him corresponding strategies for self-regulation

An example of the visuals used to teach a student to identify his regulatory state and what to do to 'get to green':

My Self -Management Plan

	The behaviors I exhibit when I feel this way	What I need to do-
 I AM HIGH	■ I grab others ■ I hit and bite ■ I yell loud ■ I cry loudly	■ Sit and breath- deep breaths ■ I need to be in a safe place ■ go to the beanbag and stay there! ■ Get to yellow
 I AM LOW	■ I look tense, my shoulders and body are tense ■ I bite my tongue ■ I click my neck and fingers ■ I look red and sad ■ I need everything to be in its place	■ Take a sensory break ■ Ask for help ■ I need someone to write and explain what's going on! ■ I need to take DEEP breaths
 I AM CALM	■ I can sit and focus ■ I can follow my schedule ■ I can answer with my voice ■ I do respond to others and I look relaxed!	■ I can earn my points and get preferred breaks

■ *Sensory and social:* Each student has a systematic exposure to community and or social outings that includes the golden rule--no community and/ or social access when the student is in any other state but green. This decreases the chances for the student to be in dangerous situations where staff have to try to manage behavior and risk inadvertently reinforcing behaviors because the safety risk is too high.

Social skills are focused on as reciprocal interaction, not necessarily frustrating, overwhelming exposure to typical students. The social success is based on the student being motivated and able to access the social situation. Start small and be successful. Building confidence in the student has to come first and regulation is key to that confidence.

What might I need to know about Managing a Crisis Situation?

Generally, when a child is engaged in the active, disruptive stage of a behavior, such as a tantrum or aggression, the essential focus has to be on the safety of the individual, those around them, and the protection of property. It is important to keep in mind that when he is in full meltdown mode, he is not capable of reasoning, being redirected, or learning replacement skills. However, this level of agitation does not usually come out of thin air. You can learn skills to help anticipate and turn around an *escalating* situation that seems to be headed in this direction.

In case of emergency, call 9-1-1. Always take suicide threats seriously!

"Both my husband and I have thought of calling 911 before but we were too scared of the unknown. Finally one afternoon we were in a difficult situation with our son and we knew it was time to make the call. It was one of the hardest decisions we have ever had to make, but it was the right one – for our son's safety and ours as well."
–CH, Mother

Have a Plan

Preparation and strategies for coping and staying safe in these situations is essential and it is important for the team, including the family, to develop a *crisis plan* together. A well-designed plan will include:

- Defined setting events, triggers or signs that a crisis situation might develop
- Tools and strategies for keeping the individual and those around him safe in any setting (school, home, community)
- Intervention steps and procedures promoting de-escalation that are paired at each level with increasing levels of agitation
- Lists of things to do and NOT to do specific to the history, fears and needs of the individual
- Hands on training and practice for caregivers and staff
- Data collection and monitoring for continued re-evaluation of the effectiveness of the plan
- Knowledge of the best prepared facility if hospitalization or an Emergency Room visit might be necessary
- Secured guardianship if your child is above age 18 and you need to continue to make decisions for him (See the Autism Speaks Transition Tool Kit for more information)

Providers and families who have experienced crisis highlight the need to maintain safety first and foremost. This is not the time to teach, make demands, or to shape behavior.

Know Ways to Calm an Escalating Situation

- Be on alert for triggers and warning signs.
- Try to reduce stressors by removing distracting elements, going to a less stressful place or providing a calming activity or object.
- Remain calm, as his behavior is likely to trigger emotions in you.

- Be gentle and patient.
- Give him space.
- Provide clear directions and use simple language.
- Focus on returning to a calm, ready state by allowing time in a quiet, relaxation-promoting activity.
- Praise attempts to self-regulate and the use of strategies such as deep breathing.
- Discuss the situation or teach alternate and more appropriate responses once calm has been achieved.
- Debrief with the individual, as well as the team, to prepare for increased awareness of triggers and strategies for self-regulation in future experiences.

In the midst of a Crisis Situation

- Remain as calm as possible
- Assess the severity of the situation
- Follow the Crisis Plan and focus on safety
- Determine whom to contact:
  - Dial 211 for free, confidential crisis counseling
  - Dial 911 for an emergency: fire, life-threatening situation, crime in process, serious medical problem that requires mental health and basic life support ambulance services
  - Call local police for non-emergencies

Disclosure to a Police Officer:

"The decision to disclose your (or your child's) diagnosis to a police officer will always be yours to make. If you have learned through experience that disclosure would be helpful in the particular situation, you may decide to disclose to a police officer. Law enforcement officers report that they make their best decisions when they have their best information. A good, strong autism or Asperger Syndrome diagnosis disclosure that includes the use of an information card, contact information for an objective professional, and proof of diagnosis should be considered."

– Dennis Debbaudt, a parent and leading voice on autism training for law enforcement and emergency responders

When severe and dangerous behaviors pose a risk of physical harm to the individual or to others in the vicinity, physical restraints or seclusion as a brief intervention are sometimes necessary to maintain safety.

Physical restraints are physical restrictions immobilizing or reducing the ability of an individual to move their arms, legs, body, or head freely.

Seclusion (putting the individual briefly in a room by himself to 'calm down') is often employed in schools and other group environments. Seclusion can provide a quick halt to an immediate threat, but in the long run, seclusion is not a solution to the behavior itself, especially if the function of the behavior is to escape or avoid something. School programs should be focused on developing functionally based, positive behavior intervention plans to eliminate the need for seclusion practices all together.

It is important to note that while restraints and seclusion can serve to maintain safety, it is an intervention of last resort and should only be used when less restrictive and alternative interventions are not effective, feasible,

or safe. Improper use of these techniques can have serious consequences physically and emotionally. Parents and caregivers should seek out and receive professional guidance and training on positive behavior interventions and supports, crisis prevention, and the safe implementation of restraints and seclusion techniques when necessary.

