Developmental and Behavioral Pediatrics Section

Autism Spectrum Disorder: Part 2

WHEC Practice Bulletin and Clinical Management Guidelines for healthcare providers. Educational grant provided by Women's Health and Education Center (WHEC).

Autism Spectrum Disorder: Part 1. Available @ Women's Health and Education Center (WHEC) - Newborn Care - Autism Spectrum Disorder: Part 1
http://www.womenshealthsection.com/content/obsnc/obsnc020.php3
http://www.womenshealthsection.com/content/obsnc/AutismSpectrumDisorder-Part-1.pdf

Autism spectrum disorders (ASD) are a diverse group of conditions. They are characterized by some degree of difficulty with social interaction and communication. Other characteristics are atypical patterns of activities and behaviors, such as difficulty with transition from one activity to another, a focus on details and unusual reactions to sensations. Characteristics of autism may be detected in early childhood, but autism is often not diagnosed until much later. People with autism often have co-occurring conditions, including epilepsy, depression, anxiety and attention deficit hyperactivity disorder (ADHD). The level of intellectual functioning among autistic people varies widely, extending from profound impairment to superior levels. The abilities and needs of autistic people vary and can evolve over time. While some people with autism can live independently, others have severe disabilities and require life-long care and support. Evidence-based psychosocial interventions can improve communication and social skills, with a positive impact on the well-being and quality of life of both autistic people and their caregivers. Care for people with autism needs to be accompanied by actions at community levels for greater accessibility, inclusivity and support.

The purpose of this document is literature review of approaches to intervention, medical, psychological and behavioral management; human rights and Women's Health and Education Center's (WHEC's) efforts and response. WHEC calls on all Member States of the United Nations (UN) and World Health Organization (WHO) to address the current significant gaps in early detection, care, treatment and rehabilitation for mental and neurodevelopmental conditions, which include autism. It also calls for countries to address the social, economic, educational and inclusion needs of people living with mental and neurological disorders, and their families, and to improve surveillance and relevant research.

Human Rights

All people, including people with autism, have the right to the enjoyment of the highest attainable standard of physical and mental health. And yet, autistic people are often subjected to stigma and discrimination, including unjust deprivation of healthcare, education and opportunities to engage and participate in their communities. The 67th World Health Assembly (WHA) adopted a resolution entitled: Comprehensive and coordinated efforts for the

management of autism spectrum disorders,[1] which was supported by more than 60 countries. The resolution urges to collaborate with Member States and partner agencies to strengthen national capacities to address ASD and other developmental disabilities.

People with autism have the same health problems as the general population. However, they may, in addition, have specific healthcare needs related to autism or other co-occurring conditions. They may be more vulnerable to developing chronic non-communicable conditions because of behavioral risk factors such as physical inactivity and poor dietary preferences, and are at greater risk of violence, injury and abuse. Autistic people are more likely to die prematurely.

The Comprehensive Mental Health Action Plan 2013 – 2030;[2] builds upon its predecessor and sets out clear actions for Member States, the World Health Organization (WHO) Secretariat and international, regional and national partners to promote mental health and wellbeing for all, to prevent mental health conditions for those at-risk and to achieve universal coverage for mental health services.

People with autism require accessible health services for general healthcare needs like the rest of the population, including promotive and preventive services and treatment of acute and chronic illnesses. Nevertheless, autistic people have higher rates of unmet healthcare needs compared with the general population. They are also more vulnerable during humanitarian emergencies. A common barrier is created by healthcare providers' inadequate knowledge and understanding of autism.

Approaches to Intervention

Applied Behavior Analysis (ABA)

ABA has been defined as "the process of systematically applying interventions based upon the principles of learning theory to improve socially significant behaviors to a meaningful degree, and to demonstrate that the interventions employed are responsible for the improvement in behavior."[3] ABA programs are typically designed and supervised by professionals certified in behavior analysis. Children younger than 12 years receiving more hours per week of ABA were found to be more likely to achieve the individualized goals identified in their programs. More intense ABA therapy was associated with achieving optimal developmental outcomes. Given the heterogeneity of ASD phenotype, the service needs of children, youth, and adults need to be individualized by using available clinical data.

Developmental Relationship-Focused Interventions

Through interaction with others, children learn to communicate and regulate emotions and establish a foundation for increasingly complex thinking and social interaction. Therefore, developmental models designed to promote social development in children with ASD are focused on the relationship between the child with ASD and his or her caregiver through coaching to help increase responsiveness to the adult (i.e., the interventionist, parent, or caregiver) through imitating, expanding on, or joining into child-initiated play activities. This approach may address care symptoms of ASD, such as joint attention, imitation, and affective social engagement.[4] Developmental models for intervention are focused on teaching adults to

engage in non-directive interactive strategies to foster interaction and development of communication in the context of play. One approach is known as DIRFloortime (The Developmental, Individual Differences, and Relationship-Based model). More research is needed to evaluate efficacy and community use.

