

Identifying Autism in Young Children

A Collection of Recommended Resources from Autism CARES Grantees



Preface

In 2006, Congress passed the “Combating Autism Act” (PL 109-416) that targeted and coordinated every available system in order to efficiently and effectively address the increasing rate of Autism Spectrum Disorder (ASD) among U.S. children. It focused on expanding research and coordination at the National Institutes of Health (NIH), increasing awareness and surveillance at the Centers for Disease Control and Prevention (CDC), and enabling the Health Resources and Services Administration (HRSA) to expand the interdisciplinary training of health professionals to identify and support children with ASD and their families. This law also created the Interagency Autism Coordinating Committee (IACC), responsible for strategic planning, summarizing research advances, monitoring federal activities, and providing a forum for public input. The law was reauthorized in 2011 and then again in 2014, when it was rebranded – with several content changes regarding oversight, IACC responsibilities and membership, and the inclusion of adults and transition-age youth with ASD – as the “Autism Collaboration, Accountability, Research, Education, and Support (CARES) Act”.

Since 2008, HRSA has supported annual theme-based gatherings of its CARES (formerly “Combating Autism Act Initiative” or CAAI) grantees representing three areas: (1) Interdisciplinary training programs, including Leadership Education in Neurodevelopmental and Related Disabilities and Developmental Behavioral Pediatrics; (2) research programs, including Autism Intervention Research Networks in Behavior and Physical Health, the Developmental Behavioral Pediatrics Research Network, and R40 Extramural MCH Research and Secondary Data Analysis; and (3) state planning and demonstration

Grantees meet in person every other year and conduct virtual activities in between. The 2015 meeting, titled “Implementing Evidence-Based Practices in Real-World Settings,” was held on July 16-17 in Bethesda, Maryland. More than 175 attendees representing all three grantee areas (along with federal officials and technical assistance providers) shared information about their work, discussed emerging trends, and explored new avenues for collaboration. The resources listed in this document were recommended by grantees during small group discussions that focused on the identification of autism in young children. Grantees were asked to briefly share a resource they’ve either developed or used with success; this activity led to broader conversations about best practices, challenges, possible solutions, and opportunities for future grantee collaboration.

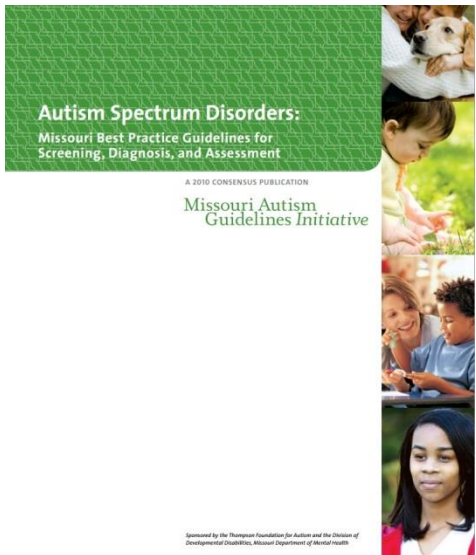
This is not meant to be an exhaustive list of identification resources, but rather a starting point that incorporates guidance from a diverse group of national autism experts. Some items (webinars, mapping tools, brochures, etc.) can be used immediately by parents or professionals, while others are models that can be replicated and/or adapted to meet the needs of different communities.

If you have questions or are a grantee and would like to submit an additional resource for consideration, please contact Ben Kaufman (bkaufman@aucd.org) or Shannon Haworth (shaworth@aucd.org) at the Association of University Centers on Disabilities.

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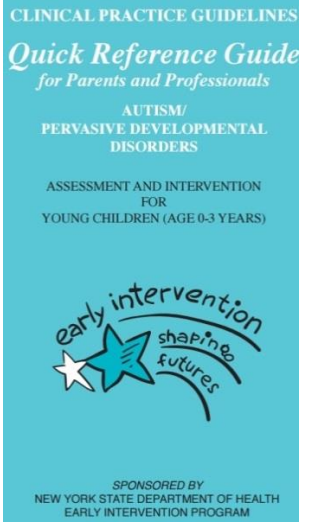
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Community Practice Guidelines and Initiatives

Title	<i>Autism Spectrum Disorders: Missouri Best Practice Guidelines for Screening, Diagnosis, and Assessment</i>	
Description	This document (a product of the Missouri Autism Guidelines Initiative) includes recommendations, guidance, and information about current best practice in screening, diagnostic, and assessment services for individuals with autism spectrum disorders (ASDs). Tailored for Missouri health and education professionals and families of individuals with ASDs, the Guidelines are intended to help with informed decision making regarding identification, diagnosis, and assessment for intervention planning. Overviews for parents, clinicians, and services providers and educators are also available online.	
How to Access	http://autismguidelines.dmh.mo.gov/pdf/Guidelines.pdf <ul style="list-style-type: none"> A companion document, <i>Autism Spectrum Disorders: Guide to Evidence-Base Interventions</i>, can be accessed at: http://autismguidelines.dmh.mo.gov/documents/Interventions.pdf 	
Grantee Contact(s)	Micah Mazurek (mazurekm@missouri.edu)	

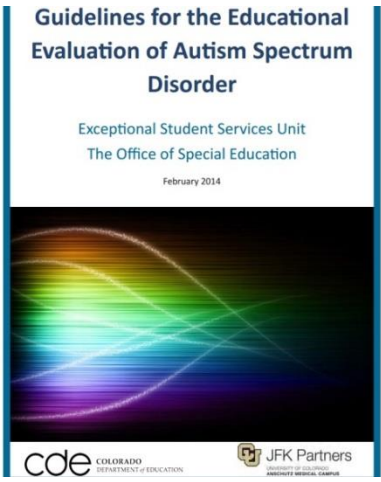
Title	“Improving Screening and Early Identification Practices for Children with Autism Spectrum Disorders in State Public Health Offices”
Description	Lessons learned and materials from a training and technical assistance program implemented in South Dakota public health / Title V to improve effective screening practices and early identification strategies for Autism Spectrum Disorder. Copies of a culturally competent developmental milestones brochure developed in partnership with tribal nations (and other related materials) are available upon request.
How to Access	http://bit.ly/ASD_ID1
Grantee Contact(s)	Eric Kurtz (eric.kurtz@usd.edu)