Managing a Crisis at Home

Having a Crisis Plan is an important step, and it might be helpful to create this with your team or behavioral provider. Some families have emergency information cards with vital information and signs posted to alert first responders. Strategies for keeping the individual with autism and other family members safe during episodes of aggression or self-injury are most important. Being prepared for an individual who is inclined to outbursts and times of aggression or property damage can help everyone feel safer. The strategies outline in Making Homes that Work might be helpful.

Managing a Crisis at School

For school age children, there are protections under the *Individuals with Disabilities Education Improvement Act (IDEIA)* that pertain to behavioral considerations, functional behavior assessments, and positive supports. The school will need to have a behavior intervention plan (BIP), and your child's educational team should provide you with materials to explain your rights and your child's rights under educational law. You need to approve the plan, and the defined behavioral targets, expectations and interventions should be clear to you, your loved one and his entire team. If you need information or training, ask! Be persistent.

In the case of a significant aggressive or other concerning behavior at school, the staff or the family can call an emergency IEP meeting to discuss placement, BIP and other considerations. Special Needs, Special Gifts offers some insights into challenging behaviors in the school environment and the responsibilities and warning signs.

Your school team may suggest the use of seclusion and/or restraints, but these controversial interventions should not be undertaken lightly. It may also be helpful to know the regulations as they pertain to challenging behaviors and the use of suspensions and expulsions. There are certain protections afforded students with special needs under a provision in IDEA. The Wrightslaw page Behavior Problems & Discipline: What Parents and Teachers Need to Know contains great information on this topic.

Managing a Crisis in the Community

"My daughter has had quite a few tantrums in our community that have escalated. This encouraged my family and I to take steps to let my local neighborhood know about my daughter's behavior — by posting autism cards, in my car window, on our front door, etc.

The other thing that really helps my family is that we travel in pairs. This means that someone is always around to help whomever my daughter is with. As a parent, I always worry about my child's safety, so I try to find a "safe place" while I'm out to take her to when there's a problem, Places like family bathrooms or even dressing rooms in clothing stores work when she needs to calm down or re-focus. I also spoke to our state's DMV about getting a handicap placard for my car that I only use when my daughter is with us--so I can make that bee-line to the car even faster!

The other thing that helps a lot is placing a Family Emergency Kit in the trunk of each car we travel in. Much like the ones used during pregnancy and in Disaster Emergency Preparedness Kits, I add a comfortable change of shoes/clothes, personal items, an extra insurance card, her medic alert necklace info, even my CPI card-to show that I'm trained. I complete each kit with a few extra sensory items she might like and extra water and snacks, in case she might be cranky because she's hungry and cannot say so. Also, in each kit, I started packing a few care items for myself, just in case we had to go to the hospital so that I would be more at ease, during our wait. The last thing I do very

frequently, is make sure I bring any medication for my child and for myself so that neither one of us get off our meds. One time my daughter's meds had changed recently, and my daughter had to go to the ER. As it turned out ,I was the only one with the meds she needed, right there in my kit!"

– KV, a parent

Emergency Personnel Response and Interacting with Law Enforcement

Training in autism awareness is increasing, but has certainly not been universal across the United States. It is important that you understand that EMS personnel might not know that 'he has autism' means that he might have difficulty understanding directions, or respond poorly to flashing lights, a blood pressure cuff or other actions. It can be helpful to have information (on a card) ready to pass along or to find ways for your local responders to get to know your child. You might advocate for training in your local emergency departments. Visit the Autism Safety Project page for tools and more information for emergency personnel.

Police and Law Enforcement Response, Judicial System

It is important to remember that police and law enforcement officers, such as security guards and TSA agents, often have little training in autism awareness and response. Sometimes a person with autism will appear to be dangerous or on drugs to a law enforcement officer. The unpredictable behaviors and communication challenges of autism, coupled with variable social understanding of authority have been known to have dire consequences. It is important to keep these factors in mind when interacting with law enforcement.

You may encounter law enforcement when you are out in the community. If your loved one has especially troubling behaviors, you may have occasion to call them into your own home. It is important to get to know your local police department and have them get to know your child. Advocate for training and sensitivity concerns. Find resources and training information to pass along to law enforcement officers and other professionals on the Autism Safety Project page.

If police are involved and your loved one is charged with a crime, there are special considerations within the legal system. Information for Advocates, Attorneys, and Judges supplies additional background information and statistics on autism for legal representatives.

"Persons with autism who are able to navigate the community without assistance should strongly consider developing personal handouts, along with the skills and resiliency to risk necessary to appropriately disclose their need for accommodations. Remember that the initial uninformed contact with police presents the highest potential for a negative outcome. What's the best tool to use when you decide to disclose your autism or Asperger Syndrome to a police officer? A handout card:

- *Develop a handout card that can be easily copied and laminated.*
- *Remember that the handout card is replaceable. You can give it away to the officer on the scene.*
- *Carry several at all times.*
- *The handout card can be generic or specific to you.*
- *Work with an autism support organization to develop a generic handout.*
- *Work with persons whose opinions you trust and value to develop a person-specific handout."*

– Dennis Debbaudt, a parent and leading voice on autism training for law enforcement and emergency responders

How do I know it is time to get more help?

Many families work diligently at home to help their children with autism negotiate the many challenges the world presents for them. However, it is important and necessary to seek professional help when:

- Aggression or self-injury become recurrent risks to the individual, family or staff
- Unsafe behaviors, such as elopement and wandering, cannot be contained
- A threat of suicide is made
- An individual presents with persistent change in mood or behavior, such as frequent irritability or anxiety
- A child shows regression in skills
- The family can no longer care for the individual at home

Sometimes this journey starts with a trip to the Emergency Room, when a person is in crisis and the caregiver or family needs immediate help. Sometimes it occurs in a more planned way, at the advice or urging of a doctor, mental health provider or other member of a team.

What can I expect at the Emergency Room?

Whether it is for behavioral concerns or just necessary medical care, the emergency room can be a difficult place for people with autism. Treating autism patients in emergencies presents challenges describes some of the challenges and makes suggestions for medical staff regarding how they might be more accommodating. It might be helpful to pack this in your emergency prep kit and pass it along to ER staff upon your arrival. Be prepared to advocate yourself.

