

# Resource List: Autism Spectrum Disorder

This list was developed to accompany the educational session, "Autism: From Diagnosis to Transition and Beyond" presented by the Council on Children with Disabilities at the 2016 AAP National Conference & Exhibition

## AAP RESOURCES

**American Academy of Pediatrics** [www.aap.org](http://www.aap.org) Professional medical organization of 66,000 pediatricians dedicated to the physical, mental, and social health and well-being of infants, children, adolescents, and young adults

**HealthyChildren.org** [www.healthychildren.org](http://www.healthychildren.org) AAP parenting website backed by pediatricians. Site includes everything from general child health guidance to information on specific issues and conditions. A sampling of such information:

- [Autism Spectrum Disorder](#)
- [Early Signs of Autism Spectrum Disorders](#)
- [How Pediatricians Screen for Autism](#)
- [How is Autism Diagnosed?](#)
- [If Autism is Suspected, What's Next?](#)
- [Public Health Minute: Early Identification of ASD](#)
- [What are the Early Signs of Autism?](#)
- [When Not to Worry About Autism](#)
- [Words of Support for Parents of a Child with Autism](#)



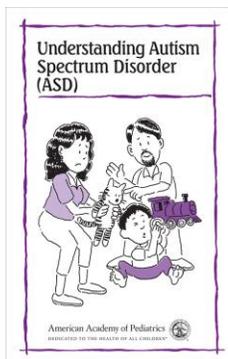
## Autism Initiatives

American Academy of Pediatrics  
DEDICATED TO THE HEALTH OF ALL CHILDREN™

**AAP Autism Initiatives** [www.aap.org/autism](http://www.aap.org/autism) The AAP Council on Children With Disabilities (COCWD) is dedicated to optimal care and development of children with disabilities and to the support of their families within a medical home. The COCWD Autism Subcommittee is the main point of contact for the AAP on issues related to autism.

Find these Titles at [shop.aap.org](http://shop.aap.org)

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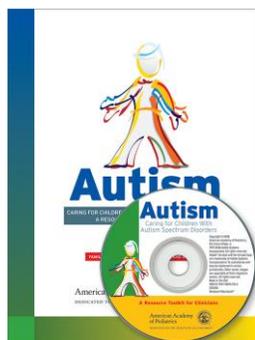
### Understanding Autism Spectrum Disorder (ASD)

This 36-page booklet provides answers to questions parents have about autism including: symptoms, diagnosis, treatment strategies, and transitioning to adulthood. This resource helps identify symptoms so that an intervention program can be started as soon as possible.



### Is Your Toddler Communicating With You?

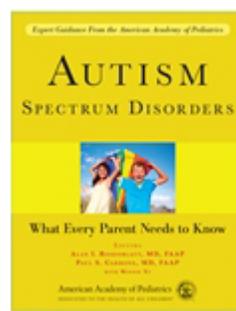
This brochure encourages parents to share any concerns they have about their baby's language development with their pediatrician as early as possible. It also provides early language and social milestones in a checklist format.



### Autism: Caring for Children With Autism Spectrum Disorders: A Resource Toolkit for Clinicians, 2nd Edition

This toolkit, available as a Digital Download or a CD-Rom provides clinical guidance, interactive algorithms, expert ASD screening, surveillance, diagnosis and treatment tools, tracking aids, coding tips, and more. Also

included are dozens of ready-to-print clinical fact sheets and family handouts on popular autism topics, in English and Spanish.



### Autism Spectrum Disorders: What Every Parent Needs To Know

This award-winning book is an invaluable resource for parents of children who have been diagnosed with ASD. Prepared under the editorial direction of 2 pediatricians who are autism experts, this book helps parents understand how ASD is defined, diagnosed, and provides

information on the types of behavioral and developmental therapies. It also helps parents prepare for a smooth transition from adolescence through the teen years and into adulthood.

Please note: This is not an all-inclusive list and listing here does not imply an endorsement by the American Academy of Pediatrics (AAP). The AAP is not responsible for the content of the resources. Information is as current as possible but may change at any time. Updates will be made to this list periodically and can be found at [www.aap.org/autism](http://www.aap.org/autism).

**Advancing Futures for Adults with Autism.** [www.afa-us.org](http://www.afa-us.org). AFAA is a national consortium of organizations working together, led by the vision of individuals with autism and their families, to promote a collaborative spirit and develop both public and private sector support that improve the lives of adults living with autism.