Community Practice Guidelines and Initiatives

Title	<i>Clinical Practice Guideline for Autism / Pervasive Developmental Disorders: Report of the Recommendations</i>	
Description	This guideline, developed by the New York State Department of Health and key partners, is intended to help families, service providers, and public officials by offering recommendations based on scientific evidence and expert clinical opinion on effective practices for the following: (1) early identification of children at risk or suspected of having a disability through routine developmental surveillance and screening targeted to identify specific disabilities; (2) provision of multidisciplinary evaluations and assessments that result in reliable information about a child's developmental strengths and needs and, when possible, a diagnosis; (3) the determination of effective intervention strategies and reaching agreement on the frequency, intensity, and duration of early intervention services that will lead to positive outcomes for children and families; and (4) the measurement of outcomes achieved.	
How to Access	https://www.health.ny.gov/community/infants_children/early_intervention/disorders/autism/ <ul style="list-style-type: none"> For summary information, refer to the <i>Quick Reference Guide</i>: http://www.health.ny.gov/publications/4216.pdf 	
Grantee Contact(s)	Patricia Towle (ptowle@wihd.org)	

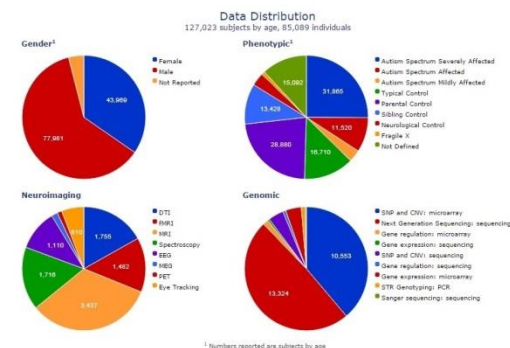
Title	“Considering Culture in Autism Screening” Kit	
Description	The Massachusetts Act Early team developed materials (available online for free download) for pediatric clinicians and community health center providers to use when screening children from families whose primary language is not English. It is designed to strengthen provider knowledge and confidence when working with families from diverse backgrounds, and to increase the likelihood that all children, regardless of cultural or linguistic barriers, can access high-quality autism screening.	
How to Access	http://www.maactearly.org/uploads/9/2/2/3/9223642/4_considering_culture_asd_screening.pdf or http://bit.ly/ASD_ID2	
Grantee Contact(s)	Alison Schonwald (alison.schonwald@childrens.harvard.edu)	

Community Practice Guidelines and Initiatives

Title	“Guidelines for the Educational Evaluation of Autism Spectrum Disorder” Handbook	
Description	This guidance document, collaboratively written by JFK Partners and the Colorado Department of Education, was designed to assist school district personnel and families in becoming familiar with the wide range of characteristics and abilities of their students with an autism spectrum disorder (ASD) and in applying Colorado's new eligibility category of Autism Spectrum Disorder (ASD) to identify students eligible for special education services.	
How to Access	http://www.cde.state.co.us/cdesped/guidelines_autismedid <ul style="list-style-type: none"> JFK Partners also offers a free, online course called “Identification of Autism Spectrum Disorder in a School Setting” that school personnel can complete on their own time and at their own pace. It is available at: http://www.ucdenver.edu/academics/colleges/medicalschooll/programs/JFKPartners/educationtraining/onlinecourses/Pages/onlinecourses.aspx or http://bit.ly/ASD_ID3 	
Grantee Contact(s)	Sandra Friedman (sandra.friedman@childrenscolorado.org)	

Databases

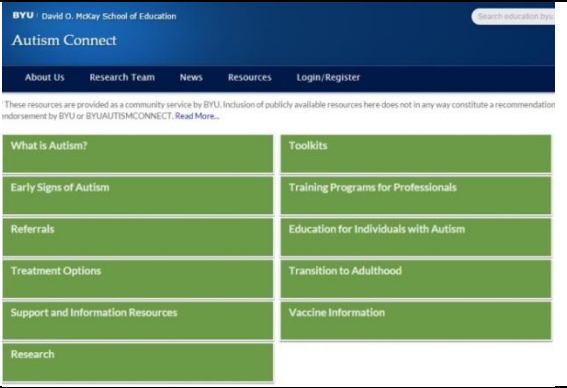
Title	National Database for Autism Research	
Description	The National Database for Autism Research (NDAR) is an NIH-funded research data repository that aims to accelerate progress in autism spectrum disorders (ASD) research through data sharing, data harmonization, and the reporting of research results. NDAR also serves as a scientific community platform and portal to multiple other research repositories, allowing for aggregation and secondary analysis of data.	
How to Access	https://ndar.nih.gov/	
Grantee Contact(s)	David Richman (d.richman@ttu.edu)	




Research and Scholarly Literature

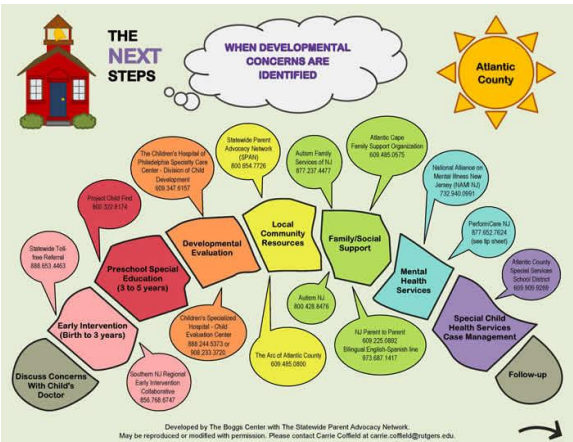
Title	<i>Current perspectives on motor functioning in infants, children, and adults with ASD</i>
Description	In this perspective article, the authors propose that a diverse set of motor impairments (gross motor, fine motor, postural control, and imitation / praxis impairments) are present in children and adults with ASDs. Moreover, the authors propose that early motor delays within the first two years of life may contribute to the social impairments of children with ASDs; therefore, it is important to address motor impairments through timely assessments and effective interventions. Lastly, they acknowledge the limitations of the evidence currently available and suggest clinical implications for motor assessment and interventions in children with ASDs. In terms of assessment, they believe that comprehensive motor evaluations are warranted for children with ASDs and infants at risk for ASDs.
How to Access	http://ptjournal.apta.org/content/91/7/1116.short or http://bit.ly/ASD_ID4
Grantee Contact(s)	Sandra Heimerl (sheimerl@salud.unm.eu)


Resource Guides and Directories

Title	"Autism Connect" Resource Directory	
Description	An online, topic-by-topic (e.g. early signs of autism, training programs for professionals, transition to adulthood) listing of autism resources for various stakeholders, hosted by the David O. McKay School of Education at Brigham Young University.	
How to Access	http://education.byu.edu/autism?page=resources	
Grantee Contact(s)	Ashley Stevens (ashley.l.stevens@utah.edu)	