Naturalistic Developmental Behavioral Intervention

Naturalistic developmental behavioral interventions (NDBIs) incorporate elements of applied behavior analysis (ABA) and developmental principles, such as emphasis on developmentally based learning targets and foundational social learning skills, with delivery of interventions in the context of naturally occurring social activities within natural environments.[5] They use child-initiated teaching episodes, naturally occurring opportunities for learning, and turn-taking interactions within play routines and implement ABA-based approaches to address measurable goals.[5] The most extensively studied NDBI approach is the ESDM (Early Start Denver Model)[6] which prepares children to learn in naturalistic environments. Early age at entry to therapy and more hours of total therapy are associated with improved outcomes.[6]

Combined Approaches

Common factors in combined developmental behavioral approaches include use of principles of ABA to reinforce skill building; a systematic approach with a manual for training practitioners who would use the intervention in a standard fashion; individualized treatment goals for the child and means of measuring progress; child-initiated teaching, imitation, and modeling; and adult prompting that fades over time to promote independence.[7] It is always accurate to describe the common characteristics of empirically supported interventions and recommend that families seek interventions that incorporate these features.

Parent-Mediated Treatment or Parent Management Training

Increasing evidence reveals that focused interventions delivered by trained parents or other caregivers can be an important part of a therapeutic program.[8] More randomized clinical trials (RCTSs) have been published on parent-mediated therapies than on other pharmacologic interventions. What is sometimes called parent management training is divided into 2 categories: Parent support; and Parent-mediated Interventions. Parent support interventions, which are knowledgeable-focused and provide indirect benefit to the child, include care coordination and psychoeducation. Parent-mediated interventions, which are technique-focused and provide direct benefit to the child, may target core symptoms of ASD or other behaviors or skills and may built on ABA approaches in natural settings.[9]

Training sessions for caregivers may be delivered in the home, clinic, school, or other community settings or remotely by telehealth. A parent training approach may be used to promote compliance with instruction, social communication, and other identified goals of the caregiver, such as reducing maladaptive behaviors. Including parents in the intervention process is critically important. [10]

Educational Interventions

Classroom-Based Models

It is the expectation that school-aged children will be educated in classroom settings with support for a broad effect on the symptoms of ASD and associated deficits. Educating students with ASD

in the least restrictive environment typically requires in individualized program that is modified to meet the Individualized Education Program (IEP) goals set by the family, student, and school team. Some students who do not qualify for an IEP by educational criteria may be supported with accommodations through a Section 504 plan or with classroom-level accommodations. Many students with ASD are educated in inclusive classrooms with supports. Other school-aged children and youth benefit from disorder-specific approaches. Examples of classroom-based approaches include Learning Experiences and Alternative Programs for Preschoolers and their Parents (LEAP) and Treatment and Education of Autistic and Related Communication-Handicapped Children (TEACCH).[11] LEAP blends principles of ABA with special and general education teaching techniques for elementary-aged pupils in inclusive settings for teaching social interaction.

TEACCH class settings are visually organized to promote engagement and learning. The TEACCH approach to skill acquisition includes assessment-based curriculum development and an emphasis on structure, including predictable organization of activities and use of visual schedules, organization of the physical environment to optimize learning and avoid frustration, and adaptation and organization of materials and tasks to promote independence from adult directions or prompts. Instruction is organized in a predictable fashion and uses visual schedules with promotion of independence in activities planned into the instruction. This approach is associated with a small, but measurable, benefit n perceptual, motor, verbal, and cognitive skills in students with ASD, with less measured effect on adaptive and motor function and challenging behaviors.

Education in the Least Restrictive Educational Environment

Pediatricians have an important role in advocating for children and youth with special healthcare needs, including ASD, in the educational setting. Students have a right to a free and appropriate public education. Educational programs for school-aged children with ASD should promote language, academic, adaptive, and social skills development and prepare them for postsecondary education or employment.[12] Most, but not all, students with ASD will have some individualization of their education under the guidance of an IEP determined by the school multidisciplinary team in conjunction with the family. Attention to the needs of the individual student must be central to the IEP process. Social skills of students with ASD may benefit from students being in class and on the playground with peers with typical development.[13] However, spending more than 75% of their time in an inclusive educational setting alone was not sufficient in transition-aged youth to increase rates of college attendance, high school graduation, or functional ratings.

Social Skills Instruction

Social-Skills deficits may present differently depending on language abilities, developmental level, and age. examples of social skills deficits include the following:[14]

1. Challenges with entering, sustaining, and exiting interactions;
2. Difficulty attending to, understanding, and using non-verbal and verbal social cues, such as eye contact, facial expressions, and gestures;
3. Difficulty in understanding the perspective of others;
4. Struggling with negotiation, compromise, and conflict resolution; and
5. Problems with interactive play or participation in leisure activities.

Interventions addressing social skills may increase the child's knowledge of the cues for social behavior and teach strategies for social problem-solving. A popular method uses the social narrative to help a child define the social context of an anticipated or experienced situation, put it in perspective, and then develop statements on how it makes the child feel and on what to do in response to the event and feelings. This coached rehearsal strategy may be included within other programmatic approaches. Implementation may use a cognitive behavioral intervention strategy in which child identifies feelings and thoughts and learns to substitute more socially appropriate alternatives. Families should be counseled to include development of social skills with discrete goals and interventions in the IEP or educational plan as well as to be cognizant of potential opportunities to promote social interaction in the natural environment and in the context of other therapeutic.[15] Implementing IEP goals across the day and generalizing specific skills to promote conversion and non-verbal communication, such as providing eye contact, directing facial expressions, and using appropriate gestures, is important, independent of age, and should involve both the caregivers and professionals.