**American Academy of Child & Adolescent Psychiatry: Autism Resource Center.**

[www.aacap.org/aacap/families\\_and\\_youth/resource\\_centers/Autism\\_Resource\\_Center/Home.aspx](http://www.aacap.org/aacap/families_and_youth/resource_centers/Autism_Resource_Center/Home.aspx) Resource Centers provide consumer-friendly information, definitions, FAQs, clinical resources, expert videos, and literature relevant to autism.

**American Occupational Therapy Association.** [www.aota.org/About-Occupational-Therapy/Patients-Clients/ChildrenAndYouth](http://www.aota.org/About-Occupational-Therapy/Patients-Clients/ChildrenAndYouth). Tip sheets on autism and OT.

**American Speech-Language-Hearing Association.** Information for families on autism:

[www.asha.org/public/speech/disorders/Autism](http://www.asha.org/public/speech/disorders/Autism) and for clinicians: [www.asha.org/Practice-Portal/Clinical-Topics/Autism](http://www.asha.org/Practice-Portal/Clinical-Topics/Autism).

**Association for Science in Autism Treatment.** [www.asatonline.org](http://www.asatonline.org). Research summaries of the full array of autism treatments for families and professionals to make informed choices before considering treatment options. Specific resources for journalists, medical providers, and parents of newly diagnosed children are available.

**Association of Maternal and Child Health Program (AMCHP) State Public Health Autism Resource Center**

**(SPHARC).** <http://www.amchp.org/programsandtopics/CYSHCN/projects/spharc>. Web-based resource center intended to provide ongoing technical assistance and facilitate cross-state learning to increase the capacity of states, particularly Title V programs, in developing and implementing systems of care for children and youth with autism spectrum disorders and other developmental disabilities through resource development, technical assistance and peer learning.

**Association of University Centers on Disabilities Interdisciplinary Technical Assistance Center (ITAC) on Autism and Developmental Disabilities.**

[www.aucd.org/itac](http://www.aucd.org/itac). Provides technical assistance to interdisciplinary training programs (ie, the LENDs and DBP programs) to better train professionals to utilize valid and reliable screening tools to diagnose or rule out and provide evidence-based interventions for children with ASD and other developmental disabilities.

**Autism Asperger's Digest** [www.autismdigest.com](http://www.autismdigest.com). Created to meet the needs of teachers, therapists, and family members who face the challenge of autism.

**Autism Navigator®.** <http://autismnavigator.com/> Site has an extensive video glossary with clips of toddlers at 18 to 24 months of age showing behaviors that are hallmarks of ASD, alongside video clips of typically developing toddlers in similar settings. These videos may help parents and health care providers distinguish between sometimes subtle behavioral differences and identify children who may benefit from ASD screening. Site also offers online training to support families and professionals.

**Autism NOW: The National Autism Resource and Information Center** [www.autismnow.org](http://www.autismnow.org). National autism resource and information center is a central point of resources and information for individuals with ASD and other developmental disabilities, their families, and other key stakeholders. (The Arc)

**Autism Science Foundation** [www.autismsciencefoundation.org](http://www.autismsciencefoundation.org). Supports autism research by providing funding and other assistance to scientists and organizations conducting, facilitating, publicizing and disseminating autism research. Also provides information about autism to the general public and serves to increase awareness of ASD and the needs of individuals and families affected by autism. Resources for/on:

Parents and siblings: [www.autismsciencefoundation.org/resources/support-for-parents-and-siblings](http://www.autismsciencefoundation.org/resources/support-for-parents-and-siblings);

Transitions: [www.autismsciencefoundation.org/resources/transitioning-into-adulthood](http://www.autismsciencefoundation.org/resources/transitioning-into-adulthood);

Insurance: [www.autismsciencefoundation.org/resources/autism-and-insurance](http://www.autismsciencefoundation.org/resources/autism-and-insurance).

**Autism Society of America** [www.autism-society.org](http://www.autism-society.org). Increases public awareness about the day-to-day issues about people across the spectrum, advocate for appropriate services for individuals of every age, and provide the latest information regarding treatment, education, research, and advocacy.