Title	Project Connect Autism Resource Guide	
Description	A collection of resources to help Arkansas families navigate service systems and make more informed decisions regarding the well-being of their child with autism. The resources gathered and identified are in accordance with the National Professional Development Center on Autism Spectrum Disorders and the National Autism Center's evidence-based practices guides for families and professionals.	
How to Access	http://www.adcpti.org/Assets/projectconnect_resourceguide_smallsize.pdf or http://bit.ly/ASD_ID5	
Grantee Contact(s)	Peggy Whitby (pschaefe@uark.edu)	


Resource Guides and Directories

Title	“The Next Steps” Handout	
Description	A county-specific flow chart created by the Boggs Center on Developmental Disabilities and New Jersey’s Statewide Parent Advocacy Network that connects families to local resources when developmental concerns are identified. These one-page documents also include tips on how to contact early intervention and preschool special education, schedule a developmental evaluation, find family support, and more.	
How to Access	http://rwjms.rutgers.edu/boggscenter/projects/ActEarlyFlowCharts.html	
Grantee Contact(s)	Jeannette Mejias (jmejias@spannj.org) Deepa Srinivasavaradan (deepas@spannj.org)	

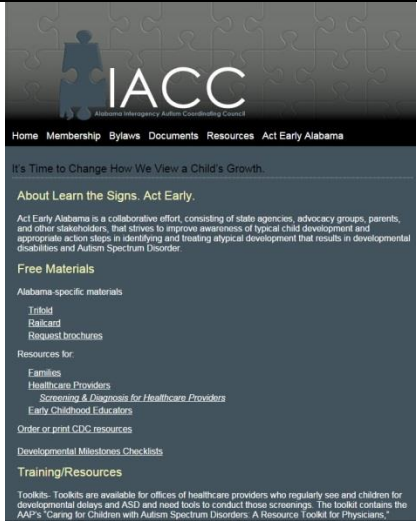
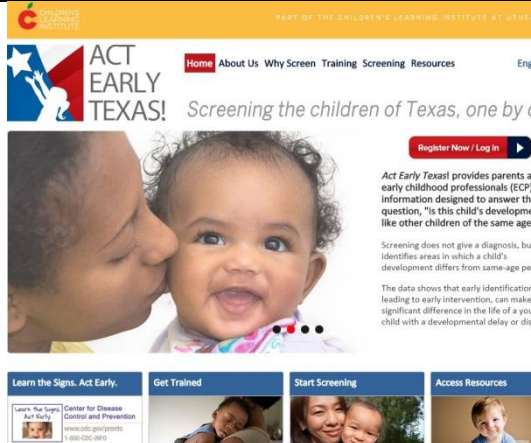
Title	Utah Parent Center Website	
Description	The Utah Parent Center is a training and information center founded by parents of children and youth with disabilities to help other parents facing similar challenges. It staffed primarily by parent-advocates who provide accurate information, peer support, and training. They have compiled several resource lists, including one specifically for the autism community that covers topics such as: clinics, diagnostic evaluations, early intervention, parent and family support, educational resources, and assistive technology.	
How to Access	http://www.utahparentcenter.org/ <ul style="list-style-type: none"> A list of autism-specific resources, compiled by Utah Parent Center staff, is available at: http://www.utahparentcenter.org/publications/autism-resource-lists/ 	
Grantee Contact(s)	Kristina Cottle (kristina.cottle@utah.edu)	

Policy, Advocacy, and Awareness


Title	“Learn the Signs. Act Early.” Website	
Description	The Centers for Disease Control and Prevention’s (CDC) “Learn the Signs. Act Early.” program aims to improve early identification of children with autism and other developmental disabilities so children and families can get the services and support they need. Through this program, the CDC and designated state ambassadors promote awareness of healthy development during early childhood, the importance of tracking each child’s development, and the importance of acting early if there are concerns. They have created free materials (in multiple languages) to help programs address the need for child development resources; programs can customize CDC materials with their own contact information and distribute them to the populations they serve.	
How to Access	http://www.cdc.gov/ncbddd/actearly/index.html <ul style="list-style-type: none"> All free materials can be accessed at: http://www.cdc.gov/ncbddd/actearly/downloads.html 	
Grantee Contact(s)	Dan Crimmins (dcrimmins@gsu.edu) Lillie Huddleston (lhuddleston@gsu.edu)	

Title	“Autism Motion Graphic Video”	
Description	A video created by the Nebraska Act Early State Autism Team that provides a basic overview of ASD using narration, word graphics, and pictures. It offers recommendations for how community members can support the expansion of services for people with ASD and their families, and also points them to a website that contains more information and resources.	
How to Access	http://asdinnebraska.org/	
Grantee Contact(s)	Cindy Ellis (cellis@unmc.edu) Kellie Ellerbusch (kellerbusch@unmc.edu) Therese Mathews (tmathews@unmc.edu)	

Policy, Advocacy, and Awareness


Title	“Act Early Alabama” Website	
Description	Act Early Alabama is a collaborative effort, consisting of state agencies, advocacy groups, parents, and other stakeholders; this group strives to improve awareness of typical child development and appropriate action steps in identifying and treating atypical development that results in developmental disabilities and Autism Spectrum Disorder. Their website contains state-specific adaptations of CDC informational materials that are available for free download.	
How to Access	http://autism.alabama.gov/act_early_alabama.html	
Grantee Contact(s)	Fred Biasini (fbiasini@uab.edu) Sarah O'Kelley (sokelley@uab.edu)	
Title	“Act Early Texas!” Website	
Description	A website created by the Children’s Learning Institute and the University of Texas Health Sciences Center that outlines the importance of developmental screening, offers four web-based training modules for early childhood professionals, connects parents and professionals to evidence-based screening tools, and lists state/national resources.	
How to Access	https://actearlytexas.org/	
Grantee Contact(s)	Pauline Filipek (Pauline.A.Filipek@uth.tmc.edu)	

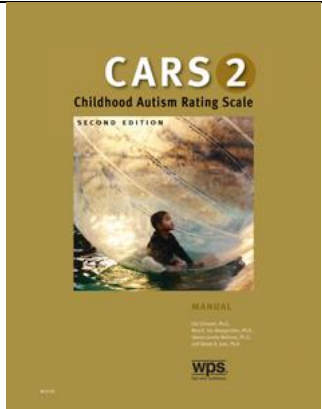
Policy, Advocacy, and Awareness

Title	“Act Early Wisconsin” Website	
Description	Act Early Wisconsin aims to support state and regional systemic efforts to promote the early identification and intervention for children with signs of Autism Spectrum Disorders (ASD) and other Developmental Disabilities (DD). Their website contains state-specific adaptations of CDC informational materials for parents and professionals that are available for free download.	
How to Access	http://actearly.wisc.edu/materials.php	
Grantee Contact(s)	Anne Harris (harris@waisman.wisc.edu)	