Other Therapeutic Interventions

Speech and Language Interventions

Delayed language is an early concern for many children who are later diagnosed with ASD. The communication symptoms included in the DSM-5 criteria for ASD reflect core deficits in social communication and interaction, such as failure of back-and-forth communication, deficits in non-verbal communication (such as eye gaze and use of gesture), difficulty adjusting behavior to suit the social context, and restricted and repetitive behaviors leading to perspective vocalization, echolalia, and pre-occupation with restricted topics of interest. Children with ASD should have documentation of specific coexisting speech and language diagnoses so that appropriate intervention might be provided.

Speech-language therapy is the most commonly identified intervention provided for children with ASD.[16] The strategies used by speech-language pathologists to reinforce sound repetition and word use in children with typical development are often initially used with young children with ASD. The strategies include reinforcement of speech sounds and communicative acts, imitation of the sounds the child makes, and exaggerated imitation and slowed tempo. The literature offers the most support for approaches with preverbal children with ASD in which adult prompts are used for communication, prompt fading, and reinforcement of their own attempts at communication. Intervention in naturalistic settings and involvement of caregivers may help reinforce the initiation of communication and functional use of sounds, gestures, and words.

A significant minority (up to 30%) of individuals with ASD ultimately do not require verbal speech. Delayed onset of speech may be complicated by general delays in development (intellectual disabilities) or coexisting speech disorders, such as childhood apraxia of speech. Although using communicative spoken phrases before age 4 years is considered a good prognostic sign for language development in youth with ASD, emergence of phrase speech may occur to at least age 10 years, especially in children with preserved non-verbal skills and evidence of social engagement.

When children do not spontaneously speak, augmentative and alternative communication (AAC) may be introduced. Examples of AAC strategies include sign language, the Picture Exchange Communication System, and speech-generating devices.[17] The use of AAC may help promote social interaction and understanding of the purpose of communication and does not delay onset of speech. Indeed, it may enhance emergence of spoken words by pairing nonverbal and verbal communication.

Motor Therapies
Children with ASD may have low muscle tone or a developmental coordination disorder. Although the ages for sitting and walking do not differ between children with ASD and children with typical development, both fine and gross motor skills may be delayed in preschool-aged children with ASD.[18] Attention to position in space in children with a coexisting diagnosis of attention deficit / hyperactivity disorder (ADHD) may further complicate delays in coordination. Occupational therapy services may be indicated to promote fine motor and adaptive skills, including selfcare, toy use, and handwriting. Almost two-thirds of preschool-aged children with ASD are reported to receive occupational therapy services.[19]

Toe walking is common among children with ASD as well as in other developmental disorders in early childhood. The etiology of toe walking in ASD is unclear, although sensory aversion and habit or preservation have been proposed. Common interventions for toe walking may include passive stretching, orthopedics, and casting.

Sensory Therapies
Sensory symptoms exhibited by young children, such as food selectivity, covering their ears for certain sounds, and visual scrutiny of aspects of objects, may be among the earliest differences families identify in their children's development. Sensory goals may be included in treatment objectives for students with ASD. Adult directed approaches provided through sensory based interventions may be included in the context of motor and behavioral therapies and in educational settings. Commonly used sensory-based interventions, including brushing of the skin, proprioceptive stimulation by using weighted vests, or kinesthetic stimulation (such as swinging or use of specialized seating, such as therapy ball, to modulate level of arousal), are not yet supported in the peer-reviewed literature.[20] As with any other intervention, specific goals for sensory-based therapies should be identified, and outcomes should be monitored so that the utility for any child can be documented.

Medical Management of Co-occurring Conditions

Co-occurring medical and other conditions, such as seizures, sleep disorders, gastrointestinal (GI) disorders, feeding disorders, obesity, catatonia, and others, have a significant effect on the health and quality of life for children and youth with ASD and their families.[21]

Seizures
There is both an increased risk for ASD among children and youth with epilepsy and an increased risk for seizures in those with ASD. The pooled risk of ASD among children with epilepsy is 6.3%, with almost 5 times as many in samples with the highest rate of co-occurring intellectual disabilities. The rate of seizures among people with ASD in community-based

populations has been reported to range from 7% to 23%, with rates as high as 46% reported in clinically ascertained samples.[22] Risk factors for increased likelihood of seizures in people with ASD include intellectual disability (as noted), female sex, and lower gestational age (pre-term delivery). An overnight EEG should be considered when the clinical history suggests seizures and atypical regression. Response to conventional antileptic drug therapy varies greatly, with some reports suggesting an increased risk for treatment-resistant epilepsy in individuals with early onset of seizures and delayed global development.[23]

GI Symptoms

GI Symptoms, such as abdominal pain, constipation, diarrhea, gastroesophageal reflux, and feeding problems, are more commonly reported in children and adolescents with ASD than in those with developmental delay or typical development. Because of language delays and atypical sensory perception or report of pain, individuals with ASD may be less likely to report specific GI discomfort and may present with agitation, sleep disruption, and other behavioral symptoms rather than GI discomfort.[24] Selective eating is common in children with ASD. A limited diet may influence GI symptoms, such as constipation, and alter the intestinal microbiota. The indicated GI workup will depend on the specific symptoms.