If you are requesting a *psychiatric evaluation*, it is important to bring documentation of the behaviors that are causing concern, information about psychiatric history, any previous psychiatric evaluations, recent FBA and/or BIP, a list of current and past medications and other relevant information. Names and contact information for doctors, your behavioral provider or other important team members will be helpful. Having all of this information in writing, in one place, will help you be prepared in the event of a crisis.

Alternately, a call to the police might trigger their concern for the person or those around him, and the officer might issue orders to have the individual transferred to the ER, even if that is not your wish. In either case, the police officer or the hospital staff can place the person on a *Mental Health Hold*. When a person is placed on a mental health hold, they can usually be held for up to 72 hours for a psychiatric evaluation. This does not necessarily mean that the person will be held for the entire 72 hours. The evaluation often takes place within 24 hours.

Before a psychiatric evaluation can occur, the ER staff must evaluate and medically clear the individual. In many cases, they are likely to do a drug screen and toxicology report. The process to get medical clearance may take several hours, and maybe longer based on the staffing and volume at the ER and the complexity of the medical situation. Then a psychiatric evaluation will be performed, and will include interviews, a record review and an examination. For more information, see Psychiatric Evaluations in the Emergency Room.

Many trips to the emergency room will involve calming the individual, often with medication, and then releasing him and sending him home. Arriving at an ER does not necessarily translate into an admission to the hospital. Sometimes, the ER visit will turn into a longer stay of 1-2 weeks, with the length of stay sometimes a reflection of insurance issues.

If the hospital staff decides that the individual is at particular risk of harm to himself or others, they may recommend commitment to a mental hospital or psychiatric ward. It is important to know that if you or the adult patient does not approve, the law provides for a process known as *Involuntary Commitment* or *Civil Commitment*. This allows for court-ordered commitment of a person to a hospital or outpatient program against his will or protests.

Psychiatric Inpatient Hospitalization: How do you choose a facility?

Often individuals are brought to the nearest hospital or the closest one that has an open bed. While this may be the fastest response in a crisis, it is best to be at a facility that can best respond to the needs of your child. If possible, discuss with your providers ahead of time if there is a preferred treatment setting for individuals with autism in the event of crisis. Some hospitals have a psychiatric emergency room.

In a few states, there are specialized hospital programs specifically designed for individuals with autism and other developmental disorders. These Crisis Intervention Centers can often provide more targeted treatment options and assessment expertise. Pre-planned stays in *bio-behavioral units* may be hard to arrange since so few of these facilities exist, but the length of stay is generally a 3 to 6 month period.

What happens when you check into a hospital?

Just as you might do when planning a trip, it is important to remember to bring your loved one's necessary supports, including communication devices, visual supports, preferred toys and sensory items, as well as a familiar blanket or pillow. Entering a hospital can be quite stressful, so anything you can do to reduce anxiety and increase predictability should be considered.

If your child or loved one is placed in a psychiatric facility or ward, it will be important for you to help the staff understand his particular skills and challenges. You should be prepared for the fact that unlike many medical situations you may have experienced, a psychiatric ward is likely to have locked doors and may have stricter limits on visitation. You may not be able to be present during your child's entire stay or there to be his 'interpreter' of behaviors, food aversions, fears and anxieties as you might otherwise do. These facilities are not obliged to provide behaviorally-based treatments and interventions, though some do.

You may need to advocate for a role in helping the hospital to understand your child. In particular, it might be important to advocate against the use of restraints for your loved one, as this may increase anxiety and the intensity of negative behavioral responses. There are established policies on the use of restraints and seclusion in healthcare that you can read here. You can also request that a medical provider who knows your child be involved with the hospital staff.

"When Kevin ended up in the psych unit at our state hospital, it was incredibly valuable to have out autism doctor involved in his care. The hospital staff did not get it when it came to autism and Kevin, and our doctor was very helpful at running interference."

– SB, parent

Most hospitals are family-friendly and have extended visiting hours for children. Separating from your child can be difficult and leave you with feelings of guilt, but it is essential to remember that this is in the child's best interest. He needs specific help, and you need an opportunity to recover from a challenging situation.

Patient Rights

Patients receiving services in a hospital have the same human, civil and legal rights accorded all minor citizens (those under the age of 18) or adults. Patients have the right to a humane psychological and physical environment. They are entitled to respect for their individuality and to recognition that their personalities, abilities, needs and aspirations are not determined on the basis of a psychiatric label. Patients are entitled to receive individualized treatment and to have access to activities necessary to achieve their individualized treatment goals.

Commitment-Involuntary vs. Voluntary: As mentioned above, a psychiatric evaluation will be performed to determine if the individual is a danger to himself or others. If he is considered a danger, he can be committed against his (or your) will with a court order.

Parent Rights

Parents (or guardians) retain their legal rights for decision-making regarding the health and welfare of their child under the age of 18. Parents have the right to informed consent to treatment, including notification of the possible risks and benefits of any treatment that is proposed. Parents have the right to be involved in the treatment that is provided to their child, which includes visiting their child during the course of their treatment, ongoing communication from the providers about the child's progress, and copies of medical, behavioral and educational records.

If you feel your child would be better served in a different setting, you should engage the attending physician and other members of the hospital clinical team in a discussion of the risks and benefits of changing treatment programs. While you know your child best, it is important to evaluate the implications for safety and treatment in any setting being considered.

Age of Majority and Guardianship: For many years, you have been making decisions on behalf of your loved one with autism. But at the age of 18, the law says he gets to decide for himself and can give the required *'informed consent.'* He can refuse treatment or be declared unfit to decide. Either way, unless you apply for and are granted *guardianship*, the decisions are now out of your hands. If you think your loved one will need your assistance in making medical, safety and/or financial decisions, it will be important for you to learn about and consider your state's laws and procedures for obtaining guardianship status. This may take some time and the process involves a series of procedures, so it is important to consider this in advance of his 18th birthday, if possible. Sometimes there are allowances for temporary guardianship status while guardianship proceedings are in process. Guardianship is different from conservatorship, which allows for financial responsibility of another person. You can learn more in the Transition Tool Kit section on Legal Matters to Consider.