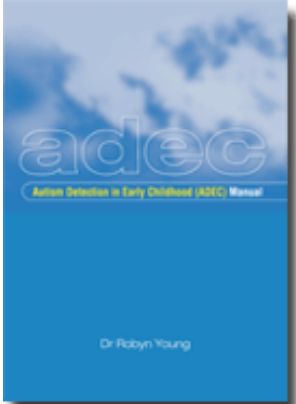
Title	South Carolina Presumptive Eligibility Policy
Description	This model policy, developed through the collaborative effort of the South Carolina Act Early team, provides for children under age 3 years to be eligible for Early Intensive Behavioral Intervention (EIBI) services through the Part C program (BabyNet) if they are found at risk of Autism Spectrum Disorder (ASD) based on a two-tiered screening system implemented by approved screeners: the Modified Checklist for Autism in Toddlers (M-CHAT) along with the Screening Tool for Autism in Toddlers (STAT). Since the policy was introduced, the number of South Carolina children eligible for EIBI under Part C has increased from 86 (2012) to 331 (2014).
How to Access	http://bit.ly/ASD_ID6
Grantee Contact(s)	Jane Charles (charlesj@musc.edu) David Rotholz (david.rotholz@uscmed.sc.edu)


Screening and Diagnostic Measures: Autism

Title	Autism Behavior Checklist (ABC)	
Description	The Autism Behavior Checklist (ABC) is a list of questions about a child's behaviors. The ABC was published in 1980 (Krug et al., 1980) and is part of a broader tool, the Autism Screening Instrument for Educational Planning (ASIEP). The ABC is designed to be completed independently by a parent or a teacher familiar with the child who then returns it to a trained professional for scoring and interpretation. Although it is primarily designed to identify children with autism within a population of school-age children with severe disabilities, the ABC has been used with children as young as three years of age. The ABC has 57 questions divided into five categories: (1) sensory, (2) relating, (3) body and object use, (4) language, and (5) social and self-help.	
How to Access	http://www.proedinc.com/customer/productView.aspx?ID=4217 or http://bit.ly/ASD_ID7	
Grantee Contact(s)	Kris Gabrielsen (kris@gsti.org)	

Title	Childhood Autism Rating Scale™, Second Edition (CARS™-2)	
Description	This tool helps to identify children with autism and determine symptom severity through quantifiable ratings based on direct observation. It includes two 15-item rating scales to be completed by the clinician (each designated for a different population) and an unscored parent / caregiver questionnaire.	
How to Access	http://www.wpspublish.com/store/p/2696/childhood-autism-rating-scale-second-edition-cars-2 or http://bit.ly/ASD_ID8	
Grantee Contact(s)	Kris Gabrielsen (kris@gsti.org)	

Screening and Diagnostic Measures: Autism


Title	Autism Detection in Early Childhood (ADEC)	
Description	The Autism Detection in Early Childhood (ADEC; Young, 2007) was developed as a Level 2 clinician-administered screening tool that was time-efficient, suitable for children under 3 years of age, easy to administer, and suitable for persons with minimal training and experience with ASD. It is designed to clearly identify and detail behaviors that can indicate ASD in preverbal children. ADEC consists of a manual, a training DVD, a score sheet for each child assessed, and stimulus materials. Community-Based Autism Liaison and Treatment (CoBALT) regional teams, consisting of professionals who screen and evaluate for ASD and developmental delays across Arkansas, have been trained to use this tool.	
How to Access	https://shop.acer.edu.au/acer-shop/group/ADE <ul style="list-style-type: none"> Published reliability and validity data can be accessed at: http://www.ncbi.nlm.nih.gov/pubmed/24490680 or http://bit.ly/ASD_ID9 	
Grantee Contact(s)	David Deere (deere@uark.edu) Jill Fussell (fusselljillj@uams.edu) Letha Bell (labell@uams.edu)	


Title	Sense and Self-Regulation Checklist (SSC)	
Description	The Sense and Self-Regulation Checklist (SSC) is a measure of the frequency and severity of sensory symptoms and self-regulatory difficulties in young children with autism. The five primary senses are evaluated, with particular emphasis on responses to touch, and body areas where touch is abnormal. Difficulties with early self-regulation milestones are evaluated in the areas of sleep, digestion, self-soothing, attention and behavior.	
How to Access	http://qsti.org/resources/assessment-evaluation-tools/sense-and-self-regulation-checklist/	
Grantee Contact(s)	Kris Gabrielsen (kris@qsti.org)	

Screening and Diagnostic Measures: Autism


Title	Guidelines for Early Intervention (EI) providers to introduce STAT, a Stage 2 autism screener
Description	Through the ABCD Early Screening Project, a group of UMass-Boston researchers are attempting to reduce health disparities in the rates and ages of autism diagnosis and service receipt; they aim to change the screening practices implemented by federally mandated EI agencies serving children ages 0-3. They have established and are using a set of guidelines to train EI providers in the Screening Tool for Autism in Toddlers and Young Children (STAT), which is a play-based Stage 2 screener for children who have already been identified as “at risk” for autism and other developmental disabilities based on scores from previous questionnaires.
How to Access	http://bit.ly/ASD_ID10 <ul style="list-style-type: none">Guidelines and instructional materials (e.g. orientation video) are available upon request – <i>see contact information below</i>
Grantee Contact(s)	Alice Carter (alices.carter@umb.edu) Abbey Eisenhower (abbey.eisenhower@umb.edu)


Screening and Diagnostic Measures: Development

Title	Child Health and Development Interactive System (CHADIS)	
Description	CHADIS is a screening, decision support and patient engagement system designed to streamline and optimize healthcare by providing Clinicians with evidence-based data that improves diagnosis and management of health, emotional, developmental and behavioral concerns. This system (approximately \$650/year per FTE physician) is used in pediatrician and family physician offices throughout Rhode Island, where they integrate screening into the statewide immunization registry and have state coordinators link families to services.	
How to Access	http://www.chadis.com/site/clinicians	
Grantee Contact(s)	Pamela High (phigh@lifespan.org)	


Title	Survey of Wellbeing of Young Children (SWYC)	
Description	The SWYC is a freely-available, comprehensive screening instrument for children under five years of age. It assesses three domains of child functioning: (1) developmental, (2) behavioral / emotional, and (3) family context. The SWYC was written to be simple to answer, short, and easy to read. The entire instrument requires 15 minutes or less to complete and is straightforward to score and interpret. It is translated into four languages besides English and contains supplementary forms for every age on the pediatric periodicity schedule.	
How to Access	http://www.theswyc.org/	
Grantee Contact(s)	Abbey Eisenhower (abbey.eisenhower@umb.edu)	