Feeding Disorders

Because feeding problems are so common among children with ASD, a dietary history should be obtained at health supervision visits. Physiologic needs for macronutrients and micronutrients are the same for children with ASD as for other children. As with other children in the United States, insufficient intake of fiber, vitamin D, and calcium are common.[25] Rare cases of severe nutritional deficiencies, such as rickets (vitamin D), scurvy (vitamin C), and keratoconus (vitamin A), have been reported in children with ASD with severe food aversions. Consultation with a registered dietitian may be helpful to be able to guide families regarding the nutritional sufficiency of their child's diet. Children with ASD need to be offered new foods multiple times to become familiar with them. Food refusal may stem from discomfort, so consultation with gastroenterologist may be helpful. Gastrostomy-tube placement and non-oral feeding should only be considered after appropriate behavioral intervention has failed.

Obesity

Children and youth with ASD have greater risk for overweight and obesity than those in the general population.[26] Sleep disorders, lack of exercise, energy-dense food and more likely prescribed medications, such as atypical neuroleptics and anticonvulsants, often contribute to excessive weight gain. Programs that address healthy weight for children and youth with typical development may need to be modified for successful use for patients with ASD.[27]

Dental Health

Children with ASD commonly have unmet dental needs. As this other children, anticipatory guidance should include attention to dental hygiene and fluoride use, if appropriate, with a young age. Behavioral strategies may be helpful to prevent the need for dental care under sedation. Even when insurance coverage is available, children with ASD have fewer visits for routine care. There are limited data about the prevalence of caries and gingival disease in children with ASD.[28]

Pica
Pica is reported in up to one-quarter of preschool-aged children with ASD and is documented to persist in individuals with intellectual disabilities.[29] Obstruction and perforation need to be considered in children with pica who have acute abdominal symptoms. Iron deficiency is associated with pica in the general population. Laboratory monitoring of blood lead and iron deficiency in children with pica is suggested in the context of primary care. Behavioral intervention includes reinforcing appropriate behaviors, ensuring adult supervision, and putting into place environmental safeguards for prevention.

Sleep Disorders
Problems with initiating and maintaining sleep are reported for 50% to 80% of children with ASD.[30] Children who are later diagnosed with ASD are reported to have had sleep problems by 30 months of age. Adolescents are more likely to have shorter sleep duration, daytime sleepiness, and delayed sleep onset compared with younger children with ASD, who are more likely to have bedtime resistance, parasomnias, and night-waking. Reasons for the increased frequency of sleep disturbance in children and youth with ASD may include differences in melatonin metabolism, developmental disruption of other neurotransmitter systems critical to sleep, and lack of social expectations, among other explanations. Genetic disorders such as Smith-Magenis syndrome, are associated with both ASD and sleep disruption.[31] Biological reasons for disrupted sleep that are **not** unique to children with ASD may include restless leg syndrome, which may be associated with low iron stores, and coexisting neurologic or behavioral diagnoses, such as epilepsy, anxiety, ADHD, or mood disorders.[32]

No medication is currently approved by the US Food and Drug Administration (FDA) for the treatment of insomnia in children with or without ASD. Any medication selected should be started at a low dose and monitored for adverse effects. Sleep onset may be aided by treatment with melatonin at doses from 1 to 6 mg., and may be maintained with long-acting melatonin. Adverse effects are uncommon but may include nightmares. α-adrenergic agents (e.g., clonidine) and antihistamines (e.g., diphenhydramine) are often prescribed to help with sleep onset or to address night-waking in children, but the literature provides little support for their use. Disordered sleep is associated with challenging daytime behaviors in children with ASD, addressing one may help the other.

Wandering
Accidents, including drowning, are a major cause of morbidity and mortality in children and youth with developmental disabilities, including ASD.[33] Wandering off (also called elopement) places them at risk for injury. Nearly half of children with ASD between the ages of 4 and 10 years had tried to elope, and may persist into adulthood.[34] Consistent, adequate adult supervision is important in all environments: school, home, and community settings. Families may need to consider deadbolts, fencing, and alarm systems for safety as well as personal GPS devices and identification bracelets or other identification. All children with ASD, no matter their level of cognitive skills, are at risk for wandering.

Medications Options for Common Target Symptoms

I. Hyperactivity, Impulsivity, Inattention and Distractibility

Medications: Psychostimulants (methylphenidate, dexmethylphenidate, mixed amphetamine salts, lisdexamfetamine, dextroamphetamine);
Selective norepinephrine reuptake inhibitor (SNRIs) (atomoxetine); α-2 adrenergic agonists (clonidine, guanfacine); Atypical (second generation) antipsychotics (aripiprazole, risperidone.
Adverse Effects: Psychostimulants – appetite suppression and insomnia, also irritability, depressive symptoms, and social withdrawal; it does not appear to worsen repetitive behavior or oppositional behavior. Guanfacine, clonidine: drowsiness, fatigue and irritability; may also include appetite suppression, nausea, sleep disturbance, and decreased blood pressure and heart rate; rebound if not weaned.