**Autism Speaks** [www.autismspeaks.org](http://www.autismspeaks.org). Leading autism science and advocacy organization, dedicated to funding research into the causes, prevention, treatments and a cure for autism, increasing awareness of autism spectrum disorders, and advocating for the needs of individuals with autism and their families. Autism Speaks offers online toolkits for families and adults on topics such as: a new autism diagnosis, therapies, medication, medical procedures, feeding, sleep, ABA, toileting training, puberty, transitioning to adulthood, IEPs, etc. All toolkits are available here: [www.autismspeaks.org/family-services/tool-kits](http://www.autismspeaks.org/family-services/tool-kits)

**Autism Spectrum News** [www.mhnews-autism.org](http://www.mhnews-autism.org). Publication that provides news, information, and resources about scientific research, evidence-based clinical treatments, and family issues

**Autism Wandering Awareness Alerts Response and Education (AWAARE) Collaboration.**

<http://awaare.nationalautismassociation.org/about/>. Information and tools designed to address autism-related wandering.

**Autistic Self Advocacy Network.** <http://autisticadvocacy.org> ASAN is run by and for people with autism. It was created to provide support and services to individuals on the autism spectrum while working to educate communities about autism.

**Birth to 5: Watch me Thrive** [www.acf.hhs.gov/ecd/child-health-development/watch-me-thrive](http://www.acf.hhs.gov/ecd/child-health-development/watch-me-thrive). A federal effort to encourage healthy child development, universal developmental and behavioral screening for children, and support for the families and providers who care for them.

**Center for Parent Information and Resources (CPIR)/OSEP.** [www.parentcenterhub.org/find-your-center/](http://www.parentcenterhub.org/find-your-center/) Families with a child who has a disability often need information about the disability of their child, about early intervention (for babies and toddlers), school services (for school-aged children), therapy, local policies, transportation, and much more. Every State has at least one Parent Training and Information Center (PTI). Many states also have a Community Parent Resource Center (CPRC), which offers the same type of support and training to parents of children with disabilities.

**Centers for Disease Control and Prevention** [www.cdc.gov/ncbddd/autism](http://www.cdc.gov/ncbddd/autism). CDC is committed to continuing to provide essential data on ASD, search for factors that put children at risk for ASD and possible causes, and develop resources that help identify children with ASD as early as possible.

**Autism Case Training (ACT).** [www.cdc.gov/ncbddd/actearly/autism/case-modules/](http://www.cdc.gov/ncbddd/actearly/autism/case-modules/). An AAP-endorsed curriculum designed to educate future pediatricians on identifying, diagnosing, and managing ASDs through case-based

scenarios. Based on the curriculum, the Web-based Continuing Education course includes 3 modules, which can be taken separately or together, are based on real-life scenarios and include up-to-date information, illustrative videos, and pertinent references and resources. Free continuing education credits (CME, CNE, and CEU) are available for each of the modules.

**Learn the Signs. Act Early.** [www.cdc.gov/ncbddd/actearly/](http://www.cdc.gov/ncbddd/actearly/). The CDC early identification awareness campaign to educate parents about childhood development, including early warning signs of autism and other developmental disorders. The earlier a child with a developmental delay receives appropriate assessment and intervention, the better the developmental outcome.:

**Find an Early Intervention program:** [www.cdc.gov/ncbddd/actearly/parents/states.html](http://www.cdc.gov/ncbddd/actearly/parents/states.html)

**ClinicalTrials.gov.** [www.clinicaltrials.gov/](http://www.clinicaltrials.gov/) A registry and results database of publicly and privately supported clinical studies of human participants conducted around the world.

**Data Resource Center for Child & Adolescent Health: Autism Portal.** [www.childhealthdata.org/browse/asd](http://www.childhealthdata.org/browse/asd). Portal provides the autism community with access to data and resources to support data-driven advocacy and policy. Also provides easy access to data on the health and wellbeing of children and families with ASD from several national surveys.

**DIR® / DIRFloortime®** [www.icdl.com](http://www.icdl.com). Among its objectives, the Developmental, Individual Difference, Relationship-based (DIR)/Floortime model includes building healthy foundations for social, emotional, and intellectual capacities rather than focusing on skills and isolated behaviors.

**Early Childhood Technical Assistance Center (ECTA Center).** <http://ectacenter.org/families.asp>. To help families understand their rights under the Individuals with Disabilities Education Act (IDEA), connect with other families, and find high-quality resources related to caring for infants, toddlers and young children with disabilities.