What happens when the Hospital Stay is over? What is a Discharge Plan?

When the hospital stay is complete, your child or loved one should leave with a Discharge Plan created by the hospital, ideally with the input of other team members. It is not necessary for you to agree to the terms or components of the plan, but the hospital is required to counsel you, your loved one and other relevant team members about the components of the plan. The hospital is also supposed to begin implementation of the plan and assist in the coordination and connection to local social services organizations, making referrals or transfers and forwarding information and records. Such a plan is not likely to occur after a brief ER stay, but should be developed for your child over the course of an extended inpatient hospitalization. A discharge plan should include:

- A statement of your child's need, if any, for:
  - Supervision
  - Medication (what, when, how much)
  - Aftercare services and supports
  - Assistance in finding employment
- Recommendation of the type of residence in which your child is to live and a listing of the services available to your child in such residence
- Lists of the organizations, facilities, and individuals who are available to provide services in accordance with each of your child's identified needs
- Notice to the appropriate school district, if relevant, regarding the proposed discharge or release of your child
- An evaluation of your child's need and potential eligibility for public benefits following discharge, including public assistance, Medicaid, and *Supplemental Security Income*
- Follow-up evaluation plans

For anyone who has been hospitalized for any reason, recovery is best when there is a solid support network. This network can be family, friends or team members, often working together. Involving others in the discharge process will help your loved one and support you in moving forward. To learn more, visit Discharge Planning in Mental Health.

Contributions to this section were made by Matthew Siegel, M.D.

Long Term Solutions: What if we just can't do this anymore?

Sometimes, a team gels beautifully and medical supports and positive interventions are effective in bringing an individual with autism the sense of security and the skills he needs to thrive in his home or community environment. However, sometimes factors such as limited resources, dual diagnoses, biological triggers or learning history can mean that a family needs more support than can be provided at home, and alternate solutions need to be considered.

This is not an easy decision to make, and often comes with considerable stress for everyone involved. It is important to remember that this decision is NOT giving up on your child. In many ways, it is recognizing that your child needs more than you can provide, and taking the steps necessary to allow him to grow and thrive in a place that is able to provide what he needs. This might mean a place with a 24-hour staff who can provide something that is not possible for a single individual, or a residential facility that supports his physical concerns as much as his behavioral needs. It is hard to be consistent and upbeat and follow a behavior plan when you are exhausted and deflated. It is difficult to be a family and support each person's needs, wants and growth, when everyone is afraid. Many families who have experienced a family member with significant challenging behaviors have reported on a much-improved relationship with their child once he was placed in a residential program that met his needs.

"If I could give any advice to parents going through this, I would tell them that it's not always an easy road, and a lot of times it can be scary. But you aren't alone, it can get better. I would tell them to reach out for help, because you can't walk this road alone. Each day is a new adventure, new challenges and new successes."

– DM, a mother

Residential placement is a personal decision that should be made when a family is no longer able to care for the needs of their child at home. For individuals with challenging behaviors such as aggression or self-injury, this may occur earlier in life than the usual transitions that occur in adulthood. It is also important to note that a residential placement is not necessarily permanent. If your team is able to build supports and skills and address underlying concerns, it may be possible for your child to return home.

A case manager or service coordinator from your school or social services agency can help to search for an appropriate setting for your child. Often, parents want to find something close to home so that they can maintain a relationship and contact with the child and his providers.

For help, visit these resources:

- Autism Speaks Housing & Residential Supports Tool Kit
- Autism Speaks Catalog of Residential Services
- National Disability Rights Network
- Disability.gov Housing Resources
- Global & Regional Asperger Syndrome Partnership (GRASP) – list and map of GRASP support groups

Where can we learn more?

Family and Caregiver Training

This tool kit is a lot of information in writing, and that is not always the best way to learn. Families who need additional information and supports will benefit from specific training and supports.

- *Hands on Training:* Ideally, this is from a behavior analyst or other behavioral provider who is part of your child's team at school or home who can individualize training to your child's needs. It is individually designed to the needs of your child, your family, and responsive to the findings of the functional behavior assessment. It would occur in your home or in the settings where you need the assistance and training. Insurance laws are increasingly providing coverage for autism services, including ABA and behavior supports. Ask your doctor or case manager for suggestions.
- *State or local ABA or autism conferences:* Many conferences, presentations and workshops will focus on autism and case studies related to the treatment of challenging behaviors, or skills that might help to replace those behaviors. Visit ABA International to learn more.
- *Training Classes in Behavioral Approaches:* Parenting classes are often held at autism support groups, local hospitals, YMCAs, social services agencies, and the National Alliance on Mental Illness. Only some will be autism specific. These classes may provide you with tips and skills, as well as access to people and resources you might not already know about who can provide or suggest more specific services. Mental Health First Aid USA may also be a helpful resource.
- *Watch SuperNanny episodes on TV or YouTube:* She employs good behavioral strategies with respect to setting boundaries and expectations, staying calm, rewarding desired behavior and incorporating fun. These principles apply in autism just as they do with typical children.
- *Take care of yourself:* Parenting is hard enough, let alone when the demands of a child with special needs and challenging behaviors are added into the mix. Find strategies to improve your sleep, your *resilience* and your ability to remain calm and nourished. Classes in yoga, mindfulness and other stress reducers might be helpful. Talk to your friends and family, and find some time for fun. Seek out local supports for *respite* from community agencies, your place of worship or friends and family. Spend time with your other children and your spouse. Ask for help. Breathe. Visit the Autism Speaks Resource Guide to find respite care and support groups in your area.

"My friends were always reaching out to me to get lunch or a cup of coffee. Most of the time I felt too busy to step away from taking care of my son. Any time away from his needs felt like I wasn't being a good parent. One day my friend happened to call just as I was running out to the grocery store – she convinced me to meet her for a cup of coffee beforehand. Once I met her and sat down to chat and relax for a few minutes, I realized how much I needed it. I now make time every week to see my friends, or have a little 'me' time. Ultimately I think I'm a better parent and person because of it."