II. Irritability and Severe Disruptive Behavior

Atypical (second generation) antipsychotics (aripiprazole, risperidone). Medication most effective if combined with behavioral strategies addressing identified environmental causes for the behavior and developing more appropriate responses for the child. Risperidone and aripiprazole are currently the only medications with FDA-approved labeling specific to irritability in ASD.
Adverse effects: weight gain and dyslipidemia. Monitoring: periodic assessment for extrapyramidal symptoms, measurement of weight, height and BMI (Boday Mass Index); and laboratory monitoring of glucose and lipid levels. Metformin might be a useful treatment for help control weight gain. α-2 adrenergic agonists (clonidine, guanfacine)[35] – small studies documenting beneficial effects on irritability; need larger trials; may have better adverse effect profiles than atypical antipsychotics.
Selective norepinephrine reuptake inhibitor (SSRIs) (fluvoxamine, citalopram) – few studies focused on irritability and/or aggression; some reporting improvement in irritability; insufficient evidence to advise practice.
Anticonvulsant mood stabilizers (valproic acid and divalproex sodium) – small studies suggestive of improvement in irritability; need larger studies; a limited number of placebo-controlled studies either do not support or are inconclusive regarding anticonvulsant medication as a treatment of irritability in patients with ASD. Serotonin-norepinephrine reuptake inhibitor (venlafaxine) – effect size of improvement associated with venlafaxine was small, and irritability was not the primary outcome measured.[35]

III. Repetitive Behavior, Stereotyped Motor Mannerisms, Compulsions and Behavioral Rigidity, Insistence on sameness

Atypical (second generation) antipsychotics (aripiprazole, risperidone) – multiple double-blind placebo-controlled trials documenting improvement in repetitive behavior; short-term treatment
Anticonvulsants (valproic acid and divalproex sodium) – modest improvement has been reported with divalproex sodium treatment. Most antiseizure drugs have potential for sedation, cognitive adverse events. Studies to date have not revealed effectiveness of SSRI medications for repetitive behaviors related to ASD, although they may diminish anxiety.

Adverse effects: include increased appetite, fatigue, drowsiness, dizziness, and drooling; more effective for targets of tantrums, aggression, and self-injurious behavior,

IV. Anxiety, Depression

SSRIs; anxiety relief has been reported in trials of citalopram and buspirone, with fluvoxamine and buspirone, with fluvoxamine revealing some effect in female patients with ASD; documented utility in children and youth without ASD. A-adrenergic (clonidine, guanfacine); hyperactivation is an adverse effect of SSRIs in children and youth with ASD that may result in stopping the medication. The anxiety disorders most amenable to treatment are generalized anxiety disorder, separation anxiety disorder, and social phobias.

Atypical (second generation) antipsychotics[36] if a mood dysregulation disorder is identified, treatment with a mood stabilizer and/or a second-generation antipsychotic is recommended, although an SSRI may be used to treat comorbid anxiety, OCD (obsessive-compulsive disorder), or depression; behavioral activation with hypomanic or manic switches has been reported.

First-line treatment is a program of cognitive behavioral therapy to reduce symptoms. Few studies have examined the specific effects of these symptoms; clinicians may consider use of these agents; although SSRIs, SNRIs, and/or buspirone may be effective for the treatment of anxiety in children with ASD, they have not been rigorously evaluated for this purpose.

Medications to consider include sertraline, fluoxetine, citalopram, or escitalopram for symptoms of anxiety and α-2 agonists (e.g., guanfacine and clonidine and β-blockers such as propranolol), which may be useful for anxiety-related physiologic symptoms and behavioral dysregulation, and a short-acting benzodiazepine, such as lorazepam, could be considered for event related anxiety.

Medication may be helpful to address co-occurring symptoms of disorders. Clinicians should carefully weigh potential risks and benefits before prescribing medication for behavior and use psychotropic medications as part of a comprehensive treatment approach. Psycho-pharmacogenomic testing for genetic variants that increase the likelihood of adverse effects is an emerging area for precision medicine. Prescribers should consider SSRIs, for example, despite limited data at present to guide practice. The limited data on the utility of psycho-pharmacogenomic testing at the time of this publication limits insurance coverage for many patients. Recommendations for testing are expected to rapidly change ongoing research

Support our National Agenda for Basic, Clinical, and Health Services Research and Advocacy about Autism Spectrum Disorder (ASD)

The Women's Health and Education Center (WHEC) supports the current approach taken by the World Health Organization (WHO), American Academy of Pediatrics (AAP), including representative stakeholders in planning a meaningful research agenda. Stakeholders include families and affected individuals, scientists, clinicians, and public health agencies. Our strategic plan identifies these areas for research funding:

1. Early Detection;
2. Underlying Biology;
3. Genetic and environmental risk factors;
4. Treatments and Interventions;
5. Services and Implementation science;
6. Life-span Services and Supports; and
7. Epidemiological surveillance and Infrastructure.

It is important that multiple levels of inquiry be pursued simultaneously to inform evidence-based clinical care. These include the following:[37]

Integrative, Complementary and Alternative Therapies

The National Center for Complementary and Integrative Health maintains a Web site in which current information on novel therapies in popular use for people with ASD is reviewed.[38] Many interventions, although still widely used, remain unproven. Complementary therapies are often attractive to families because they are purported to correct putative biological causes of behavioral symptoms and may be discussed with and optimism about outcome that is often not conveyed with the recommendation for conventional therapies. Complementary, alternative, and integrative therapies used for ASD can be grouped into 3 general areas:[38]

1. Natural products (including herbs, vitamins and minerals, and probiotics);
2. Mind and body practices (including yoga, chiropractic, massage, acupuncture, progressive relaxation, and guided imagery); and
3. Other therapies (including traditional medicine and naturopathy).