Screening and Diagnostic Measures: Parental Stress

Title	Parenting Stress Index™, Fourth Edition (PSI™-4)	
Description	The PSI-4 is commonly used as a screening and triage measure for evaluating the parenting system and identifying issues that may lead to problems in the child's or parent's behavior. This information may be used for designing a treatment plan, for setting priorities for intervention, and/or for follow-up evaluation. Other common settings for administration of the PSI-4 include medical centers where children are receiving medical care, outpatient therapy settings, pediatric practices, and treatment outcome monitoring.	
How to Access	http://www4.parinc.com/products/Product.aspx?ProductID=PSI-4 or http://bit.ly/ASD_ID11	
Grantee Contact(s)	Connie Wong (connie.wong@unc.edu)	

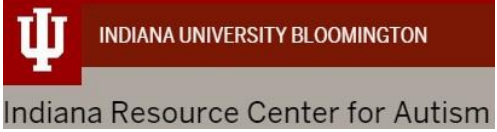
Title	Autism Parental Stress Index (APSI)	
Description	The Autism Parenting Stress Index is a measure of parenting stress, as perceived by parents of young children with autism. It reflects the time, effort and actual difficulty of parenting in light of the physical, social and communication barriers imposed by the disability.	
How to Access	http://qsti.org/resources/assessment-evaluation-tools/autism-parenting-stress-index/	
Grantee Contact(s)	Kris Gabrielsen (kris@qsti.org)	

Tools for Families: Basic Information


Title	"Autism Characteristics by Age" Handout	<div><div><div>AUTISM CHARACTERISTICS BY AGE In autism children, signs appear as early as age 6 months. In others, signs appear as late as 24-30 months.</div></div><table><thead><tr><th>BEHAVIORAL FEATURES</th><th>OBSERVABLE AT 6-12 MONTHS</th><th>OBSERVABLE AT 12-30 MONTHS</th></tr></thead><tbody><tr><td>Response to others' social input</td><td>Poor eye contact</td><td>Poor eye contact Inrequent or delayed response when name is called Inattentive to others' pointing or eye direction cues Inrequent playful imitation of others' actions Shows little interest in other children</td></tr><tr><td>Social interaction</td><td>Passive Limited facial expression during social interaction Inrequent smiling at others with eye contact</td><td>Inrequent attempts to point out or share objects or events of own interest Limited facial expression during social interaction Inrequent smiling at others to show enjoyment Rarely initiates social smiles to share enjoyment</td></tr><tr><td>Communication and play</td><td>Delayed babbling Limited exploration of toys and objects</td><td>Low variety of speech sounds or gestures when trying to communicate Delayed language development Limited variety of play with toys Inadequately coordinates eye contact with gestures and speech sounds to communicate</td></tr><tr><td>Sensory and motor</td><td>Tenses hands, arms, legs or mouth Low muscle tone, "floppy" Poor motor coordination or motor delay (sitting, crawling) Seeks firm pressure on body Intense interest in shiny or moving things</td><td>Tenses hands, arms, legs or mouth Poor motor coordination or motor delay Seeks firm pressure on body Intense interest in shiny or moving things</td></tr></tbody></table><div><small>Source: Kennedy Krieger Institute research studies Landa, R. (2006). <i>Neuro Clinical Practice Neurology</i>, 4 (36) 147. Sullivan, M., Finkel, J., Marini, A., Givelli-Mayer, S., Bauman, M., & Landa, R. (2007). <i>Autism and Developmental Disabilities</i>, 9 (3) 46. Thompson, A. Landa, R. (2007). <i>American Educational Therapy Association</i>. West A. Givelli, C. & Landa, R. (2007). <i>Society for Research in Child Development Conference</i>. Landa, R., Palmer, A., & Givelli-Mayer, S. (2007). <i>Archives of General Psychiatry</i>, 64, 833-844. Landa, R. & Givelli-Mayer, S. (2006). <i>Child Development and Psychology</i>, 41, 823-836.</small></div></div>	BEHAVIORAL FEATURES	OBSERVABLE AT 6-12 MONTHS	OBSERVABLE AT 12-30 MONTHS	Response to others' social input	Poor eye contact	Poor eye contact Inrequent or delayed response when name is called Inattentive to others' pointing or eye direction cues Inrequent playful imitation of others' actions Shows little interest in other children	Social interaction	Passive Limited facial expression during social interaction Inrequent smiling at others with eye contact	Inrequent attempts to point out or share objects or events of own interest Limited facial expression during social interaction Inrequent smiling at others to show enjoyment Rarely initiates social smiles to share enjoyment	Communication and play	Delayed babbling Limited exploration of toys and objects	Low variety of speech sounds or gestures when trying to communicate Delayed language development Limited variety of play with toys Inadequately coordinates eye contact with gestures and speech sounds to communicate	Sensory and motor	Tenses hands, arms, legs or mouth Low muscle tone, "floppy" Poor motor coordination or motor delay (sitting, crawling) Seeks firm pressure on body Intense interest in shiny or moving things	Tenses hands, arms, legs or mouth Poor motor coordination or motor delay Seeks firm pressure on body Intense interest in shiny or moving things
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Sensory and motor	Tenses hands, arms, legs or mouth Low muscle tone, "floppy" Poor motor coordination or motor delay (sitting, crawling) Seeks firm pressure on body Intense interest in shiny or moving things	Tenses hands, arms, legs or mouth Poor motor coordination or motor delay Seeks firm pressure on body Intense interest in shiny or moving things															
Description	This one-page handout – based on Kennedy Krieger Institute research – for parents and professionals lists the observable, concrete behaviors that a child at risk for autism or related developmental disabilities might display at 6-12 months and 12-30 months.																
How to Access	http://issuu.com/kennedykrieger/docs/autism-characteristics-by-age-chart-2013/1?e=3306856/1903445 or http://bit.ly/ASD_ID12																
Grantee Contact(s)	Rebecca Landa (landa@kennedykrieger.org)																


Title	Translated Autism Fact Sheets	
Description	An autism fact sheet that has been competently translated into 14 different languages and made available for free download through the California Autism Professional Training and Information Network (CAPTAIN).	
How to Access	http://www.uscucedd.org/publications-resources/autism-pubs/autism-fact-sheets	
Grantee Contact(s)	Patricia Schetter (patricia.schetter@ucdmc.ucdavis.edu) Patrice Yasuda (pyasuda@chla.usc.edu) Marian Williams (mwilliams@chla.usc.edu)	

