

Talking with Parents about Autism Spectrum Disorders

Web-based Resources on Autism Spectrum Disorders For Families of Young Children

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National-International

American Academy of Pediatrics Resources for families and professionals on children's developmental disorders, including autism spectrum disorders. Includes AAP Policy papers on *Identification and Evaluation of Children with ASD* and *Management of Children with ASD* as well as *Sound Advice on Autism*, a series of recorded interviews with developmental pediatricians, autism researchers and parents addressing common questions about autism.

<http://www.aap.org/healthtopics/autism.cfm>

Association for Behavior Analysis (ABA) International The professional organization of behavior analysts. Behavior analysis is the scientific study of behavior. This is the portal to access the special interest group for autism. <http://www.autismsig.org>

Autism Speaks Dedicated to funding global biomedical research into the causes, prevention, treatments, and cure for autism and to raising public awareness about autism and its effects on individuals, families, and society. Includes First 100 Days Kit, Autism Video Glossary, Family Services Resource Guide. <http://www.autismspeaks.org/goals.php>

Autism Society of America "The voice of the autism community" for individuals with autism, parents, family members or friends, professionals or other interested advocates. Services include annual conference, publications, research support, advocacy, and local chapters across the nation. Also *Autism 101*: A free online course introduction to autism spectrum disorder. www.autism-society.org or in Spanish <http://www.autismsociety.org/site/PageServer?pagename=autismo>

Centers for Disease Control and Prevention Autism Information Center. Read about autism spectrum disorders, as well as CDC research projects at the federal, state, and local levels. Find the most current information regarding the prevalence of autism or the association between vaccines and autism. Also interactive tools for parents on detection and community awareness materials (Know the Signs/Act Early campaign). <http://www.cdc.gov/ncbddd/autism>

Center on the Social and Emotional Foundations for Early Learning Develops and disseminates evidence-based, user-friendly information to

help early childhood educators meet the needs of the growing number of children with challenging behaviors and mental health challenges in child care and Head Start programs. Practical resources for classroom settings and staff development training modules (some in Spanish)
<http://csefel.uiuc.edu/whatworks.html>

Educating Children with Autism. National Academy Press, National Academy of Sciences (2001) At the request of the U.S. Office of Special Education Programs a group of researchers evaluated the scientific evidence regarding intervention for young children with autism to come up with specific recommendations for effective educational services.
http://newton.nap.edu/execsumm_pdf/10017.pdf

Interactive Collaborative Autism Network (ICAN) Free online instructional modules for anyone who lives with, teaches, or otherwise supports children and youth with autism spectrum disorders (ASD), including parents, teachers, and individuals with ASD.
www.autismnetwork.org

National Autism Center (NAC) National Standards Project (NSP)
The NAC is a nonprofit organization that sponsored the recently completed National Standards Project, an effort to use scientific merit to identify evidence-based guidelines for treatments of individuals with ASD younger than 22 years of age. The focus of the project was limited to interventions that can reasonably be implemented with integrity in most school or behavioral treatment programs (excluding biomedical literature for ASD). A panel of multidisciplinary autism researchers applied a rigorous scoring system to evaluate the quality and usefulness of interventions for individuals with ASD described in nearly 1,000 studies. In September 2009, the NSP released a 160-page report classifying ASD treatments as established, emerging, or unestablished. A 2-page summary, summary of findings, or full report can be downloaded from the website, along with subsequent publications including Evidence-Based Practice and Autism in the Schools (2009) and Autism Manual for Educators (2010). <http://www.nationalautismcenter.org/>

NECTAC Clearinghouse on Early Intervention & Early Childhood Special Education The NECTAC web page on autism spectrum disorders has resources on early identification, prevalence, elements of effective practices, appropriate services, family support, federal resources and low-cost or no-cost NECTAC publications.
<http://www.nectac.org/topics/autism/autism.asp>

National Information Center for Children and Youth with Disabilities (NICHCY) This site is part of a "suite" of pages on disorders along the

autism spectrum.

<http://www.nichcy.org/Disabilities/Specific/Pages/autism.aspx>

National Institute of Child Health and Development The goal of this site is to provide easy access to the most current information about NICHD research projects, publications, news releases, and other activities related to autism and similar disorders. The NICHD is one of several institutes doing research into various aspects of autism, including its causes, prevalence, and treatment.