Nutritional counselling is recommended if a trial of dietary interventions is elected. Popular dietary supplementation include vitamin D, vitamin B_{12}, vitamin B_6, with magnesium, omega-3 fatty acids, and multivitamin preparations. The literature to date is controversial with respect to vitamin supplementation as a treatment of symptoms of ASD, and at this time, no conclusive evidence exists that people with ASD require different nutrient intake than that recommended in the Dietary Reference Intakes: https://www.ncbi.nlm.nih.gov/books/NBK225472/

Impact of ASD on the Family & Working with Families

The impact of having child with ASD on other family members and on society is considerable. Parents of children with ASD report more stress and increased costs than do parents who do not have a child with ASD. The largest societal costs associated with ASD are special education, residential care and lost days of caregiver work. Best practice includes giving families contact information for a family support group at the time of diagnosis. Clinicians should summarize themselves with local and national resources of support and information. Comorbid conditions, such as intellectual disability and/or psychiatric disorders, add to the impact of ASD on family functioning and access to care. https://mchb.hrsa.gov/programs-impact/autism

It appears that positive parental attitudes and a supportive family setting are associated with better sibling adjustment as well. The pediatrician should monitor the wellbeing and need for behavioral health support of siblings as well as parents. Increasing family awareness and

understanding of the medical home can provide partnership of the parents and primary care provider in planning and coordinating the child's care through a medical home results in fewer unmet needs, including dental needs. Helping children and youth with ASD understand their diagnosis within the context of their development level can help them understand their symptoms and participate in decision-making. Shared decision-making requires clarity of the question to be answered, the options to be understood, and the family context and beliefs to be respected. It is often a process rather than a single conversation.

Transition to Adulthood

Planning for children with ASD to understand and participate in their own healthcare should begin early in adolescence, with adaptation for development abilities. 6 core elements that need to be addressed without disruption are:

1. A transition policy for the practice;
2. Tracking and monitoring transition;
3. Assessing transition readiness for youth and/or family;
4. Actively planning the details of transition,
5. Transfer of care, and
6. Transition completion.

Planning for medical transition for all aspects of healthcare should start around ages 12 to 14 years. educational transition at the school level at age 14 years and should involve the student as much as possible. As a child approaches legal adulthood, the family may need to consider guardianship, either full guardianship in cases in which an adult child cannot make health, financial, or other decisions because of cognitive impairment; limited guardianship in cases in which an individual can participate in decision making; or conservatorship in cases in which the oversight extends only to financial decision-making. Many young adults with ASD will be capable of independent decision-making should be prepared for transition to adulthood like other teenagers.

Puberty and Adolescence Resource by Autism Speaks. Puberty and Adolescence Resource.pdf
It is important to give your child time to process the idea of his or her body changes before puberty actually starts.[39] Boys will typically show signs of puberty around the age of 11 or 12. Girls usually experience changs in their bodies earlier, around the age of 9 or 10.

State Programs, Supports and Laws

State laws related to education, social service, and insurance for individuals with ASD vary significantly. Although the federal government mandates early intervention for children at risk for development delay and a free and appropriate education for students aged 3 to 21 years, who have specific educationally handicapping conditions, the implementation of educational services varies by state and locally. The law states that services need to be appropriate, not necessarily optimal. No legal mandate for adult services exists, although the agencies that provide residential services, service coordination, job training, and adult day services typically are funded through the states.

The healthcare providers should be familiar with the requirements for programs in their state that might lead to a Medicaid waiver, service coordination, respite care and other financial or behavioral supports afforded a family when a child has special needs for eligibility. [40] However, later on, at the time of transition to adulthood, if they experience difficulty with employment and daily-living skills, they may quality for support services.

Areas of Research and Service Needs

More than $1.5 billion of private and public research funding was devoted to ASD between 2008 and 2010. Multiple levels of inquiry be pursued simultaneously to inform evidence-based clinical care; such as, basic and translational science in the areas of genetics and epigenetics, neurobiology, and psychopharmacology to understand typical and atypical brain development and function to develop ASD-specific behavioral and pharmacologic therapies. Clinical trials to test focused interventions based on the underlying biological processes involved with ASD to determine if they are appropriate for community applications. Health services research is essential to provide guidance for comprehensive, accessible, and culturally appropriate medical, educational and behavioral care for children, youth, adults, and families affected by ASD.

Key Facts of Autism[41]

- Autism – also referred to as autism spectrum disorder – constitutes a diverse group of conditions relations related to development of the brain.
- In 2021 about 1 in 127 persons had autism.
- Characteristics may be detected in early childhood, but autism is often not diagnosed until much later.
- The abilities and needs of autistic people vary and can evolve over time. While some people with autism can live independently, others have severe disabilities and require life-long care and support.
- Evidence-based psychosocial interventions can improve communication and social skills, with a positive impact on the well-being and quality of life of both autistic people and their caregivers.
- Care for people with autism needs to be accompanied by actions at community and societal levels for greater accessibility, inclusivity and support.

WHO Training for Caregivers of Children with developmental delays and disabilities
https://www.youtube.com/watch?v=LfOcTVu6pcU&t=56s

Summary

To provide appropriate care to all children and families affected by ASD, health, children, and public health systems need to collaborate and build integrated and adequately funded and staffed systems. The Women's Health and Education Center's (WHEC's) Pediatric Recommendations are:

1. **Early identification and treatment**. Healthcare providers should use screening and surveillance to provide accurate and early identification, cost-effective and timely

diagnosis, prompt implementation of evidence-based interventions, and elimination of disparities to access to care for children with ASD. Delays in diagnosis and treatment must be avoided.

