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PAautism.org

The ASERT Collaborative Justice Project

JUDGE'S GUIDE TO AUTISM

CONTENTS

Autism Services, Education, Resources, and Training (ASERT) is a statewide initiative funded by the Bureau of Supports for Autism and Special Populations, Pennsylvania Department of Human Services. ASERT is a key component of the Bureau of Supports for Autism and Special Populations strategy for supporting individuals with autism and their families throughout the Commonwealth of Pennsylvania.

THE ASERT MISSION

Innovate, collaborate, and lead to improve access to quality services, data, and information; to provide support, training and education in best practices; and to facilitate the connection between individuals with autism, developmental disabilities, and special populations, families and key stakeholders at local, state and national levels.

The ASERT Collaborative is funded by the Office of Developmental Programs, PA Department of Human Services.

HOW TO USE THIS GUIDE

The Judge's Guide to Autism is a resource for judges that come in contact with individuals on the autism spectrum that have contact with the criminal justice/mental health systems in their communities. The guide is divided into many parts including: What is ASD?, Screenings/Assessments, Diagnosis, Supports, Evidence Based Treatments, Supports for the Courtroom, Data, FAQs, Resources, and Acronyms.

Each section consists of entries that provide a concise overview and when available, suggest where to go for more information.

The Judge's Guide to Autism is intended for informational uses only; diagnoses and treatment recommendations can only be made by trained and licensed professionals.

I. What is Autism Spectrum Disorder

Autism Spectrum Disorder (ASD) is a complex neurodevelopmental disability that is characterized by core deficits in two primary areas: social communication and social interaction and repetitive and restrictive behavior, interests, or activities. ASD is a lifespan disorder, meaning that symptoms may change over time but the diagnosis persists into adulthood. Common symptoms of ASD include:

- Poor eye contact (either too much or too little)
- Topics of conversation may be overly focused on details unrelated to the conversation and/or may be "one-sided" (i.e., not a fluid "back and forth" discussion/reciprocal)
- Repetitive motor movements (e.g., flapping, spinning, rocking, flicking)
- Repetitive speech (e.g., "scripting",repeating words or phrases)
- Rigid behaviors or actions and anxiety/anger when things deviate from expected routine
- A flat vocal affect (i.e., monotone voice with little to no inflection) or increased speech latency (i.e., long delays in responding to questions)
- Sensory sensitivities to light, sound, taste, and/or touch

*Individuals with ASD may or may not have a co-occurring intellectual disability or may have an average, above average, or superior IQ. There is no physical presentation associated with ASD. ASD occurs in all genders, races, and ethnicities.

II. Screenings/Assessments

Many individuals with ASD will have records indicating diagnosis(es), functional ability, intellectual ability, as well treatment history and recommendations. If you have been informed an individual in your courtroom has an ASD diagnosis or your suspect an ASD diagnosis, request a record review before requesting a screening or assessment for ASD.

- Proper screening and assessment are vital in ensuring an individual is referred to the correct level of behavioral health care.
- It is important that individuals in question are screened and then referred to a properly trained professional to complete an in-depth evaluation assessing the individual's skills related to their charges and overall functioning.

What language can a judge use to request records that would be helpful to learn more about the individual?

- **Example:** "The medical, behavioral health, mental health, educational, psychosocial, and psychiatric records are requested for John Doe."

What is a screening?

- The purpose of screening is to determine if an individual needs an assessment.
- It is a structured process which involves surveys, questionnaires, and/or set interview questions to identify potential areas of developmental concern.
- It is not used to diagnose or determine the severity of a disorder.
- Screenings oftentimes do not require extensive training to complete.

Who can screen for ASD?

- Medical doctors
- Speech therapists
- Occupational therapists
- Teachers
- Social workers
- Psychologists

Who can screen in the Justice System?

- Intake coordinators/officers
- Court officers
- Correction officers
- Probation officers
- Clerks
- Youth aid workers
- Public defenders

What are some common screening tools?

- Modified Checklist for Autism in Toddlers, Revised (M-CHAT-R)
  - 16-30 months old
- Social Communication Questionnaire (SCQ)
  - Mental age of at least 2 years
- Autism-Spectrum Quotient (AQ) questionnaire

What language can a judge use to request a screening?

- **Example:** "A screening for Autism Spectrum Disorder is requested to rule in or out the necessity for further evaluation."

What is an assessment?

- An assessment is an evaluation to gather information and data to establish/confirm diagnosis(es) and make treatment recommendations. It is more in-depth and comprehensive than screening. An assessment may examine the context in which a disorder may be most impairing.

Who can conduct an assessment?

- Assessments require special training to conduct.
  - Clinically trained and qualified Licensed psychologists
  - Psychiatrists
  - Nurse practitioners
  - Developmental pediatricians
  - Neurologists

What are some common assessment tools?

- Autism Diagnostic Observation Schedule, Second Edition (ADOS-2)
  - The gold standard assessment for ASD includes administration of the ADOS-2 which is a semi-structured interview completed by a trained clinician, often a psychologist.
- Autism Diagnostic Interview-Revised (ADI-R)
  - This semi-structured interview requires specialized training and is time intensive (1.5-3 hours to complete), but it is highly reliable in establishing/confirming ASD.
- Childhood Autism Rating Scale, Second Edition (CARS-2)
- Gilliam Autism Rating Scale, Third Edition (GARS-3)
- Social Responsiveness Scale, Second Edition (SRS-2)
- Autism Spectrum Rating Scales (ASRS)

What language can a judge use to request formal assessment?