<http://www.nichd.nih.gov/autism/>

National Professional Development Center (NPDC) on ASD Based on published criteria of efficacy established through peer-reviewed research, the NPDC has to date confirmed the evidence base for 24 interventions for individuals with ASD. Online instructional modules will be developed for each of the following strategies (in alphabetical order): Computer-aided instruction; Differential reinforcement; Discrete trial training; Extinction; Functional behavior assessment; Functional communication training; Naturalistic interventions; Parent-implemented interventions; Peer-mediated instruction/intervention; Picture Exchange Communication System; Pivotal response training; Positive behavioral supports; Prompting; Reinforcement; Response interruption/redirection; Self-management; Social skills training groups; Stimulus control/ Environmental modification; Structured work systems; Task analysis; Time delay; Video modeling; Visual supports; VOCA/Speech generating devices. The center is partnering with the **Ohio Center for Autism and Low Incidence (OCALI)** in creating Autism Internet Modules that can be accessed world-wide. Modules completed to date are available at

<http://www.autisminternetmodules.org/>

Sibling Support Project Based on belief that all disabilities, illness, and mental health issues affect the lives of all family members. Mission is to increase peer support and information for brothers and sisters of people with special needs and to increase parents' and providers' understanding of sibling issues through workshops, websites, and written materials. <http://www.siblingsupport.org/>

Technical Assistance Center on Social Emotional Intervention (TACSEI) Sponsored by the Office of Special Education Programs, this grant takes the research that shows which practices improve social-emotional outcomes for young children with, or at risk for, developmental delays or disabilities and creates free products and resources to help decision makers, caregivers, and services providers apply these best practices in the work they do every day.

<http://www.challengingbehavior.org/>

Treatment and Education of Autistic and other related Communication Handicapped Children (TEACCH) Funded since 1964, this research based approach centers around understanding autism, adopting appropriate adaptations, and a broadly-based intervention strategy building on the skills and interests of the individual. Sponsor of *The Journal of Autism and Developmental Disorders* and other publications. <http://www.teacch.com/>

WrightsLaw Parents, educators, advocates, and attorneys will find information about special education law, education law, and advocacy for children with disabilities, including autism. www.wrightsLaw.com

Kansas

Birth to 3 Years

Kansas Infant-Toddler Services is a comprehensive, statewide system of community-based, family-centered early intervention services for young children (birth through age 2) with disabilities and their families. The services are provided through the implementation of Part C of the Individuals with Disabilities Education Act (IDEA), US Department of Education, Office of Special Education Programs. Information about this program can be accessed at <http://www.kdheks.gov/its/> For a brief overview of Part C/Infant Toddler Services, also known as *tiny k* services, go to http://www.kdheks.gov/its/download/Part_C_and_Autism.pdf

3 to 5 Years

Early Childhood Special Education

Comprehensive special education services for children 3 to 5 years of age are provided through the Kansas State Department of Education (KSDE). The KSDE Guide to Special Education for parents (English/Spanish) can be downloaded at this site, along with other technical information, including the Kansas Special Education Process Handbook <http://www.kansped.org/ksde/resources/techassist.html>

Birth to 5 Years

The Beach Center of the University of Kansas has launched a Community of Practice to share evidence, values, and wisdom among families, practitioners, researchers, and policy makers about supports for families of young children with disabilities (including parent-to-parent supports). <http://www.beachcenter.org/>

Easter Seals Capper Foundation

The mission of Easter Seals Capper Foundation is to enhance the independence of people with disabilities, primarily children. Services include early intervention, pediatric therapies (physical, occupational and speech-language therapy), therapeutic recreation, Kidlink preschool & childcare, augmentative communication and professional and family training. Click on *Autism Spectrum Disorders Services* to view the **Autism Resource Directory** with national, state, and local information for families. <http://capper.easterseals.com>

Families Together, Inc is a statewide non-profit organization assisting Kansas families which include sons and/or daughters who have any form of disability. In addition to disability specific information on autism spectrum disorders

<http://www.familiestogetherinc.org/developmentaldisabilities2.html>

you will find links to other state and national resources, information about Families Together conferences, newsletters, and other helpful materials.