**Easterseals** [www.easterseals.com](http://www.easterseals.com). Provides services for individuals with autism, developmental disabilities, physical disabilities, and other special needs as well as their families. [www.easterseals.com/our-programs/autism-services/](http://www.easterseals.com/our-programs/autism-services/)

**Family-to-Family Health Information Centers (F2F HICs)** [www.fv-ncfpp.org/f2fhic/about\\_f2fhic/](http://www.fv-ncfpp.org/f2fhic/about_f2fhic/) Family-staffed organizations that assist families of CYSHCN and the professionals who serve them. F2F HICs provide support, information, resources, and training around health issues. Find an F2F HIC in your state: [www.fv-ncfpp.org/f2fhic/find-a-f2f-hic/](http://www.fv-ncfpp.org/f2fhic/find-a-f2f-hic/).

**Family Voices** [www.familyvoices.org](http://www.familyvoices.org). A national nonprofit, family-led organization promoting quality healthcare for all children and youth, particularly those with special health care needs.

**First Words® Project.** <http://firstwordsproject.com/> Site highlights 16 common gestures most children learn to use by age 16 months. Also features video clips with examples of toddlers reaching developmental milestones in related areas, including play, emotional regulation, social interaction, and self-directed learning. The website may be helpful both for families with typically developing children and children with ASD or developmental delays.

**Got Transition/Center for Health Care Transition Improvement** [www.gottransition.org](http://www.gottransition.org). National resource that supports optimal transitions from pediatric to adult models of health care for youth with and without special health care needs

**Grandparent Autism Network.** [www.ganinfo.org](http://www.ganinfo.org) Networking and information site for grandparents of children and youth with autism.

**Health Care Transitions Research Network (HCT-RN) for Youth and Young Adults with Autism Spectrum Disorders** [www.autismtransition.net](http://www.autismtransition.net). Research network aimed to address the health, family, and social needs of adolescent and young adults on the autism spectrum.

**Human Genetics Initiative.** [www.nimhgenetics.org/available\\_data/autism/](http://www.nimhgenetics.org/available_data/autism/). National resource of clinical data and bio-materials collected from people with autism and other mental disorders. (NIMH)

**Interactive Autism Network** [www.iancommunity.org](http://www.iancommunity.org). Online project that brings together people affected by ASDs and researchers; goal is to facilitate research that will lead to advancements in understanding and treating ASDs

**Interagency Autism Coordinating Committee.** <https://iacc.hhs.gov/> IACC coordinates all efforts within the Department of Health and Human Services (HHS) concerning autism spectrum disorder (ASD). Through its inclusion of both Federal and public members, the IACC helps to ensure that a wide range of ideas and perspectives are represented and discussed in a public forum.

**International Society for Autism Research.** [www.autism-insar.org/](http://www.autism-insar.org/) Scientific and professional organization devoted to promoting the highest quality autism research in order to improve the lives of individuals affected by ASD. The Society holds an annual scientific meeting - the International Meeting for Autism Research (IMFAR).

**M-CHAT** (Modified Checklist for Autism in Toddlers). [www.mchatscreen.com](http://www.mchatscreen.com) Download the M-CHAT, instructions and permissions for use, scoring instructions, and follow-up interview by clicking on the links below. The follow-up interview is designed to reduce the false positive rate (meaning children who fail the M-CHAT but are not likely to have an ASD).

**MedlinePlus.** <https://medlineplus.gov/autismspectrumdisorder.html>. Service of the NIH/National Library of Medicine.

**National Association of Special Education Teachers** [www.naset.org](http://www.naset.org). Dedicated to rendering all possible support and assistance to those preparing for or teaching in the field of special education. NASET was founded to promote the profession of special education teachers and to provide a national forum for their ideas. ASD information: [www.naset.org/2561.0.html](http://www.naset.org/2561.0.html)

**National Autism Indicators Report: Transition into Young Adulthood.** Part of a publication series produced by the AJ Drexel Autism Institute's Life Course Outcomes Research Program. <http://drexel.edu/autisminstitute/research-projects/research/ResearchPrograminLifeCourseOutcomes/IndicatorsReport/>. Report focuses on the transition into young adulthood and presents evidence about a wide range of experiences and outcomes of young adults on the autism spectrum between high school- early 20s. This report is responsive to the call in the Autism CARES Act of 2014 for more research on transition.

**National Center of Medical Home Initiatives for Children with Special Needs (NCMHI).** [www.medicalhomeinfo.org](http://www.medicalhomeinfo.org) The NCMHI works with federal agencies to ensure that children with special needs have access to a medical home. Site has resources, information, and tools on providing medical homes for children and youth with special health care needs.