- **Example:** A psychodiagnostics assessment, to determine the presence of ASD including severity, an intellectual disability, as well as adaptive behavior assessments that indicate functional ability according to the DSM-5, including treatment recommendations is requested for John Doe. The court clinic should report immediately if they do not have the capacity to conduct requested assessments by X date so the court can determine an alternative clinic to conduct requested assessments.[1]

[1] Huerta, M., & Lord, C. (2012). Diagnostic evaluation of autism spectrum disorders. Pediatric Clinics of North America, 59(1), 103.

Snap Shot of the Screening/Assessment Hierarchy

	PURPOSE	KEY COMPONENTS	BY WHOM	TIME AND COST CONSIDERATIONS
LEGAL SCREENING	To determine legal eligibility To examine public safety risk	Current charge Criminal history Diagnosis history Circumstances of offense	Criminal Justice System: Prosecution Defense, Probation officer, Court police, Pre-trial/In-take coordinator/ Officer, Court officer, Correction officer, Clerk, Youth aid worker, Public defender	These activities are conducted under normal criminal proceedings. Cost is minimal.
CLINICAL SCREENING	To determine if further assessment is necessary	Process explained Releases signed Brief assessment-social history and other diagnoses	Pretrial Services, Probation, Court clinicians Providers, doctors, speech therapists, occupational therapists, teachers, social workers, and other professionals	Typically 5-30 minutes. Costs are associated with instruments, staff time and staff training
CLINICAL ASSESSMENT	Diagnosis and treatment recommendations	Examine scope and nature of disability Identify full range of service needs Match participants to appropriate services	Clinically trained and qualified psychologist, psychiatrist, medical provider, nurse practioner developmental pediatrician, neurologist	1-2 hours or more depending on the nature of problems Costs are associated with instruments, staff time, and staff training.

How do I read an evaluation?

- Look for the Discussion,Results, or Summary section
- Diagnosis list (Look for diagnosis and severity level.)
  - According to the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), "the severity specifiers may be used to describe succinctly the current symptomatology (which might fall below level 1), with the recognition that severity may vary by context and fluctuate over time".[2]
  - Impact is rated from 1 ("requiring supports") to 3 ("requiring very substantial supports") and is indicative of the degree of impairment an individual experiences.
  - Severity level is rated from 1 ("requiring supports") to 3 ("requiring very substantial supports") and is indicative of the degree of impairment an individual experiences.
  - The descriptive severity categories should not be used to determine eligibility for and provision of services; these can only be developed at an individual level and through discussion of personal priorities and targets.
  - Regarding the specifier "with or without accompanying intellectual impairment," understanding the (often uneven) intellectual profile of a child or adult with ASD is necessary for interpreting diagnostic features.
  - Separate estimates of verbal and nonverbal skills are necessary (e.g., using untimed nonverbal tests to assess potential strengths in individuals with limited language).

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[2] American Psychiatric Association. (2013). Diagnostic and statistical manual of mental disorders (5th ed., text revision).

- When looking at specific tests, bear in mind they have specific cutoff scores
  - However, obtaining a score above a certain threshold does not guarantee that an individual has ASD.
  - An evaluator must consider scores in conjunction with observation and other factors.

How to interpret an IQ assessment/evaluation

- IQ assessments are interpreted by standard scores and follow the following parameters listed below. The most widely used are the Wechsler Intelligence Scale for Children - Fifth Edition (WISC-V; ages 6-16), Wechsler Adult Intelligence Scale - Fourth Edition (WAIS-IV; ages 16-90), as well as the Stanford-Binet Intelligence Scales, Fifth Edition (SB-5; ages 2-85+). Standard scores are calculated using aged based norms arriving at the Intelligence Quotient or a Full Scale IQ (FSIQ).

IQ RANGE ("DEVIATION IQ)	IQ CLASSIFICATION
above 130	Very gifted
121-130	Gifted
111-120	Above average intelligence
90-110	Average intelligence
80-89	Below average intelligence
70-79	Cognitively impaired
Below 70	Intellectually Disabled

How to interpret an adaptive functioning assessment/evaluation:

- Adaptive behaviors include real-life skills such as grooming, getting dressed, avoiding danger, safe food handling, following school rules, managing money, cleaning, and making friends. Adaptive behavior also includes the ability to work, practice social skills, and take personal responsibility.
- Adaptive Behavior Assessment System Third Edition (ABAS-3) (One of the most widely used adaptive functioning measures):
  - Description: For the 11 skill areas assessed—norm-referenced scaled scores. For the 3 adaptive domains and the General Adaptive Composite (GAC)—norm-referenced standard scores, confidence intervals for standard scores, and percentile ranks. In addition, all scores can be categorized descriptively
  - Scores are compiled on each domain-any standard score below a 70 would be an area of clinical significance. These scores should be referenced by a qualifier (eg. Average, Below Average)
- Vineland Adaptive Behavior Scales, Third Edition (Vineland-3) is another popular test. It is set up in a similar fashion to the ABAS-3. It gives scores over several domains within confidence intervals and standard scores. Anything below a 70 would be considered a weakness and should be considered an area to work on with an individual.