– AC, a mother

Resources:

211 Database Service
Available in much of the US, this service connects people with important community services, sponsored by United Way Worldwide (UWW) and the Alliance for Information and Referral Systems (AIRS).

ABA Training & Treatment - Behavior Frontiers

Asperger Syndrome and Difficult Moments: Practical Solutions for Tantrums, Rage and Meltdowns
by Brenda Smith Myles and Jack Southwick

Managing Threatening Confrontations DVD
from the Attainment Company

No More Meltdowns: Positive Strategies for Managing and Preventing Out-Of-Control Behavior
by Jed Baker Ph.D.

The Way to A: Empowering Children with Autism Spectrum and Other Neurological Disorders to Monitor and Replace Aggression and Tantrum Behavior
by Hunter Manasco

Provider Training

Many schools and service providers will have trained staff accustomed to handling challenging behaviors. Others will not. Service providers who need additional information on positive supports and crisis prevention and management can utilize the following resources for information and training:

- Positive Behavior Supports
- Kansas Institute for Positive Behavior Support
- The New England Center for Children "CALM" Curriculum
- Safe and Civil Schools
- Crisis Prevention Institute
- Quality Behavioral Solutions to Complex Behavior Problems
- Mental Health First Aid USA

Conclusion

Autism can bring a family many challenges, especially when a loved one with autism exhibits behaviors that are challenging, disruptive, or dangerous. These are often experiences that our siblings, parents and best friends do not quite understand, since they have not necessarily faced the same concerns. As a result, many families with loved ones with autism experience significantly high levels of stress, which can be disruptive and unsettling. However, many families have also shown resilience and an ability to bounce back from the challenges that autism presents with humor, grace and increasing strength.

It is important to get help. Cry when you need to. Lean on your friends, extended family, and other social supports. Connect with other parents who are experiencing similar challenges and swap stories and vent together—find them at support groups or places like www.meetup.com. Investigate counseling supports through your insurance plan, place of worship or community services agency.

Use the information in this tool kit to seek out information and team members who will support you, and help your loved one to grow to become all he can be. Take small steps, and celebrate the growth and accomplishments along the way. Be the detective that helps you better understand—and hopefully better accept—your child and the difficulties he faces as he goes through life. Use the strategies and resources in this kit and from your team to help you build a place in which everyone feels safer and more successful. Advocate for help when you need it. Find resources or create a plan for respite care so that you get a break too, and use it!

Recognize the resilience your loved one with autism shows each and every day. Celebrate the things he says or does that make you laugh: his dimples, his artwork, his smile. Sure, you may cry or swear sometimes. But also rest. Breathe. And celebrate the successes one at a time, whenever and wherever they come.

"A multidimensional, comprehensive approach to ASD that emphasizes the development of positive, constructive behavior, builds family cohesiveness and mutual support, focuses on successful home and community living, and addresses systemic barriers to progress will not "cure" autism, but it will make it possible to live happily with autism. These goals are realistic and can be achieved now."

– Ted Carr, Ph.D.,
State University of New York at Stony Brook

Challenging Behaviors Glossary

- *A-B-C Analysis:* an approach to understanding behavior by examining the Antecedent (the cause), the Behavior, and the Consequence (the result)
- *ADHD (Attention Deficit Hyperactivity Disorder):* a problem with inattentiveness, over-activity, impulsivity, or a combination, that is out of the normal range for a child's age and development
- *Age of majority:* the age established under state law when an individual is no longer a minor and has the right to make certain legal decisions without consent
- *Allergies:* adverse immune responses or reactions to substances that are usually not harmful (i.e. pollen, peanuts, gluten)
- *Anxiety disorder:* a pattern of constant worry or tension under many different circumstances
- *Applied Behavior Analysis (ABA):* the systematic approach to the assessment and evaluation of behavior, and the application of interventions that change behavior
- *Audiologist:* a professional who diagnoses and treats a patient's hearing and balance problems using advanced technology and procedures
- *Autism Spectrum Disorders:* a group of complex disorders of brain development characterized, in varying degrees, by difficulties in social interaction, verbal and nonverbal communication and repetitive behaviors
- *Aversive:* an unwanted stimulus designed to change an individual's behavior through punishment
- *Behavior Improvement Plan (BIP):* a plan to improve a student's behavior in school created based on the results of a Functional Behavior Assessment
- *Behavioral disorder:* a condition in which behavior significantly deviates from acceptable norms
- *Behavioral drift:* changes in behavioral patterns resulting from gradual and subtle adjustments over time
- *Behavioral stereotypy:* repetitive or ritualistic movements such as body rocking or crossing and uncrossing of legs
- *Biobehavioral unit:* a psychological and psychiatric clinic within a hospital or research center that treats behavioral, anxiety and mood disorders
- *Biomarker:* an indicator of a certain biological state
- *Bipolar disorder:* a brain disorder that causes unusual shifts in mood, energy, activity levels, and the ability to carry out day-to-day tasks; also known as manic-depressive illness
- *Blinded:* unaware of a new or different intervention, which prevents bias during evaluation
- *Board Certified Behavior Analyst (BCBA):* a professional certified to provide ABA therapy by the Behavior Analyst Certification Board (BACB)
- *Bulimia:* an illness in which a person binges on food or has regular episodes of overeating and feels a loss of control, then uses different methods – such as vomiting or abusing laxatives – to prevent weight gain