Tools for Families: Basic Information


Title	“What to Do if You Suspect Your Son / Daughter Might Have an Autism Spectrum Disorder”	 <p>INDIANA UNIVERSITY BLOOMINGTON</p> <p>Indiana Resource Center for Autism</p>
Description	An article written by experts (including a parent) representing four Indiana autism organizations. Its purpose is to make getting an accurate diagnosis and knowing what to do after a diagnosis has been made less confusing and overwhelming for parents. The article clarifies options, highlights characteristics, and suggests next steps – including what parents can do while waiting for an assessment or diagnosis.	
How to Access	http://www.iidc.indiana.edu/pages/What-to-Do-If-You-Suspect-Your-Son-Daughter-Might-Have-an-Autism-Spectrum-Disorder or http://bit.ly/ASD_ID13 <ul style="list-style-type: none"> Articles on other important topics can be accessed at: http://www.iidc.indiana.edu/pages/articles 	
Grantee Contact(s)	Angela Tomlin (atomlin@iu.edu)	


Tools for Families: Planning

Title	Center for Autism Research (CAR) Autism Roadmap™	
Description	An interactive, web-based tool that helps families learn about ASD, including symptoms, diagnosis, and the impact on families and individuals; get the latest information on treatments, therapies, and how to get services; and connect with resources for children, youth, and adults.	
How to Access	https://www.carautismroadmap.org/	
Grantee Contact(s)	Judith Miller (millerj3@email.chop.edu)	


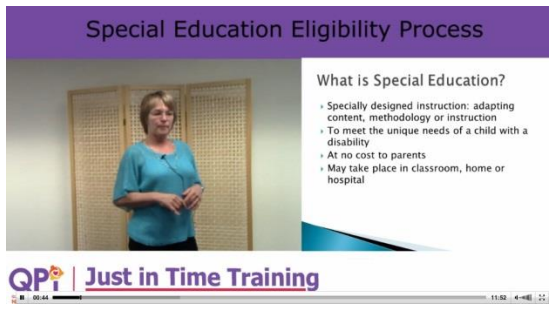
Title	“Road Map for Helping Your Child Grow!”	
Description	A simple, one-page document created by New Hampshire's Act Early Regional Summit Team that helps parents / guardians stay organized and plan next steps once concerns about their child's development have been brought forth. It also contains contact information for relevant state agencies, as well as links to helpful resources.	
How to Access	http://www.nhvirtualautismcenter.info/RESOURCESfamily/FAMILYfiles/NH_FamilyRoadMapFollowingScreening.pdf or http://bit.ly/ASD_ID14	
Grantee Contact(s)	Jenn Pineo (jsp@nhfv.org) Brian Huckins (bhuckins@communitybridgesnh.org) Betsy Humphreys (elizabeth.humphreys@unh.edu) Elizabeth Collins (ecollins@dhhs.state.nh.us)	

Tools for Families: Planning

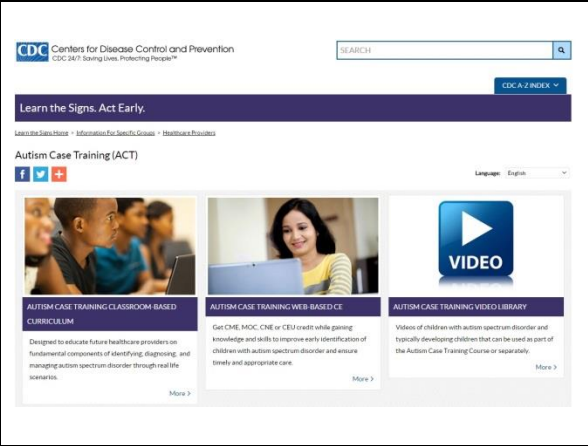
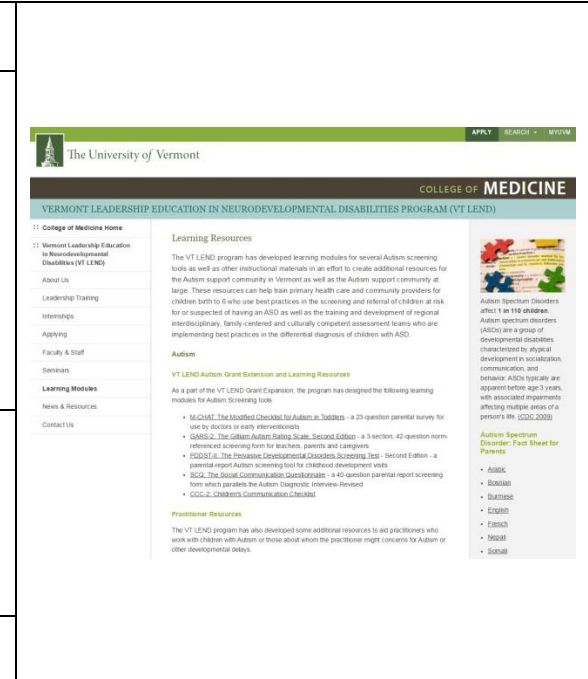
Title	South Carolina Roadmap to Developmental Screening	
Description	A resource created by the South Carolina Act Early Team that uses flowcharts to explain where to receive assistance for a child that may be at risk for an Autism Spectrum Disorder. It also provides an explanation of services, state agencies, assessments, and interventions relevant to this issue.	
How to Access	http://uscm.med.sc.edu/cdrhome/Roadmap.pdf	
Grantee Contact(s)	David Rotholz (david.rotholz@uscm.edu) Michelle Macias (maciasm@musc.edu)	

Title	Well Visit Planner	
Description	The Well Visit Planner (WVP) is a free, online tool developed by the Child and Adolescent Health Measurement Initiative (CAHMI) that improves care for young children by collecting information and concerns from parents prior to the visit. It allows each visit to be tailored to the individual family while adhering to national recommendations for the content of preventive pediatric care. The WVP tool also enables providers to establish an ongoing system of engaging parents in well-child care. Parents answer a questionnaire about their child and family, pick their priorities for what they want to talk or get information about at their child's well visit, and receive a visit guide that the family and health care provider can use to tailor the visit to meet everyone's needs.	
How to Access	http://wellvisitplanner.org/	
Grantee Contact(s)	Marilyn Hartzell (hartzell@ohsu.edu)	