III. Diagnosis

ASD is often diagnosed at a young age, but can also be newly diagnosed in adulthood if the symptoms are mild or misdiagnosed. There are no blood tests or other biomedical exams to test for ASD. ASD is diagnosed through clinical observations in multiple contexts and by self- and other- report of symptoms.

- Individual clinical characteristics are noted through the use of specifiers: with or without accompanying intellectual impairment, and with or without accompanying language impairment, associated with a known medical or genetic condition or environmental factor, associated with another neurodevelopmental, mental, or behavioral disorder, or with catatonia.

What is the DSM-5 definition of ASD?

Autism Spectrum Disorder (ASD):

- ASD a neurodevelopmental disorder that is characterized by varying degrees of "persistent deficits in social communication and social interaction" as well as the presence of "restricted, repetitive patterns of behavior, interests, or activities."[2]
- In previous iterations of the Diagnostic and Statistical Manual of Mental Disorders (DSM), ASD was comprised of five distinct diagnostic categories: Autistic Disorder, Asperger's Disorder, Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS), Rett's Disorder, and Childhood Disintegrative Disorder. As of 2013 with the release of the DSM-5, these diagnoses were either combined into Autism Spectrum Disorder/Social Communication Disorder/or in the case of Rett's- a medical condition that requires genetic testing.

- Individuals with ASD can have a range of symptomatic expression from mildly impaired (previously labeled as Asperger's) to severely impaired. Individuals with ASD may need varying degrees of ongoing support (from minimal to substantial) depending on how affected their abilities are in the areas of thinking and learning, social communication, social interaction, and restricted/repetitive behaviors.[3] Some individuals who are mildly impaired may still require substantial support.

Examples of Social and Communication Impairments:

a. Individuals with ASD may have difficulty understanding social situations and may misread social cues from others.

b. Individuals with ASD may have difficulty integrating verbal and non-verbal communication (e.g., speaking, smiling, making eye contact) to regulate social interactions.

c. Individuals with ASD may have difficulty forming developmentally appropriate social relationships.

Examples of Restricted/Repetitive Behaviors:

a. Individuals with ASD may repeat words or phrases (also called scripting or echolalia) which are not contextually appropriate. Individuals may be prone to doing this when experiencing intense emotions (either positive or negative).

b. Individuals with ASD may present with abnormal and repetitive movements which can involve their whole body (e.g., body rocking) or an isolated part (e.g., finger flicking). These are called motor

[3] Centers for Disease Control. (2015). Facts about ASD. Retrieved from http://www.cdc.gov/ncbddd/autism/facts.html

stereotypies and are also more likely to be exhibited when an individual is experiencing extreme emotion (positive or negative).

c. Individuals with ASD may have a strict adherence to routine and familiarity and have challenges with transitions and adjusting to new situations.

d. Individuals with ASD may have intense aversions or attractions to sensory stimuli (e.g., tastes, smells, sounds, sights, textures).

e. Individuals with ASD may have interests in things that are abnormal either in intensity (e.g., interest in child-focus themes as an adolescent) or focus (e.g., unexpected hobby).

- Individuals with ASD may also present with facial tics or have a history of seizures.
  - Individuals with ASD may also have an intellectual disability (approximately 33%(with a range from 25-70%) co-occurrence rate) and a history of seizures (30% co-occurrence rate with those also having an intellectual disability being particularly vulnerable).
- Some individuals with ASD have complex communication needs or are "non-verbal." These individuals may use a device such as an iPad to communicate.
  - 40% of individuals with ASD also have complex communication needs (frequently termed "non-verbal"). These individuals are also more likely to have intellectual disability and 67% do not have effective communication strategies to let others know their needs. This lack of effective communication can be a precipitant factor for aggressive behavior. Individuals who do have communication systems in place often use technology such as an iPad to communicate.

Who Can Diagnose ASD?

- An ASD diagnosis must officially come from a medical provider (psychiatrist, developmental pediatrician, neurologist, nurse practitioner) or a psychologist, preferably those with experience in neurodevelopmental disorders.

How is ASD diagnosed in adults?

- "Some individuals come for first diagnosis in adulthood, perhaps prompted by the diagnosis of autism in a child in the family or a breakdown of relations at work or home. Obtaining detailed developmental history in such cases may be difficult, and it is important to consider self-reported difficulties. Where clinical observation suggests criteria are currently met, autism spectrum disorder may be diagnosed, provided there is no evidence of good social and communication skills in childhood. For example, the report (by parents or another relative) that the individual had ordinary and sustained reciprocal friendships and good nonverbal communication skills throughout childhood would rule out a diagnosis of autism spectrum disorder; however, the absence of developmental information in itself should not do so. Manifestations of the social and communication impairments and restricted/repetitive behaviors that define autism spectrum disorder are clear in the developmental period. In later life, intervention or compensation, as well as current supports, may mask these difficulties in at least some contexts. However, symptoms remain sufficient to cause current impairment in social, occupational, or other important areas of functioning."[2]

- An adult with no prior history must receive an evaluation by a psychologist, psychiatrist, or physician to receive an ASD diagnosis, preferably via a comprehensive biopsychosocial assessment.

Co-Occurring Diagnoses and ASD

ASD is a neurodevelopmental disorder and not a mental illness; however, many individuals with ASD have co-occurring mental health diagnoses or additional developmental disabilities that will further complicate how they participate in criminal proceedings.