- *Case manager:* a professional from a school or service agency such as the Department of Developmental Disabilities who serves as a direct contact for families and helps gather resources, team members and ideas
- *Catatonia:* a state in which a person does not move and does not respond to others
- *Challenging behaviors:* behaviors that are destructive and harmful to the individual or others, that prevent learning and cause others to label or isolate the individual for being odd or different
- *Civil Commitment:* a legal process in which an individual experiencing a mental health crisis is ordered into treatment against his or her will, including to a hospital
- *Comorbid:* pertaining to a disease or disorder that occurs simultaneously with another
- *Cognitive behavioral therapy:* a type of therapy designed to help improve an individual's inappropriate or challenging behaviors by replacing the negative thoughts that cause these behaviors with positive thoughts
- *Compulsion:* the drive to do something in particular or in a particular way, such as the need to straighten all the forks at the dinner table
- *Conservatorship:* the legal right given to a person to be responsible for the assets and finances of a person deemed fully or partially incapable of providing these necessities for himself or herself
- *Crisis plan:* a document that outlines in specific detail the necessary strategies and steps that must be taken when a crisis occurs
- *Data analysis:* the process of thoroughly inspecting information related to challenging behaviors in order to draw out useful information and conclusions that may result in strategies to improve behavior
- *De-escalation:* the process of stopping a challenging behavior or crisis from intensifying, and calming the situation
- *Depression:* a mood disorder in which feelings of sadness, anger, or frustration interfere with everyday life for an extended period of time
- *Differential diagnosis:* distinguishing between two or more diseases with similar symptoms to identify which is causing distress or challenging behavior
- *Disruption:* an event that causes an unplanned deviation from a situation
- *Dual diagnosis:* the identification of an additional mental health disorder individuals with developmental disabilities
- *Elopement:* a situation in which an individual leaves a safe place, a caretaker, or supervised situation, either by 'bolting,' wandering or sneaking away
- *Epilepsy:* a brain disorder in which a person has repeated seizures (episodes of disturbed brain activity or convulsions) over time
- *Escalating:* increasing or worsening rapidly
- *Extinction:* a response used to eliminate a behavior that involves ignoring a mild behavior when it is used for attention

- *Extinction burst:* the short term response to extinction in which there is a sudden and temporary increase in the response's frequency, followed by an eventual decline
- *Face blindness:* an impairment in the recognition of faces
- *Fecal digging:* the process in which an individual puts his fingers into his rectum
- *Fecal smearing:* the process in which feces are spread on property or the individual himself
- *Food allergies:* an adverse immune response to a food protein (i.e. dairy products) that may cause rashes, gastrointestinal or respiratory distress
- *Function:* the purpose or desired result
- *Function of behavior:* the purpose or reason behind a specific behavior for an individual
- *Functional Behavior Assessment (FBA):* the process by which a school thoroughly examines a student's problem behavior using strategies such as close observation, questionnaires, active listening, previous experiences, etc.
- *Functional communication:* effective and appropriate communication that an individual uses across his daily activities to meet his or her needs
- *Gastroenterologist:* a professional specializing in disorders of the digestive system
- *Guardianship:* the legal right given to a person to be responsible for the food, health care, housing, and other necessities of a person deemed fully or partially incapable of providing these necessities for himself or herself
- *Hormones:* chemical messengers that travel in an individual's bloodstream to tissues or organs slowly, over time, and affect many different processes, including brain activity and behavior
- *Immunologist:* a physician specially trained to diagnose, treat and manage allergies, asthma, and other immunologic disorders
- *Incontinence:* the (usually) involuntary passing of feces or urine, generally not into a toilet or diaper
- *Individualized Education Program (IEP):* a written statement for each child with a disability that is developed, reviewed, and revised in meetings within the school so an individual's education best meets his or her needs
- *Individuals with Disabilities Education Improvement Act (IDEIA):* the 2004 reauthorization of the Individuals with Disabilities Act that states that in exchange for federal funding, states must provide a free appropriate public education (FAPE) to individuals with disabilities in the least restrictive environment (LRE)
- *Individuals with Disabilities Education Act (IDEA):* a law ensuring services to children with disabilities throughout the nation that governs how states and public agencies provide early intervention, special education and related services to more infants, toddlers and children with disabilities
- *Informed consent:* a process of communication between a patient and physician that results in the patient's authorization or agreement to undergo a specific medical intervention
- *Intervention:* a strategy or process put in place in order to improve or modify an individual's behavior (i.e. medication, Applied Behavior Analysis)

- *Intolerance:* the inability, unwillingness or refusal to endure something (i.e. specific foods)
- *Involuntary Commitment:* a legal process in which an individual experiencing a mental health crisis is ordered into treatment against his or her will, including to a hospital
- *Lyme Disease:* a bacterial infection spread through the bite of the blacklegged tick
- *Maladaptive behavior:* a type of behavior that is often used to reduce anxiety, but the result does not provide adequate or appropriate adjustment to the environment or situation
- *Medicaid:* a government program that provides healthcare coverage for low-income families and individuals with disabilities in the United States
- *Medical home:* a team based healthcare delivery model led by a physician that provides comprehensive and continuous medical care to patients
- *Mental Health Hold:* involuntary hospitalization due to a mental health crisis
- *Motor function:* the ability to move that results from messages sent from the brain to the muscular system
- *Nutritionist:* a professional specializing in diet and nutrition issues
- *Obsession:* a repetitive thought or feeling dominated by a particular idea, image or desire, such as a person who only wants to talk about elevators
- *Obsessive Compulsive Disorder (OCD):* an anxiety disorder in which people have unwanted and repeated thoughts, feelings, ideas, or sensations (obsessions) that make them feel driven to do something (compulsions)
- *Ophthalmologist/optometrist:* a professional specializing in vision issues and eye care
- *Ototoxic:* damaging to the ears, causing sound sensitivities, dizziness or balance issues
- *Over correction:* a punishment mechanism for a challenging behavior that involves requiring an individual to engage in repetitive behavior to an excessive extent in an attempt to prevent the behavior from reoccurring
- *Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections (PANDAS):* a subset of children and adolescents who have Obsessive Compulsive Disorder (OCD) and/or tic disorders, and in whom symptoms worsen following infections such as "Strep throat" and Scarlet Fever
- *Pica:* an eating disorder that involves eating things that are not food (i.e. dirt, plastic)
- *Picture Exchange Communication System (PECS):* a unique augmentative/alternative communication intervention package that involves teaching an individual to give a picture of a desired item to a “communicative partner,” and goes on to teach discrimination of pictures and how to put them together in sentences
- *Polypharmacy:* the use of multiple medications by a patient
- *Positive Behavior Supports (PBS):* an approach to helping people improve their difficult behavior by understanding what is causing it, and then developing strategies to increase positive behaviors
- *Post-Traumatic Stress Disorder (PTSD):* an anxiety disorder that can occur after witnessing or experiencing a traumatic event