Tools for Families: Post-Diagnosis

Title	Autism Intervention Research Network on Physical Health (AIR-P) Toolkits	 <p>The AIR-P website features a navigation bar with links: Who We Are, What We Do, Get Involved, News & Events, Tools, and Contact a Site. Below the navigation bar is a large photo of four diverse children smiling. The page title is 'AIR-P Tool Kits'. Below the photo, there is a section titled 'AIR-P Tool Kits' with a list of available toolkits: 'A Guide to Applied Behavior Analysis: designed to provide you with a better understanding of ABA, how your child can benefit, and where/how you can seek ABA services. Download the tool kit [link]' and 'Autism and Medication: Safe and Careful Use: created to help families work with their healthcare providers to make sure that medicine is taken safely and effectively. Download the tool kit [link]'.</p>
Description	A set of free toolkits for both caregivers and health professionals. They provide evidence-based information and strategies for improving sleep, toilet training, managing constipation, drawing blood, dentist and optometrist visits, challenging feeding behaviors, pica, and more.	
How to Access	http://www.airpnetwork.org/site/c.7oJGLPPsFiJYG/b.9151551/k.8682/AIRP_Tool_Kits.htm or http://bit.ly/ASD_ID15	
Grantee Contact(s)	Dan Coury (Daniel.Coury@nationwidechildrens.org)	
Title	Quality Parenting Initiative (QPI) Video Training Library	 <p>The QPI 'Just in Time Training' video player shows a woman in a blue shirt speaking. The video title is 'Special Education Eligibility Process'. The video content includes a section titled 'What is Special Education?' with a list of bullet points: 'Specially designed instruction: adapting content, methodology or instruction', 'To meet the unique needs of a child with a disability', 'At no cost to parents', and 'May take place in classroom, home or hospital'. The video player has a progress bar and a timestamp of 11:02 / 4:48.</p>
Description	The Quality Parenting Initiative (QPI) is one of Nevada's approaches to strengthening and rebranding foster care, helping sites become better able to develop communication materials and design recruitment training and retention systems for foster parents. They offer free, web-based "Just in Time" training videos for parents and providers, including several on disability topics (e.g. special education eligibility).	
How to Access	http://www.qpinevada.org/traininglibrary/topicindex.shtml <ul style="list-style-type: none"> For training videos related to disability issues, scroll down to "Systems and Advocating for Children & Youth" 	
Grantee Contact(s)	Erika Ryst (ryst@medicine.nevada.edu) Debra Vigil (dvigil@medicine.nevada.edu)	

Training Materials and Opportunities for Professionals: Curricula and Modules

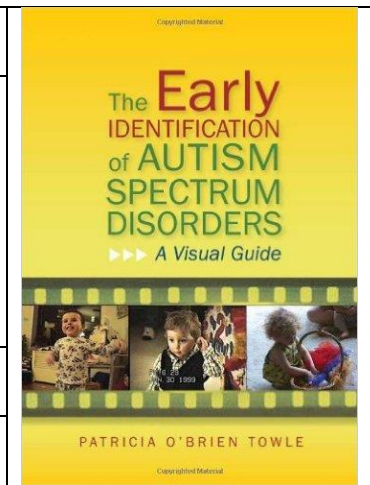
Title	Autism Case Training (ACT) Curriculum	
Description	A free curriculum from the Centers for Disease Control and Prevention (CDC) that is designed to educate future professionals on fundamental components of identifying, diagnosing, and managing autism spectrum disorder through real life scenarios. It is also available as web modules that professionals can complete to earn CME, MOC, CNE, or CEU credits.	
How to Access	http://www.cdc.gov/ncbddd/actearly/act.html	
Grantee Contact(s)	Toni Whitaker (twhitak1@uthsc.edu)	
Title	Learning Modules for Autism Screening Tools	
Description	The Vermont LEND program has developed learning modules for several Autism screening tools as well as other instructional materials in an effort support the Autism community in Vermont and beyond. These resources can help train primary health care and community providers for children (birth to 6) who use best practices in the screening and referral of children at risk for or suspected of having an ASD as well as the training and development of regional interdisciplinary, family-centered and culturally competent assessment teams who are implementing best practices in the differential diagnosis of children with ASD.	
How to Access	http://www.uvm.edu/medicine/vtlend/?Page=learning.html <ul style="list-style-type: none"> Vermont LEND has also created videos that can help practitioners express their concerns about Autism or other developmental delays with parents, both before and after screening, as well as videos geared specifically toward Somali families. 	
Grantee Contact(s)	Jean Beatson (jean.beatson@med.uvm.edu)	

Training Materials and Opportunities for Professionals: Literature


Title	"A Guide to Screening for Autism Spectrum Disorder" Brochure	Developmental Screening Tools	Child's Age	Level *	Brief Description	Administration Method	Time to Complete	Provider Training Required (Yes/No)	How to Access & Cost (All)
Description	This brochure provides a succinct overview of six research-based screening tools; three are developmental and three are specifically for ASD. It breaks down each instrument by the appropriate age, level, administration method, completion time, whether it requires provider training, and how it can be accessed.	Autism Detection in Early Childhood (ADEC)	12-36 months	2	10 item interactive assessment between child and provider to identify child's risk for ASD. Early papers validate ADEC as a screener for AD, more recent ASD.	Semi-structured observation by provider	15 mins	Yes (DVD provided with kit)	Order online from AUS \$500
How to Access	http://www.aucd.org/docs/lend/Blumenthal_AutismScreeningGuide.pdf or http://bit.ly/ASD_ID16	Communication and Symbolic Behavior Scales - Developmental Profile: Infant Toddler Checklist (ITC)	6-24 months	1 or 2	24 questions about child's behavior to assess whether child will have difficulty learning to talk. Responses are assessed & scored by provider.	Parent-completed questionnaire	5-10 mins	No	Online download Free (Questionnaire, scoring form)
Grantee Contact(s)	Brittany Blumenthal (bmbblumenthal@gmail.com)	Parent Observation of Early Markers Scale (POEMS)	3-36 months	2	61 items to cover problem areas including core deficits of ASD based on parent's observations. Responses assessed & scored by provider.	Parent-completed questionnaire	20 mins	No	Available upon request from author
		Parent Observation of Interaction (POSI)	16-36 months	1	7 item parent-rated checklist modeled from the critical items of the M-CHAT, as well as DSM-5. Items scored comparable to typical behavior. Responses are assessed & scored by provider.	Parent-completed questionnaire	5 mins	No	Online download Free (Questionnaire, scoring form)
		Modified Checklist for Autism - Revised Follow-up Interview (M-CHAT-R/F)	16-48 months	1	20 questions to assess child's risk level for Autism Spectrum Disorder. Responses are assessed & scored by provider. Level of medium risk determines need for required follow-up interview by provider.	Parent-completed questionnaire. If child is at-risk, provider conducts follow-up interview for at-risk child.	5-10 mins*	No	Online download Free (Questionnaire, scoring form)
		Screening Test for Autism in Two-year-olds (STAT)	24-36 months	2	12 item interactive assessment between child and provider to identify child's risk for Autism Spectrum Disorder.	Semi-structured observation by provider	L	Yes. Interactive online training (included in kit). Training workshop (add'l cost)	Order online \$500



*Level 1 denotes a screener intended for a general population of children and intends to detect children at risk for any disability, although some Level 1 screeners are autism-specific. Level 2 denotes a screener intended to detect ASD in referred or high risk children. Its intent is to distinguish ASD from other types of early childhood disabilities.