- Obtain a psychiatric or psychological evaluation from a professional who is familiar with ASD to identify co-occurring mental health conditions and developmental disabilities.
- Co-occurring anxiety disorders are extremely common for individuals with ASD. Multiple studies have determined that the prevalence rate of co-occurring anxiety disorders in adults with ASD is over 50%. Furthermore, this anxiety frequently takes the form of "intolerance of uncertainty" (not being able to cope with changes in the environment or unexpected social interactions) which can lead to excessive panic or "fight or flight" reactions.
- Depression is also common in individuals with ASD, with the prevalence increasing across the lifespan. Peak onset appears in the adolescent/early adult years with a high risk of recurrence during adulthood.

- Once thought to be rare, suicidal thoughts and attempts are now understood to be more common in people with autism than in the general population in individuals with ASD and can be independent of depression. Acute anxiety states are also a high risk for self-injurious and suicidal thoughts/gestures; this leaves individuals with ASD highly vulnerable to impulsive actions.
- Psychosis is rare in individuals with ASD but is more common than the general population's risk. Psychosis in individuals with ASD is more frequently associated with what are termed "negative" symptoms. These symptoms are reflective of increased social withdraw, loss of skills, and increased difficulty processing information efficiently and correctly. Although rare, individuals with ASD and co-occurring psychosis can also display "positive" symptoms (e.g., hallucinations, delusions). A comprehensive psychological or psychiatric assessment can be helpful in determining whether an individual's seemingly bizarre thoughts are part of their ASD symptomatology or reflective of a co-occurring psychosis.
- Unfortunately, individuals with ASD and other developmental disabilities are at high risk for victimization. For instance, individuals with ASD[4] are seven times more likely to be sexually assaulted than the general population. Over 85% of adolescents with ASD who are capable of self-report describe episodes of bullying during high school. Due to the high likelihood of trauma exposures, consideration for potential Posttraumatic Stress Disorder (PTSD) should be given for individuals with ASD who evidence strong avoidance behaviors and panic symptoms, especially for those who may have communication and/or emotional processing challenges making it difficult for them to describe their experiences.

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[4] Recognizing and Preventing Sexual Abuse. (n.d.). Retrieved from https://www.autismspeaks.org/recognizing-and-preventing-sexual-abuse

- According to the Centers for Disease Control and Prevention (CDC), as of 2016, approximately 33% of individuals with ASD have co-occurring intellectual disability (ID). Rather than being defined by strict IQ scores, the current understanding of ID is described by pervasive intellectual challenges impacting cognitive, social, and adaptive behavior development.[5]
- In a recent study published in the Lancet[6], meta-analyses of 96 studies conducted between 1993-2019, the following prevalence rates were determined:
  - ADHD 28%
  - Anxiety Disorders 20%
  - Sleep/wake Disorders 13%
  - Disruptive, Impulse Control, and Conduct Disorders 12%
  - Depressive Disorders 11%
  - Obsessive-Compulsive Disorder 9%
  - Bipolar Disorder 5%
  - Schizophrenia Spectrum Disorders 4%

Of note, all of these prevalence rates are substantially higher than what is seen in the general population.

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[5] Centers for Disease Control. (2016). Autism and Developmental Disabilities Monitoring (ADDM) Network. Retrieved from http://www.cdc.gov/ncbddd/autism/ addm.html

[6] Lai, M. C., Kassee, C., Besney, R., Bonato, S., Hull, L., Mandy, W., … Ameis, S. H. (2019). Prevalence of co-occurring mental health diagnoses in the autism population: a systematic review and meta-analysis. The Lancet Psychiatry, 6(10), 819–829. https://doi.org/10.1016/S2215-0366(19)30289-5

- The 2011 Pennsylvania Autism Needs Assessment, conducted by ASERT, found that 85% of individuals with ASD responding to the survey reported a co-occurring disorder. The most common co-occurring diagnoses for adults aged 21 and older are:
  - Intellectual Disability (51%)
  - (32%)
  - Anxiety Disorder (33%)
  - ADHD (30%)
  - Obsessive Compulsive Disorder
  - Depression (18%)[7]
- For children under age 21, the most common co-occurring diagnoses are:
  - ADHD (37%)
  - Learning Disability (26%)
  - Developmental Delays (35%)
  - Anxiety Disorder (20%)

[7] Bureau of Autism Services, Pennsylvania Department of Human Services. (2011). Pennsylvania Autism Needs Assessment: A Survey of Individuals and Families Living with Autism: Service Needs. Retrieved from http://www.paautism.org/asert/Needs%20 Assess_ ServiceNeeds

IV. Supports

How to get services

County Based Resources

In Pennsylvania, every county (or county joinder) has a Mental Health/ Intellectual Disability (MH/ID) office. County MH/ID offices are the place for individuals with ASD, mental health diagnoses, and/or intellectual and developmental disabilities (IDD) to enroll in services including: Early Intervention, Waiver Programs, and Intensive Behavioral Health Services.

Early Intervention (EI)

Research has shown that EI services, from birth to age 5, can greatly improve an individual's ASD trajectory over time. EI can lead to significant improvements in social communication, as well as gross motor skills and language. EI services in Pennsylvania are available through Office of Child Development and Early Learning (OCDEL), Pennsylvania Department of Human Services (DHS), and the Pennsylvania Department of Education (PDE).