- *Psychiatric evaluation:* a mental health examination by a psychiatrist or other mental health professional
- *Psychologist:* a professional with the training and clinical skills to help people learn to cope more effectively with life issues and mental health problems
- *Psychosis:* a loss of contact with reality that usually includes delusions and hallucination)
- *Psychotropic:* a medication or intervention that affects brain activity, behavior or perception
- *Puberty:* the process of physical changes that occur when a child's body matures into an adult
- *Regional center:* agencies throughout the state of California that serve individuals with developmental disabilities and their families
- *Reinforce:* to strengthen with additional material or support
- *Reinforcement strategies:* methods used to promote or increase positive behavior by providing motivating reinforcers (i.e. praise, a favorite toy, a cookie)
- *Resilience:* an ability to recover from or adjust easily to change or a difficult situation
- *Respite care:* a service that provides short-term breaks that can relieve stress, restore energy, and promote balance for caregivers
- *Restraints:* physical restrictions immobilizing or reducing the ability of an individual to move their arms, legs, body, or head freely
- *Reward:* a prize, token, or preferred activity given to an individual for good behavior, designed to promote the same behavior in the future
- *Risk factors:* conditions that increase the likelihood of aggression
- *Ritual:* a repetitive behavior that a person appears to use in a systematic way in order to promote calm or prevent anxiety, such as arranging all the pillows in a certain way before being able to settle in to sleep
- *Rumination:* the practice of (voluntarily or involuntarily) spitting up partially digested food and re-chewing it, then swallowing again or spitting it out.Rumination often seems to be triggered by reflux or other gastrointestinal concerns
- *Schizophrenia:* a chronic, severe, and disabling brain disorder that makes it hard for individuals to think clearly and tell the difference between what is real and not real
- *Seclusion:* a situation in which an individual is put briefly in a room alone to 'calm down'
- *Sedating:* calming, sleep-inducing, numbing an individual experiencing challenging behaviors or struggling during difficult situations
- *Self-advocacy:* the ability of an individual to communicate his or her wants and concerns, and make his or her own decisions
- *Sensory avoidance:* blocking or staying away from something that is painful or bothersome

- *Sensory defensiveness:* a tendency to react negatively or with alarm to sensory input which is generally considered harmless or non-irritating
- *Sensory input:* any source that creates sensation and activates one or more of the senses -vision, smell, sound, taste, and touch
- *Sensory-seeking behavior:* behaviors caused by a need for additional stimulation of certain senses as a way of maintaining attention or achieving a calmer state
- *Sleep apnea:* a usually chronic, common disorder in which an individual has one or more pauses in breathing or shallow breaths up to 30 or more times per hour during sleep, and results in daytime sleepiness
- *Special needs parent advocate:* an advocate for parents of children with special needs who helps ensures that the child's rights and needs are met in school and in the community
- *Staring spells:* occasions when an individual is in a trance staring into space, which can often signal seizure activity
- *Stimulation:* excitement or activity triggered by a stimulus either internally or externally
- *Supplemental Security Income (SSI):* a Federal income supplement program designed to help aged, blind, and disabled people who have little or no income, and provides cash to meet basic needs for food, clothing, and shelter
- *Tangibles:* items or rewards that can be touched, such as a toy or piece of candy
- *Tourette's Syndrome:* a neurological disorder characterized by tics, or repetitive, stereotyped, involuntary movements and vocalizations
- *Tracking scales:* a document or other tool used to track information such as changes in an individual's behaviors, side effects of medications, school performance, etc.
- *TRICARE:* the health care program for Uniformed Service members, retirees and their families worldwide
- *Voice output technology:* a technological device that helps people who are unable to use speech to express their needs and exchange information with other people
- *Wraparound:* an integrated, multi-agency, community-based planning process designed to build teams of providers, family members and natural supports to help keep complex youth in their homes and communities

Have more questions or need assistance? Please contact the Autism Response Team for information, resources and tools.

TOLL FREE: 888-AUTISM2 (288-4762)

EN ESPAÑOL: 888-772-9050

Email: FAMILYSERVICES@AUTISMSPEAKS.ORG

WWW.AUTISMSPEAKS.ORG

Text ART to 30644

AUTISM SPEAKS®

Autism Speaks is dedicated to promoting solutions, across the spectrum and throughout the life span, for the needs of individuals with autism and their families. We do this through advocacy and support; increasing understanding and acceptance of people with autism; and advancing research into causes and better interventions for autism spectrum disorder and related conditions.

To learn more about Autism Speaks, please visit AutismSpeaks.org.

Ten Key Interventions for ASD

Abhilash K. Desai MD, Psychiatrist. Dr.abhilashdesai@icloud.com

1. Autism diet (e.g., broccoli [has sulforaphanes], probiotics, omega 3 fatty acids, diet low in refined carbs, accommodations for individual food sensitivities [e.g., celiac disease, lactose intolerance])
2. Optimal evaluation and management of medical and neurological comorbidity (e.g., seizures, gastrointestinal problems, pain [including headaches, migraine], nutritional deficiencies [e.g., vitamin D deficiency, hypomagnesemia, B1-Thiamine, B3-Niacin])
3. Environmental adaptation (aka Nidotherapy www.nidotherapy.com)
4. Optimal demand on the individual with ASD
5. Behavioral Interventions / Stimulus control (Applied Behavior Analysis ABA) (with guidance from a BCBA [Board Certified Behavioral Analyst])
6. Multi-Sensory interventions (with guidance from an Occupational therapist)
7. Language and communications interventions (with guidance from a Speech Language Pathologist)
8. Emotional and Social Resilience Training (e.g., Secret Agent Society [www.sst-institute.net], UCLA PEERs program [www.semel.ucla.edu/peers])
9. Supplements and herbal remedies (e.g., N-Acetyl Cysteine, Omega 3, Probiotics, Vitamin D3, sulforaphane, probiotics, CBD [cannabidiol], digestive enzymes, Methyl B12, Melatonin for insomnia)
10. Psychiatric medications (e.g., Stimulants for ADHD, SSRIs for anxiety; Aripiprazole or Risperidone for severe persistent aggression / self-injurious behaviors)