2. **Collaboration of systems of care:** Communities with ASD should be provided evidence-based services to address social, academic, and behavioral needs at home and school; access to adequate pediatric and mental healthcare; respite services; and leisure activities.
3. **Informed Pediatric Providers:** To best serve patients and families affected by ASD, the clinician caring for children and youth with ASD should be familiar with issues related to diagnosis, coexisting medical and behavioral conditions, and the impact of ASD on the family to provide a medical home for these patients. Actively addressing capacity building to care for children and youth with ASD requires initiatives directed at provider education and practice quality improvement and public health, educational, and social programs to support families in their journey from diagnosis to service provision to transition to adult care.
4. **Planning for adolescence and transition to adult systems of care:** communities should build services to promote social skills appropriate for work and post-secondary education, access to appropriate medical and behavioral health services, job skills development, and community leisure opportunities. The medical home provider should support the family and youth in advocating for appropriate post-secondary work or schooling, residential supports, and activities to maintain a healthy lifestyle.

Research into the underlying neurobiology of sensory symptoms and restricted interest and repetitive behaviors to inform development of targeted interventions are needed. Research in basic and translational science in the areas of genetics and epigenetics, neurobiology, and psychopharmacology to understand typical and atypical brain development and function to develop ASD-related disability, is critical to move forward with early diagnosis, effective treatment, and evidence-based interventions at each age.

Suggested Reading

1. World Health Organization (WHO)
   Comprehensive Mental Health Action Plan 2013 - 2030
   https://www.who.int/publications/i/item/9789240031029

2. American Academy of Pediatrics (AAP)
   Autism Identification and Collaborative Care
   https://www.aap.org/Autism-Identification-and-Collaborative-Care

3. American Psychiatric Association (APA)
   Autism Spectrum Disorder
   https://www.psychiatry.org/patients-families/autism

4. **Office of Autism Research Coordination; National Institute of Health**
   The Strategic Plan for Autism Spectrum Disorder Research
   https://iacc.hhs.gov/publications/strategic-plan/2013/strategic_plan_2013.pdf

References

1. World Health Organization, 67th World Health Assembly. A67/17. Comprehensive and coordinated efforts for the management of autism spectrum disorders. Report by Secretariat. Available @ https://apps.who.int/gb/ebwha/pdf_files/WHA67/A67_17-en.pdf Last accessed 3 January 2026
2. World Health Organization (WHO). Comprehensive Mental Health Action Plan 2013 – 2030. Actions for Member States. Available @ https://www.who.int/publications/m/item/mental-health-action-plan-2013-2030-flyer-what-member-states-can-do Last accessed 3 January 2026
3. Leaf JB, Leaf JA, Milne C, et al. An evaluation of a behaviorally based social skills group for individuals diagnosed with autism spectrum disorder. *J Autism Dev Disord* 2017;47(2):143-259
4. Schreibman L, Dawson G, Stahmer AC et al. Naturalistic developmental behavioral interventions: empirically validated treatments for autism spectrum disorders. *J Autism Dev Disord* 2015;45(8):2411-2428
5. Schreibman L, Dawson G, Stahmer AC, et al. Naturalistic developmental behavioral interventions: empirically validated treatments for autism spectrum disorder. *J Autism Dev Disord* 2015;45(8):2411-2428
6. Wong C, Odom SL, Hume KA, et al. Evidence-based practices for children, youth, and young adults with autism spectrum disorder: a comprehensive review. *J Autism Dev Disord.* 2015;45(7):1951-1966
7. Lipkin PH, Macias MM; American Academy of Pediatrics, Council on Children with Disabilities, Section on Developmental and Behavioral Pediatrics; identifying infants and young children with developmental disorders through developmental surveillance and screening. *Pediatrics* 2020;145(1):e20193449
8. Bearss K, Burrell TL, Stewart L, Scahill L. Parent training in autism spectrum disorder: what's in a name? *Clin Child Fam Psychol Rev.* 2015;18(2):170-183
9. Bearss K, Johnson C, Smith T, et al. Effects of parent training vs parent education on behavioral problems in children with autism spectrum disorder: a randomized clinical trial. *JAMA* 2015;313(15):1524-1533
10. Weinbaum L, Bauman ML, Fein D, et al. Early screening of autism spectrum disorders: recommendations for practice and research. *Pediatrics* 2015;136(suppl 1):S41-S59
11. Boyd BA, Hume K, McBee MT, et al. Comparative efficacy of LEEP, TEACCH and non-model-specific special education programs for preschoolers with autism spectrum disorders. *J Autism Dev Disord* 2014;44(2):366-380
12. Lipkin PH, Okamoto J; Council on Children with Disabilities; Council on School Health. The Individuals With Disabilities Education Act (IDEA) for children with special educational needs educational needs. *Pediatrics* 2015;136(6):.e1650
13. Rey-Casserly C, McGuinn L, Lavin A, Committee on Psychological Aspect of Child and Family Health, Section on Developmental and Behavioral Pediatrics. *Pediatrics* 2019;144(4):e20192520
14. Otero TL, Schatz RB, Merrill AC, Bellini S. Social skills for youth with autism spectrum disorders: a follow up. *Child Adolesc Psychiatr Clin N Am* 2015;24(1):99-115
15. Krasny L, Williams BJ, Provencal S, Ozonoff S. Social skills interventions for the autism spectrum: essential ingredients and a model curriculum. *Child Adolesc Clin North Am* 2003;15(1):107-122 https://www.wrightslaw.com/info/iep.index.htm Last accessed on 10 January 2026
16. Anderson DK, Lord C, Risi S, et al. Patterns of growth in verbal abilities among children with autism spectrum disorder. *J Consult Clin Psychol* 2007;75(4):594-604
17. Ganz JB, Mason RA, Goodwyn FD, Boles MB, Heath AK, Davis JL. Interaction of participant characteristics and type of AAC with individuals with ASD: a meta-analysis. *Am J Intellect Dev Disabil* 2014;119(6):516-535
18. Lloyd M, MacDonald M, Lord C. Motor skills of toddlers with autism spectrum disorders. *Autism* 2013;17(2):133-146
19. Bilaver LA, Cushing LS, Cutler AT. Prevalence and correlates of educational intervention utilization among children with autism spectrum disorder. *J Autism Dev Disord* 2016;46(2):561-571
20. Barton EE, Reichow B, Schnitz A, Smith IC, Sherlock D. A systematic review of sensory-based treatments for children with disabilities. *Res Dev Disabil* 2015;37:64-80
21. Bauman ML. Medical comorbidities in autism: challenges to diagnosis and treatment. *Neurotherapeutics* 2010;7(3):320-327
22. Van Eeghen AM, Pulsifer MB, Merker VL, et al. Understanding relationships between autism, intelligence, and epilepsy: a cross-disorder approach. *Dev Med Child Neurol* 2013;55(2):146-153