EI is a free service and support for families who have a child or children 0 – 5 years old with developmental delays. EI services are determined based on an evaluation of a child's needs and may include:

- Service coordination
- Special instruction
- Speech and language therapy
- Physical therapy
- Occupational Therapy
- Vision services
- Social work services
- Psychological services
- Nutrition Services
- Hearing services for children who are deaf or have hearing loss
- Parent training and coaching

EI services may be provided in the home, early childhood education setting, or other settings.

EI services are offered by county (to find a county Mental Health/Intellectual Disability office visit: **www.paautism.org/MHID**). If a parent is concerned about their child's development they can also call the CONNECT Helpline at 1-800-692-7288. For more information about EI services in Pennsylvania, visit: **www.paautism.org/earlychildhood**

Intensive Behavioral Health Services

Intensive Behavioral Health Services (IBHS) (previously known as Behavioral Health Rehabilitation Services (BHRS, or wraparound) support children, youth, and young adults with mental, emotional, or behavioral health needs. IBHS offers a wide array of services that meet the needs of these individuals in their homes, schools, and communities. IBHS has three categories of service::

- Individual services which provide services to one child;
- Applied Behavior Analysis (ABA) which is a specific behavioral approach to services; and
- Group services which are most often provided to multiple children at a specific place. Evidence-based treatment (EBT) can be delivered through individual services, ABA services, and group services.

Office of Developmental Programs (ODP) Waivers

The Office Developmental Programs offers waivers and programs for people with ASD, ID, and IDD (of all ages except Adult Autism and the Adult Community Autism Program (ACAP) which is for individuals 21and

older). This includes the Consolidated Waiver, Person/Family Directed Support Waiver (P/FDS Waiver), the Community Living Waiver, and the Adult Autism Waiver. Waivers are programs that provide services for people who need extra support to live independently in their communities. For more information about waivers visit: **www.paautism.org/waiver**

- **Supports Coordination (SC) or Targeted Services Management (TSM)** SC and TSM are services that people who have Medical Assitance (MA) receive while they are on the waiting list for Office of Developmental Programs (ODP) waivers. The goal is to help individuals find community supports while they are on the waiting list for waiver services.

Waivers

Consolidated Waiver

The Consolidated Waiver is administered by ODP and is available statewide as a 1915(c) Medicaid program which provides home-and community-based services (including: employment services, day habilitation services, and community integration) for individuals with ID and ASD of all ages and individuals with developmental disabilities until age 8.

Person/Family Directed Support Waiver (P/FDS)

P/FDS is administered by ODP and is available statewide as a 1915(c) Medicaid program which provides home- and community-based services. This includes employment services, day habilitation services, and community integration for individuals with ID and ASD of all ages and individuals with developmental disabilities until age 8.

Community Living Waiver

The Community Living Waiver is administered by ODP and is available statewide as a 1915(c) Medicaid program which provides home- and community-based services. This includes employment services, day habilitation services, and community integration for individuals with ID and ASD of all ages and individuals with developmental disabilities until age 8.

Adult Autism Waiver (AAW)

AAW is one of two programs administered by BSASP, PA DHS to meet the needs of individuals with ASD age 21 or older throughout Pennsylvania. AAW is a 1915(c) Medicaid program which provides home- and community-based services including employment services, day habilitation services, and community integration.

Adult Community Autism Program (ACAP)

ACAP is one of two programs administered by BSASP, PA DHS to meet the needs of individuals with ASD age 21 or older. ACAP is a managed care program which provides physical health services as well as home, behavioral, and community-based services. ACAP is available in Chester, Cumberland, Dauphin, and Lancaster counties.

For more information about any of the waivers or programs, visit **www.paautism.org/waiver** or call the ASERT Resource Center **(1-877-231-4244** or **info@paautism.org)**

V. Evidenced-Based Treatments

Applied Behavior Analysis (ABA)

A widely used intervention approach for individuals with ASD uses the principles of learning theory in a systematic way to improve or change specific behaviors. At this time, ABA is one of few evidence-based interventions for specific symptoms of ASD. The term evidence-based refers to interventions that are found to be effective, beneficial, and replicable through extensive research.. Board Certified Behavior Analysts (BCBAs) are individuals who specialize in the planning, development, and implementation of ABA interventions.

Evidence-Based Practices Reference Guide

Established Interventions: Sufficient evidence is available to confidently determine that an intervention produces favorable outcomes for individuals with ASD. That is, these interventions are established as effective.

Emerging Interventions: Although one or more studies suggest that an intervention produces favorable outcomes for individuals with ASD, additional high-quality studies must consistently show this outcome before we can draw firm conclusions about intervention effectiveness.

Unestablished Interventions: There is little or no evidence to allow us to draw firm conclusions about intervention effectiveness with individuals with ASD. Additional research may show the intervention to be effective, ineffective, or harmful.[8]

0- 22 years of age:

- There are 14 established interventions that have been thoroughly researched and have sufficient evidence for us to confidently state that it is effective.
- There are 18 emerging interventions that have some evidence of effectiveness, but not enough for us to be confident that they are t ruly effective.
- There are 13 unestablished interventions for which there is no sound evidence of effectiveness.