Web resources:

1. Vanderbilt Kennedy Center https://vkc.mc.vanderbilt.edu/etoolkit/physical-health/health-watch-tables-2/checklist-autism/
2. Currently, a vasopressin 1a receptor antagonist Balovaptan is in phase 3 trial to see if it may reduce social cognition deficits and may have other benefits https://theaviationstudy.com
3. Inspirational narratives of women with late diagnosis of ASD: http://www.bbc.com/news/resources/idt-sh/women_late_diagnosis_autism

Suggested Reading:

Grinker R, R. Unstrange Minds: Remapping the world of autism. A father, a daughter, and a search for new answers. 2007. Basic Books Publishing.

Markram K, Markram H (2010): The intense world theory – A unifying theory of the neurobiology of autism. Frontiers in Human Neuroscience, 4(22), 1-29.

Hendren R. Complementary and Alternative (Biomedical) Treatments for Autism Spectrum Disorder. McDougle CJ. Editor. A Primer on Autism Spectrum Disorder. Oxford University Press 2016; pp 301-320).

Harnessing the Seven Forces of Wellness, Wisdom and Healing

Abhilash Desai MD (dr.abhilashdesai@icloud.com)

My Next Big Creation Should Come Naturally (a helpful memory tool/trick created by my friend Sunil Khushalani MD to remember the seven pillars)

M: Mindfulness: Practices that support and enhance living mindfully (aka with awareness and kindness) throughout the day may have remarkable healing properties.

N: Narratives: Our minds are constantly stitching different moments to try and make sense of the *whys* of life (e.g., why is this happening? why is it happening to me? why is the other person behaving like this?). Unfortunately, the narratives created by our minds often increase our pain and suffering. Let's become better at choosing and creating narratives that promote wellness, wisdom and healing.

B: Biomedical: Science-based (aka "Evidence-based") approaches and interventions (e.g., exercise, nutrition, stress-management, behavior therapies, medications, neurostimulation, surgical interventions, rehabilitative services, technology-based interventions [e.g., virtual reality] and complementary and alternative medicine) may promote wellness and they generally get the most (or exclusive) attention in our current culture.

C: Creative engagement: We are all artists and we need to engage in creative engagement on a routine basis to promote our healing and wellness.

S: Spirituality: We are all interconnected, and we need to engage in spiritual practices and the kind of day-to-day living that supports and nourishes our spiritual self (which is intertwined with our body-self and our social self and thus actively influences our body-wellness and our social wellness).

C: Community: We are all part of a community and we can enhance our wellness by engaging with our community on a routine basis, supporting our community members in their own wellness and accepting support from our community.

N: Nature: We are evolutionarily programmed to heal rapidly if we spend time in nature and wilderness on a regular basis.

Suggested Care Team Members for Autism Care Plan

Abhilash Desai MD (dr.abhilashdesai@icloud.com)

Team Members	Components
Family and Friends (including hired care staff)	- Assist in caring for individual with ASD - Monitor for signs and symptoms of complications (changes in physical and or mental health) and triggers (e.g., change in environment) - Help with transportation - Emotional support for parents
Individual with ASD	- Empowering the individual to participate in their own care plan - Education and job-training
Primary ASD care providers (e.g., child psychiatrist, psychiatrist, pediatrician, pediatric nurse practitioner, family physician with expertise and experience in ASD care)	- Ensures that mental and physical health needs are comprehensively assessed and met - Serves as "first call" providers for any acute concerns - Provides routine wellness visit follow ups
Primary care provider (PCPs) (also may be the primary ASD care provider)	- Co-manages chronic health conditions (e.g., migraine, epilepsy, GERD, constipation) - Assumes primary responsibility for ongoing healthcare after comprehensive ASD care visit
Board Certified Behavior Analyst (BCBA)	- Ensures understanding and implementation of behavior care plan to reinforce positive behaviors - Collaborates with primary ASD care providers and PCPs routinely
Care coordinator and navigator (preferably a nurse in PCP office)	- Coordinates health and social services among team members
Specialty consultants (e.g., developmental pediatrician, neurologist, child psychiatrist, psychiatrist, pediatric neuropsychologist, psychologist)	- Co-manages complex neurological / psychiatric problems with PCP - Provides guidance for neurological / mental health emergencies
Allied healthcare professionals (e.g., occupational therapist, speech and language pathologist, dietician)	- Co-manages relevant health needs - Collaborates with primary ASD care providers, PCP and other team members

Suggested Components of Autism Care Plan

Abhilash Desai MD (dr.abhilashdesai@icloud.com)

Topics	Components
Care team	Contact information (name, website, telephone number, address of each)
Wellness visits	Time, date, and location of visits; telephone numbers / websites to call / go to schedule / reschedule appointments
Wellness and Behavior management plan	Plan for wellness activities (e.g., exercise, spending time in nature) and Plan for reinforcing positive behaviors (created with guidance from a BCBA*)
Parent STEPS (support, training, education, praise and support) plan	Resources for community support, local training programs, mindfulness groups, reputable web resources, reputable books
Chronic health conditions care plan	Treatment plan for ongoing physical (neurological and medical) and mental health conditions with list of care team members responsible for follow-up
Psychiatric complications care plan	Plan to address behavioral emergencies such as serious self-injurious behaviors or physically aggressive episodes (e.g., use of safe restraints under the guidance of a BCBA*; psychiatric medications as needed)
Nutritional care plan	Plan to address food sensitivities, food allergies, and nutritional deficiencies (includes nutritional supplements)
Long-term care plan	Plan to address education, supported work-living, contingencies for loss of primary support network

*BCBA – Board Certified Behavior Analyst