Title	<i>The Early Identification of Autism Spectrum Disorders: A Visual Guide</i>	
Description	This visual guide provides a framework for understanding the complex nature of ASD. Each chapter focuses on a different area of development and uses photographs to illustrate and enhance understanding of presenting or absent behaviors. It is written in an accessible style and covers the core aspects of ASD, giving readers what they need to be able to successfully identify behavioral indicators. This book will be valuable for early intervention professionals and students, occupational therapists, speech and language therapists, educational psychologists, pediatricians, teachers, and parents.	
How to Access	http://amzn.to/1IXfOtD	
Grantee Contact(s)	Patricia Towle (ptowle@wihd.org)	

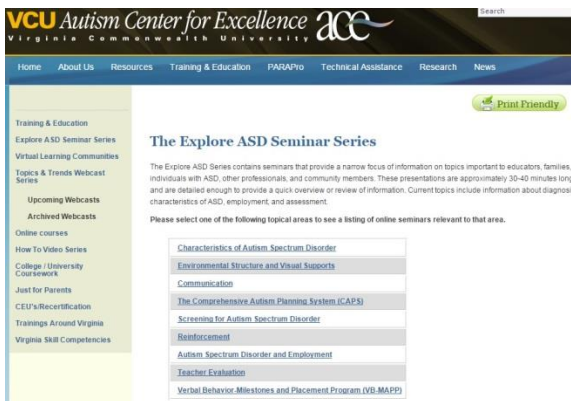



Training Materials and Opportunities for Professionals: Model Initiatives


Title	Dbp2Doc.org	
Description	A project of the Oklahoma University Department of Pediatrics to help provide developmental-behavioral consultation (phone or e-mail) to primary care providers at no cost. Participating providers can access developmental-behavioral pediatricians or a nurse practitioner. It is designed to broaden the provider's knowledge of developmental-behavioral conditions. Consultants share resources and evidence-based practices that include, but are not limited to: standards of care, behavioral practices related to specific conditions, medication management strategies, implementation of recommended services, strategies for working with education and other systems, and referral assistance.	
How to Access	http://dbp2doc.org/	
Grantee Contact(s)	Mark Wolraich (mark-wolraich@ouhsc.edu)	

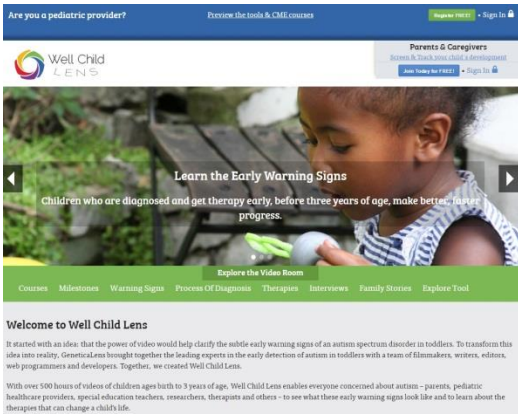
Title	ECHO Autism (University of Missouri)	 
Description	ECHO Autism is a statewide virtual learning network of medical providers offering real-time access to autism and behavioral experts. Its purpose is to help increase professionals' confidence in identifying and treating autism symptoms, and expand their knowledge about behavioral treatments. Topics include: (1) evidence-based practices for screening, diagnosis, and treatment of autism; (2) common medical and psychiatric concerns in children with autism; and (3) successful office visits for children with autism and other behavioral concerns. ECHO Autism meets virtually for two hours, twice per month, for six months; the program offers up to 24 hours of free CME.	
How to Access	http://bit.ly/ASD_ID18	
Grantee Contact(s)	Kristin Sohl (sohlk@health.missouri.edu)	

Training Materials and Opportunities for Professionals: Presentations and Seminars

Title	“Explore ASD” Seminar Series	
Description	A series of five free, 30-minute seminars available online. These seminars, created by Virginia Commonwealth University's Autism Center for Excellence as part of their “ASD Early Step” grant, address the importance of screening; screening recommendations; screening tools; the screening process, including what to do after the screening; and best practices for supporting families. The seminars are for any person who wishes to gain more information about the importance of and procedures for screening for ASD, including pediatric health care providers and other professionals who work with young children.	
How to Access	http://vcuautismcenter.org/te/seminarsByCategory.cfm?id=6 or http://bit.ly/ASD_ID19	
Grantee Contact(s)	Deana Buck (dmbuck@vcu.edu) Donna Gilles (dlgilles@vcu.edu) Tera Yoder (tyoder@vcu.edu)	
Title	“M-CHAT and Autism Screening” Webinar	
Description	This 50-minute webinar covers the latest statistics on age of ASD diagnosis, disparities in diagnosis among white and minority populations, and recommendations from the CDC and AAP to monitor, screen, and refer during well-child visits. It also provides training on the latest version of the M-CHAT-R, including the online version available to parents.	
How to Access	https://www.youtube.com/watch?v=j8Qoq5ecvlg or http://bit.ly/ASD_ID20	
Grantee Contact(s)	Karen Ratliff-Schaub (Karen.Ratliff-Schaub@nationwidechildrens.org) Amy Hess (amy.hess@nationwidechildrens.org)	

Training Materials and Opportunities for Professionals: Videos

Title	“Early Signs of Autism” Video Tutorial	
Description	To improve recognition of the early signs of ASD among pediatricians, parents, and early intervention providers, Kennedy Krieger Institute has developed a free, nine-minute video tutorial on ASD behavioral signs in one-year-olds. The tutorial consists of six video clips comparing toddlers who show no signs of ASD to toddlers who show early signs of ASD. Each video is presented with voice-over explaining how the specific behaviors exhibited by the child are either indicative of ASD or typical child development.	
How to Access	http://www.kennedykrieger.org/patient-care/patient-care-centers/center-autism-and-related-disorders/outreach-training/early-signs-of-autism-video-tutorial or http://bit.ly/1Lv7YZ0	
Grantee Contact(s)	Rebecca Landa (landa@kennedykrieger.org)	

Title	Well Child Lens Videos	
Description	Well Child Lens features more than 500 videos of varying length where professionals can view children the same age as their patients, see side by side comparisons of typical vs. at risk behaviors, and watch parents talk about receiving a diagnosis and living with autism. Upon registration, professionals can personalize their video search based on their needs and questions, then bookmark specific videos as “favorites.” They can also gain access to three CME courses, developed with grants from the National Institutes of Health, as well as interactive tools created to improve the early detection of autism during the 18 and 24 month well care visits.	
How to Access	https://www.wellchildlens.com/	
Grantee Contact(s)	Jamie Perry (jperry@aucd.org)	