Established for children | 0-22 years of age

- Behavioral interventions
- Cognitive behavioral intervention package
- Comprehensive behavioral treatment for young children
- Language training (production)
- Modeling
- Natural teaching strategies
- Parent training
- Peer training package
- Pivotal response training
- Schedules
- Scripting
- Self-management
- Social skills package
- Story-based intervention

Emerging for children | 0- 22 years of age:

- Augmentative and alternative communication devices
- Developmental relationship-based treatment
- Exercise
- Exposure package
- Functional communication Training
- Imitation-based intervention
- Initiation training

- Language training (production & understanding)
- Massage therapy
- Multi-componentpPackage
- Music therapy
- Picture exchange communication system
- Reductive package
- Sign instruction
- Social communication intervention
- Structured yeaching
- Technology-based intervention
- Theory of mind training

Unestablished for children | 0- 22 years of age:

- Animal-assisted therapy
- Auditory integration training
- Concept mapping
- DIR/floor time
- Facilitated communication/rapid prompting
- Gluten-free/casein-free diet
- Movement-based intervention
- SENSE theatre intervention
- Sensory intervention package
- Shock therapy
- Social behavioral learning strategy
- Social cognition intervention
- Social thinking intervention

For adults ages 22 and older:

- There is 1 established intervention that has been thoroughly researched and has sufficient evidence for us to confidently state that it is effective.
- There is 1 emerging intervention that has some evidence of effectiveness, but not enough for us to be confident that it is truly effective.
- There are 4 unestablished interventions for which there is no sound evidence of effectiveness.

Established Interventions for Adults | For adults ages 22 and older:

- Behavioral interventions

Emerging Interventions for Adults:

- Vocational training package

Unestablished Interventions for Adults:

- Cognitive behavioral Intervention package
- Modeling
- Music therapy
- Sensory integration package[8]

Medications

Currently, there are no medications approved by the Food and Drug Administration (FDA) to treat the core symptoms of ASD.

- Risperidone (Risperdal) and aripiprazole (Abilify) are antipsychotic medications that are FDA approved to treat irritability and aggression symptoms associated with ASD.
- It is not uncommon for individuals with ASD to be prescribed other medications to treat co-occurring diagnoses, such as anxiety or depression.

[8] National Autism Center (2015). Findings and Conclusions: National Standards Project, Phase 2. National Autism Center. www.nationalautismcenter.org

VI. Supports for the Courtroom

Stress in the Courtroom

Pretrial diversion is often preferred because the social and sensory aspects of appearing in trial are often overwhelming to individuals with ASD.

What language can a judge use to request a capacity determination?

- Example: "As a determination of capacity to withstand trial the court is requesting any available mental health, medical, educational, and psychosocial evaluations for John Doe."

Courtrooms are new and stressful environments. The resulting sensory and emotional dysregulation may greatly jeopardize how an individual with ASD participates in his/her trial. Individuals with ASD (even those who appear to have mild impairments) may require more pre-trial preparation than other clients.

- Take the individual into an empty court room to identify anything that might upset or confuse him or her.
- Monitor their comfort level and ask about sensory needs.
  - For example: Is it too bright or loud? Do you need to use the restroom?
- Break down what will occur step by step. Provide details about:
  - what to bring
  - how to dress
  - how to address the judge and other people in the courtroom
  - who can be present with him/her during the hearing

- Provide visual supports:
  - social stories or videos about court procedures
  - written lists or picture schedules about expected steps in the hearing
  - model and practice behavior beforehand whenever possible

Competency in the courtroom

ASD does NOT mean someone has an ID, but the two disabilities frequently co-occur. Regardless of IQ, their interpersonal skills may be less developed than other areas of intelligence, and they may have a complex profile of cognitive strengths and weaknesses.

A person should not assume someone with ASD does or does not understand something regardless of their appearance and intelligence in other areas!

Example: Someone who can read and remember an entire law textbook may not be able to flexibly apply the description of their crime from the book to their actions.

- It is important to check that an individual with ASD understands all terms and how they apply to his/her situation. Ask the individual to explain certain terms to check for comprehension, especially if the term is unusual or may be prone to interpretation error.
  - Example: A woman with ASD stated that she understood what “stay within the county” meant when instructed by the judge but later revealed that she thought this was related to her bank account.

- Take time to explain their Miranda Rights in depth. Take extra care to be sure the individual must not agree to anything they do not believe or understand, or say what they think people want to hear in an effort to be "cooperative".
  - Remind the individual regularly that he or she does not have to answer questions they do not fully understand or if they think their answer may make.
  - Do not simply allude to the nature of certain themes, especially those that are not typically covered in polite conversation or have to do with the perspective of others involved; his may be the first time they are learning these details.
  - E.g., Rather than saying "you made the woman feel she was being attacked", explain that "by staring at her and rubbing your genitals, even over your pants, this made her feel emotionally disturbed and frightened and is considered sexual harassment. When you approached her while doing this, the common assumption is that you were attempting to assault, molest, or rape her."
- Use literal language at all times and do not use sarcasm. Even if the person with ASD is able to use sarcasm he/she still may not be able to detect it in others.
- An individual may use certain words, phrases, or figures of speech but not fully understand the implications of the words he or she is using.
  - E.g., One man with ASD repeatedly described himself as "having a short fuse" but when asked what he meant, he revealed he believed it meant he was sensitive to criticism. While it was understandable how he mixed the two, they would have very different implications in criminal proceedings.