**National Database for Autism Research.** [www.ndar.nih.gov/](http://www.ndar.nih.gov/) NDAR is a research data repository that aims to accelerate progress in ASD research through data sharing, data harmonization, and the reporting of research results. NDAR also serves as a scientific community platform and portal to multiple other research repositories, allowing for aggregation and secondary analysis of data. (NIH)

**National Institute of Environmental Health Sciences.** [www.niehs.nih.gov/health/topics/conditions/autism](http://www.niehs.nih.gov/health/topics/conditions/autism) NIEHS works to understand how the environment affects health. NIEHS and the Environmental Protection Agency (EPA) fund children's environmental health research centers to study possible links between the environment and children's health.

**National Professional Development Center on Autism Spectrum Disorder.** [www.autismpdc.fpg.unc.edu](http://www.autismpdc.fpg.unc.edu) Develops free professional resources for teachers, therapists, and technical assistance providers who work with individuals with ASD. Resources include detailed information on how to plan, implement, and monitor specific evidence-based practices.

**Organization for Autism Research** [www.researchautism.org/resources/reading/index.asp](http://www.researchautism.org/resources/reading/index.asp). Focuses on applied research and how it provides tangible and practical benefits to people with autism and their families. Online information includes:

- [A Guide to Safety](#)
- [A Parent's Guide to Research](#) (Spanish and English)
- [An Educator's Guide to Autism](#) (Spanish and English)
- [An Educator's Guide to Asperger Syndrome](#) (Spanish and English)
- [A Guide for Transition to Adulthood](#) (Spanish and English)
  - [Understanding Autism: An Employer's Guide](#)
- [A Parent's Guide to Assessment](#)
- [A Guide for Military Families](#)
- [Navigating the Special Education System](#)

**Parent to Parent USA** [www.p2pusa.org](http://www.p2pusa.org). Offers parent to parent support for families with children who have a special health care need, disability, or mental health issue. Through a one to one "match" experienced support parents provide emotional support to families and assist them in finding information and resources. Parent to Parent programs are committed to listening and learning from families and developing an array of services and supports in response to family identified needs. Find a P2P program in your state: [www.p2pusa.org/p2pusa/SitePages/p2p-support.aspx](http://www.p2pusa.org/p2pusa/SitePages/p2p-support.aspx)

**SCERTS Model** [www.scerts.com](http://www.scerts.com). Focuses on children with challenges in social communication and emotional regulation. This guide helps parents find, understand, and evaluate autism research studies.

**Sibling Support Project** [www.siblingsupport.org](http://www.siblingsupport.org). National program dedicated to the life-long and ever-changing concerns of millions of brothers and sisters of people with special health, developmental, and mental health concerns.

**Simons Foundation Autism Research Initiative** [www.sfari.org](http://www.sfari.org). Mission is to improve the understanding, diagnosis and treatment of autism spectrum disorders by funding innovative research of the highest quality and relevance.

**Social Security** [www.ssa.gov/disability](http://www.ssa.gov/disability). Social Security and Supplemental Security Income disability programs are the largest of several Federal programs that provide assistance to people with disabilities. 2016 edition of "Benefits for Children with Disabilities" is now available: [www.ssa.gov/pubs/EN-05-10026.pdf](http://www.ssa.gov/pubs/EN-05-10026.pdf)

**Special Needs Alliance** [www.specialneedsalliance.com](http://www.specialneedsalliance.com). National not-for-profit organization of attorneys dedicated to the practice of disability and public benefits law; connects individuals with disabilities, their families, and their advisors with nearby attorneys who focus their practices in the disability law arena

**Special Olympics** [www.specialolympics.org](http://www.specialolympics.org). Through the power of sports, people with intellectual disabilities discover new strengths and abilities, skills and success.

**TEACCH Autism Program at the University of North Carolina School of Medicine** [www.teacch.com](http://www.teacch.com). Evidence-based program that uses structured teaching to work with people who have ASDs in building life skills

**Technical Assistance Center on Social Emotional Intervention for Young Children**

[www.challengingbehavior.fmhi.usf.edu/index.htm](http://www.challengingbehavior.fmhi.usf.edu/index.htm) takes the research that shows which practices improve the social-emotional outcomes for young children with, or at risk for, delays or disabilities and creates products and resources to help decision makers, caregivers, and service providers apply these best practices in the work they do. (DOE/OSEP)

**Zero to Three** [www.zerotothree.org](http://www.zerotothree.org). Provides professionals working with very young children and their families an extensive collection of resources aimed at supporting the work of professionals in a variety of early childhood settings.