<http://www.familiestogetherinc.org>

Or, in Spanish:

http://www.familiestogetherinc.org/_private/espanol/index.html

Kansas Early Learning Document (Guidelines and Standards)

Guidance from multiple state, local, and national sources was sought in the process of developing the Kansas Early Learning Document (KELD). Resources from NAEYC, NAECS/SDE, other states, and local school districts as well as Kansas resources such as the School Readiness Framework, the Kansas Quality Standards, the Core Competencies, and the Teacher Education Licensure standards were used to develop a document that is firmly grounded in appropriate early childhood beliefs, values, and educational practices. The Kansas Early Learning document has been developed for use by childcare providers, early childhood teachers, administrators, families and others who provide care to young children. The overall purpose of this document is to provide a general overview of the skills, knowledge, and abilities young children have and can learn with the help of caring and knowledgeable adults that lead them toward success in a Kindergarten setting. Each section of the document presents information that can be used by adults to create the opportunities and learning experiences ***all young children need*** in order to grow, develop, and learn.

<http://www.kskits.org/publications/KSEarlyLngGuide.shtml>

Kansas Inservice Training System (KITS) is a program of the University of Kansas Life Span Institute at Parsons and is supported through grants from the Kansas State Department of Education-Student Support Services and the Kansas Department of Health and Environment-Infant/Toddler Services. The KITS project is designed to provide a training and resource system for early intervention networks and early childhood special education program staff through collaborative training and technical assistance activities on a comprehensive statewide basis. Additionally, parents and staff of agencies collaborating with these early intervention networks and preschool programs can be involved in activities associated with the project. From the website, professionals and family members can sign up for training events, download free technical assistance packets on a wide variety of topics, find links to state and national resources, sign up for one of the list services, or locate and request materials from the resource center *at no cost*. <http://www.kskits.org> or 1-800-362-0390 Ext. 1651

Kansas Institute for Positive Behavior Support (KIPBS), in collaboration with the Kansas Department of Social and Rehabilitation Services, provides statewide training on positive behavior support and person centered planning. This training allows professionals in the fields of developmental disabilities, mental health, and child welfare to bill Medicaid for these services. To find a KIPBS trained facilitator for a Medicaid eligible child, go to the state map: http://www.kipbs.org/new_kipbs/familyInfo/map.html

Kansas Instructional Support Network (KISN) is a part of the Kansas State Department of Education's (KSDE) Kansas Statewide Technical Assistance Resource System (KSTARS). The KISN Project aims to assist Kansas school districts in building local capacity to serve students with diverse learning needs through professional development and technical assistance. This mission is carried out through the creation of networks of individuals (i.e., mini-teams) with high levels of expertise in serving children with intense cognitive, communicative, and/or behavioral concerns; the development of Communities of Practice (CoP); and the identification of local resources. More recently, in collaboration with Families Together, KITS, and the Kansas Department of Health and Environment, supports for Infant-Toddler Networks have been developed. On the website, professionals and families can find more information about KISN's services, along with a link to the free resource lending library. www.kansasasd.com

Kansas Social and Rehabilitation Services (SRS) Autism Services

Home page with links to information on autism services available through Kansas Community Developmental Disability Organizations (CDDOs) and Community Mental Health Centers (CMHCs), as well as the Kansas Early Autism Waiver.

<http://www.srs.ks.gov/services/Pages/Autism.aspx>

Make a Difference Information Network at 1-800-332-6262 is the Kansas information hotline for questions related to services for infants, toddlers, and preschoolers with special needs and their families. Now available on line: <http://www.makeadifferenceks.org/>

University of Kansas Center for Child Health and Development (CCHD) diagnoses and develops treatment recommendations for children with developmental disabilities. The teams provide assistance to families, teachers, doctors and others who work with them. Professionals, along with the family, develop a thorough understanding of the child's strengths and needs. Many children and youth seen at the CCHD present developmental and/or behavioral challenges that are often puzzling to families, physicians, or teachers. The goal is to accurately diagnose the problem, understand the reasons and recommend the most effective treatments. Call 913-588-5900 to talk with their Intake Coordinator and/or Social Worker to determine which clinic is the most appropriate for a child. <http://www.kumc.edu/cchd>

The Kansas Center for Autism Research & Training (K-CART) at the University of Kansas, established in 2008 with private and public funds, is a new multidisciplinary center that promotes research and training on the causes, nature and management of autism spectrum disorders (ASD). Committed to the highest standards of scientific rigor, K-CART will generate new scientific discoveries about ASD, disseminate research-based practices by training professionals, practitioners and families who serve children and adults with autism, and provide clinical services through the Center for Child Health and Development (CCHD) at the University of Kansas Medical Center. For information about upcoming training or to download handouts from the 2009 Autism Across the Life Span Conference go to <http://kcart.ku.edu>