- It is also common for an individual with ASD to repeat the last word or phrase he or she heard. If given a choice, he/she may repeat the last word/phrase they just heard which may not be the truth. He/She may need to be asked the question a few times and in different ways to get to the truth.

Communicating non-verbally, expressing emotion, and detecting and reacting to the emotions of others can all be impaired in an individual with ASD. How an individual with ASD appears to be reacting may not represent his/her emotions and thoughts. These deficits have the potential to influence how he/she may appear at the time of the incident, during questioning, and during trial.

- Ability to show and perceive emotions are not always directly correlated. Many individuals with ASD have learned or been coached during treatment to show expected emotional responses, even when these responses are not directly experienced. Individuals may appear able to express emotions as expected, but still face significant challenges recognizing and reacting to emotional and social information from others.
- Having ASD can make it difficult to show empathy interpersonally, yet internal empathy and desire toward prosocial behavior is just as varied among people with ASD as in the general population.
- Individuals with ASD may express one strong emotion exclusively. This can lead to confusion in interactions and make them appear insincere despite their best intentions

Some individuals may:

- make noises sounding like laughter while speaking
- have a lilting sarcastic tone to their speaking voice
- continuously smile independent of their emotional state
- frown intensely or speak in aggressive tome regardless of their emotions or situation

All of these factors can contribute to an individual with ASD falsely appearing callous or insincere.

Contrary to popular belief, people with ASD can lie. However, because they often do not have skills to understand other peoples' perspectives, they may not be particularly adept at lying.

- His/her demeaner may make him/her appear as lying when he/she is being truthful.
- His/her reasons for lying may also be surprising, like believing he/she is saying what others want to hear.
- In preparation for trial it may be helpful to explore perceived lies directly.
  - Example: "When you do not make eye contact and your voice trails off, it makes it look like you are trying to hide something".

“Statute”

On June 28, 2019, the Governor signed into law a new statute entitled “Victims and Witnesses with Intellectual Disabilities or Autism,” 42 Pa.C.S. § 5991-93.

Section 5991 expressly states as it purpose the following: “In order to promote the best interests of residents of this Commonwealth with intellectual disabilities or autism who are material witnesses or victims of crime, the General Assembly declares its intent, in this subchapter, to provide, where necessity is shown, procedures that will protect material witnesses or victims of crime with intellectual disabilities or autism during their involvement with the criminal justice system.”

Section 5992 defines “Autism spectrum disorder” as “Any of the pervasive developmental disorders defined by the most recent edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM), or its successor, including autistic disorder, Asperger’s disorder and pervasive developmental disorder not otherwise specified.”

That section also sets forth nine specific skill areas to use to measure a person’s functional limitations, any two of which would trigger the application of this statute. (i) Communication, (ii) Self-care, (iii) Home living, (iv) Social and interpersonal, (v) Use of community resources, (vi) Self-direction, (vii) Functional academic, (viii) Work, (ix) Health and safety. Section 5992 also “includes an individual, regardless of age, who has an autism spectrum disorder.”

Section 5993 then lays out the procedures to follow in order for a court to determine the unavailability of the witness or victim and the steps to take to ensure the sufficient indicia of reliability. This section is closely patterned after the existing statute that permits out-of-court statements of children under twelve years old and therefore, presumably implicates the same safeguards that have been in place since it was enacted in 1996.

VII. DATA

How frequently does ASD occur in the population?

According the CDC, as of 2018, ASD occurs in 1 out of every 59 children in the United States. In Pennsylvania, through the Pennsylvania Autism Census, ASERT found that the number of Pennsylvanians with ASD receiving publicly funded services was over 55,000 individuals.[9]

Although the incidence of ASD has been steadily increasing with time, experts in the field maintain that most of this increase is a result of improvements in understanding and accurate diagnosis of ASD as opposed to an actual increase in the number of cases of ASD in 2011. For example, individuals who may have been misdiagnosed with childhood schizophrenia are now being correctly diagnosed with ASD.

Does ASD occur more frequently in males or in females?

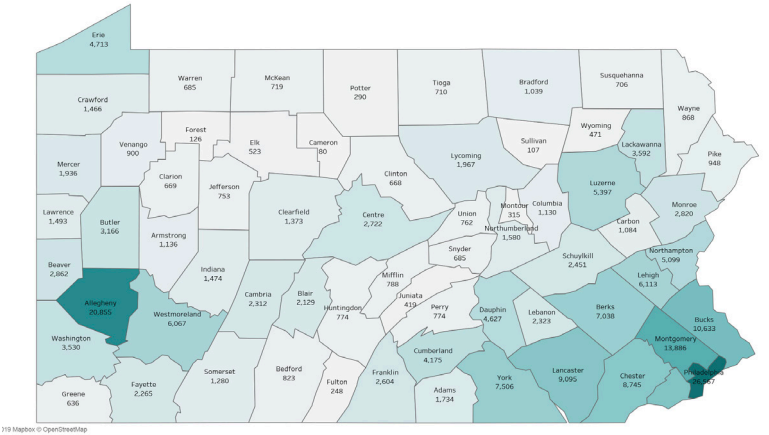
ASD is four times more likely to occur in males as in females according to CDC surveillance data. Research is exploring the reason for the differential prevalence. ASD often presents differently in males and in females. Some experts believe that females are undiagnosed; however, research in this area is still ongoing.