23. Sansa G, Carlson C, Doyle W, et al. Medically refractory epilepsy in autism. *Epilepsia* 2011;52(6):1071-1075
24. Buie T, Campbell DB, Fuchs GJ III, et al. Evaluation, diagnosis, and treatment of gastrointestinal disorders in individuals with ASDs: a consensus report. *Pediatrics* 2010;125(suppl 1):S1-S18
25. Hyman SL, Stewart PA, Schmidt B, et al. Nutrient intake from food in children with autism. *Pediatrics* 2012;130(suppl 2):S145-S153
26. De Vinck-Baroody O, Shui A, Macklin EA, Hyan SL, Leventhal JM, Weitzman C. Overweight and obesity in a sample of children with autism spectrum disorder. *Acad Pediatr* 2015;15(4):396-404
27. Dawson G, Rogers S, Munson J, Smith M, Winter J, et al. Randomized, Controlled trial of an intervention for toddlers with autism: The Early Start Denver Model. *Pediatrics* 2010;125(1):e17-e23
28. Du RY, Yiu CKY, King NM. Oral health behaviors of preschool children with autism spectrum disorders and their barriers to dental care. *J Autism Dev Disord* 2019;49(2):453-459
29. Fields V. Prevalence of pica in preschool children with and without autism spectrum disorder, study to explore early development – United States 2008 -2016. In: Proceedings from the Epidemic Intelligence Service Conference; April 29 – May 2, 2019; Atlanta, GA
30. Malow BA, Katz T, Reynolds Am, et al. Sleep difficulties and medications in children with autism spectrum disorder: a registry study. *Pediatrics* 2016;137(suppl 2):S98-S104
31. Williams SR, Zies D, Mullegama SV, Grotewiel MS. Smith-Magenis syndrome results in disruption of CLOCK gene transcription and reveals an integral role for RAI1 in the maintenance of circadian rhythmicity. *Am J Hum Genet* 2012;90(6):941-949
32. Malow BA, Adkins KW, Reynolds A, et al. Parent-based sleep education for children with autism spectrum disorders. *J Autism Dev Disord.* 2014;44(1):216-228
33. Guan J, Li G. Injury mortality in individuals with autism. *Am J Public Health* 2017;107(5):791-793
34. Rice CE, Zablotsky b, Avila RM, et al. Reported wandering behavior among children with autism spectrum disorder and/or intellectual disability. *J. Pediatr* 2016;174:232-239.e2
35. Fung LK, Mahanan R, Nozzolillo A, et al. Pharmacologic treatment of severe irritability and problem behaviors in autism: a systematic review and meta-analysis. *Pediatrics* 2016;137 (Suppl 2):S124-S135
36. Vasa RA, Mazurek MO, Mahajan R, et al. Assessment and treatment of anxiety in youth with autism spectrum disorders. *Pediatrics* 2016;137 (suppl 2):S115-S123
37. Hyman SL, Levy SE, Myers SM, Council on Children with Disabilities, Section on Developmental and Behavioral Pediatrics, et al. Executive Summary: Identification, Evaluation, and Management of Children with Autism Spectrum Disorder. *Pediatrics.* 2020;145(1):e20193448
38. National Center for Complementary and Integrative Health. *Autism* 2017 Available @ https://nccih.nih.gov/health/autism Last accessed 2 February 2026
39. Nicolaidis C, Kripke CC, Raymaker D. Primary care for adults on the autism spectrum. *Med Clin North Am* 2014;98(5):1169-1191
40. Velott DL, Agbese E, Mandell D, et al. Medicaid 1915(c) Home- and Community-Based Services waivers for children with autism spectrum disorders. *Autism* 2016;20(4):473-482
41. World Health Organization (WHO). Autism; 17 September 2025. Available @ https://www.who.int/news-room/fact-sheets/detail/autism-spectrum-disorders Last accessed 20 May 2026