[9] Shea, L. (2014). Pennsylvania Autism Census Update. Study funded by the Bureau of Autism Services, Pennsylvania Department of Human Services. Retrieved from www.paautism.org/census.

PA Needs Assessment Justice Interactions

Prevalence of ASD in PA

Race/Ethnicity



While there is thought to be no difference on incidence of ASD across different race and ethnicities, those who identify as Hispanic have a lower prevalence of ASD compared to other races and ethnicities. Additionally, to be diagnosed later and less often.[10]

[10] Baio J, Wiggins L, Christensen DL, 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(No. SS-6):1–23.

VIII. FAQs

What are the causes of ASD?

Currently, researchers are evaluating the causes of ASD. Experts believe that there is a strong genetic component to developing ASD.

There is no scientific evidence supporting the claim that vaccines cause ASD. The one published study demonstrating a link between vaccines and ASD was debunked and withdrawn from the literature.

Is there a cure for ASD?

There is no cure for ASD. Treatments and supports, including ABA, have been shown to improve outcomes in individuals with ASD, especially when intervention occurs at a young age.

IX. Resources

Autism Services, Education, Resources, & Training (ASERT) Collaborative
www.paautism.org
info@paautism.org
877-231-4244

Association for Science Autism Treatment (ASAT)
www.asatonline.org

Centers for Disease Control (CDC) www.cdc.gov

[1] Huerta, M., & Lord, C. (2012). Diagnostic evaluation of autism spectrum disorders. Pediatric Clinics of North America, 59(1), 103.

[2] American Psychiatric Association. (2013). Diagnostic and statistical manual of mental disorders (5th ed., text revision).

[3] Centers for Disease Control. (2015). Facts about ASD. Retrieved from **www.cdc.gov/ncbddd/autism/facts.html**

[4] Recognizing and Preventing Sexual Abuse. (n.d.). Retrieved from **www.autismspeaks.org/recognizing-and-preventing-sexual-abuse**

[5] Centers for Disease Control. (2016). Autism and Developmental Disabilities Monitoring (ADDM) Network. Retrieved from **www.cdc.gov/ncbddd/autism/ addm.html**

[6] Lai, M. C., Kassee, C., Besney, R., Bonato, S., Hull, L., Mandy, W., … Ameis, S. H. (2019). Prevalence of co-occurring mental health diagnoses in the autism population: a systematic review and meta-analysis. The Lancet Psychiatry, 6(10), 819–829. **https://doi.org/10.1016/S2215-0366(19)30289-5**

[7] Bureau of Autism Services, Pennsylvania Department of Human Services. (2011). Pennsylvania Autism Needs Assessment: A Survey of Individuals and Families Living with Autism: Service Needs. Retrieved from **www.paautism.org/asert/Needs%20 Assess_ServiceNeeds**

[8] National Autism Center (2015). Findings and Conclusions: National Standards Project, Phase 2. National Autism Center. **www.nationalautismcenter.org**

[9] Shea, L. (2014). Pennsylvania Autism Census Update. Study funded by the Bureau of Autism Services, Pennsylvania Department of Human Services. Retrieved from **www.paautism.org/census**.

[10] Baio J, Wiggins L, Christensen DL, 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(No. SS-6):1–23.

X. Acronyms

AAW ..... Adult Autism Waiver

AAC ..... Augmentative and Alternative Communication

ABA ..... Applied Behavior Analysis

ACAP ..... Adult Community Autism Program

AE ..... Administrative Entity

ASD ..... Autism Spectrum Disorder

BSASP ..... Bureau of Supports for Autism and Special Populations

BCBA ..... Board Certified Behavior Analyst

BSC ..... Behavioral Specialist Consultant

CAO ..... County Assistance Office

DHS ..... Department of Human Services

DSP ..... Direct Support Professional

EI ..... Early Intervention

ER ..... Evaluation Report

FBA ..... Functional Behavior Assessment

IBHS ..... Intensive Behavioral Health Services

ID ..... Intellectual Disability

IEP ..... Individualized Education Plan

IFSP ..... Individual Family Service Plan

MA ..... Medical Assistance

MCO ..... Managed Care Organization

OCDEL ..... Office of Child Development and Early Learning

OCYF ..... Office of Children Youth and Families

ODP ..... Office of Developmental Programs

OMHSAS ..... Office of Mental Health and Substance Abuse Services

OT ..... Occupational Therapy

PECS ..... Picture Exchange Communication System

P/FDS ..... Person/Family Directed Support Waiver

PT ..... Physical Therapist

RR ..... Re-evaluation Report

SC ..... Supports Coordinator

SW ..... Social Worker

SLP ..... Speech and Language Pathologist

TSS ..... Therapeutic Support Staff

ASERT Statewide Resource Center

With a database of information, our resource specialists are able to provide up-to-date and accurate information and resources. ASERT is here to help individuals with ASD, families, professionals, and community members learn more about services and resources available and assist them in navigating the service system in Pennsylvania.

Our website also offers information about local, regional and statewide events, professional trainings, community resources, services, current research and other information relevant to the autism community.

ASERT PAautism.org
bringing autism resources together.

Statewide Resource Center
877.231.4244
info@paautism.org

Contacte a ASERT en Español
877.231.4244
ASERTespanol@paautism.org