# ASD Services Toolkits and Resources

## Health, Medical and Safety Toolkits for Children

**100 Day Kit** (Autism Speaks)

This kit is designed for families with a child newly diagnosed with autism and focused on making the best use of the first 100 days following diagnosis. It covers the basics of autism symptoms and includes information on sharing the diagnosis with family and beginning to assemble physicians and service providers for addressing the needs of the child.

**Asperger Syndrome and High Functioning Autism Tool Kit** (Autism Speaks)

This kit is designed for families with a child newly diagnosed with Asperger syndrome and high functioning autism and focused on making the best use of the first 100 days following diagnosis. It covers the basics of autism symptoms and includes information on sharing the diagnosis with family and beginning to assemble physicians and service providers for addressing the needs of the child.

**Family Support Tool Kits** (Autism Speaks)

A new diagnosis of autism in a family can affect different family members in different ways. This collection comprises four support tool kits, targeted to: parents, siblings, grandparents and friends.

**Autism: Caring for children with Autism Spectrum Disorders, A resource toolkit for clinicians, 2nd Edition by American Academy of Pediatrics** (American Academy of Pediatrics)

This toolkit provides current AAP clinical guidance on autism including expert screening, surveillance, diagnosis and treatments. It also includes ready-to-print information on autism topics to be distributed to families.

**A Parent's Guide to Evidence-Based Practice and Autism** (National Autism Center, 2011)

The National Autism Center initiated the National Standards Project to conduct a comprehensive review and evaluation of existing research into treatments for children and adolescents with ASD. The resulting

National Standards Report was published in 2009 to share these findings. The NAC offers this parent manual to help fulfill the center's mission to advocate for evidence based practice and to assist parents as they make difficult decisions about how best to help their children with ASD reach their full potential.

**Toolkit for Medical Professionals: Tips & supports for working with individuals with Autism Spectrum Disorders by Hands in Autism** (Supported by grant number E/CCU524062-01 from CDC and other charitable organizations. The ongoing efforts of the project are primarily and currently supported through a grant from the Center for Exceptional Learners, Indiana Department of Education under Part B of the Individuals with Disabilities Education Improvement Act (P.L. 108-446))

This toolkit provides information for clinicians starting with diagnosis and designing treatment strategy and with a strong emphasis on strategies and techniques to ensure a productive clinic visit for an autism patient. It also includes a section of information designed for delivery to families.

**A Parent's Guide to Autism Spectrum Disorder** (National Institute of Mental Health (NIMH), Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD), Centers for Disease Control and Prevention (CDC))

This information packet focuses on autism, Asperger syndrome, and PDD-NOS, with brief descriptions of Rett syndrome and CDD in the section, "Related disorders," covering symptoms, diagnosis, co-occurring conditions, treatments and other related topics.

**A Guide for Military Families** (Organization for Autism Research)

This guide focuses on the special challenges of families dealing with autism as well as military service. It details Department of Defense policies and programs and the military healthcare system.

**Autism Tool Kit by Autism Connection of Pennsylvania** (Supported by The Advisory Board on Autism and Related Disorders (ABOARD))

This toolkit provides information and tools including communication and behavior cards to help improve social interactions for children, teens and adults with autism.

**Autism Spectrum Disorders: Missouri Best Practice Guidelines for Screening, Diagnosis and Assessment** (Missouri Department of Mental Health, Missouri Autism Guidelines Initiative, 2010)

These Guidelines are a direct outcome of the State of Missouri's Blue Ribbon Panel on Autism. Convened by Missouri State Sen. Mike Gibbons in 2007 at the request of the Thompson Foundation for Autism, the Blue Ribbon Panel consisted of 16 members whose

goal was to assist policymakers in recommending a better system to meet the needs of individuals with ASDs and their families.

**A Parent's Guide to Assessment** (Organization for Autism Research)

Assessments of a child's abilities can often be overwhelming and disappointing to parents. This guide explains assessment assays, what they measure and how to interpret the results in a way that can influence decision making.

**ATN/AIR-P Parent's Guide to Applied Behavior Analysis** (Autism Speaks, HRSA)

Applied Behavior Analysis is a basis for many behavioral treatments. This kit provides parents with a better understanding of the principles, how their child can benefit, and where to access these types of services.

**ATN/AIR-P An Introduction to Behavioral Health Treatments** (Autism Speaks, HRSA)

Behavioral challenges are a common problem for children with an autism spectrum disorder (ASD). Many children with ASD have challenges managing certain behaviors such as aggression or not following directions in addition to experiencing limitations in communication or social skills. This tool kit is designed to provide parents of children with ASD with an overview of in-home strategies as well as tips to teach and increase desirable behaviors and decrease behavior problems. This tool kit also provides caregivers with an overview of professional behavioral treatments that families can seek out from qualified professionals

**ATN/AIR-P Visual Supports and Autism Spectrum Disorder** (Autism Speaks, HRSA)

This kit provides an introduction to visual supports and the ways parents and caregivers can use them. It also provides actual visual supports to cut out and links with more detailed information.

**ATN/AIR-P Autism and Medication: Safe and Careful Use** (Autism Speaks, HRSA)

This kit aims to help families work effectively with healthcare providers to ensure that when medications are chosen as part of a treatment plan that they are used safely and effectively. It includes information on monitoring effectiveness as well as how to treat common side effects.

**ATN/AIR-P Blood Draw Tool Kit** (Autism Speaks, HRSA)

This kit provides a variety of strategies and tools to help a parent and child prepare for medical appointments. It particularly focuses on the anxiety surrounding a blood draw and preventing this anxiety from affecting the seeking of treatment and testing.

**ATN/AIR-P Medication Decision Aid** (Autism Speaks, HRSA)

This kit is designed to help families with the important decision of whether to include medications in the treatment plan for their child. It includes answers to frequently asked questions and tools to define your values and goals before talking with a healthcare provider about the use of medications.

**Participant's Guide to Autism Drug Research** (Autism Speaks)

This guide addresses the concerns related to enrolling as a participant in autism drug research. It aims to answer common questions as well as pose questions that are important to consider before enrolling in a drug research program.

**A Parent's Guide to Research** (Organization for Autism Research)

This guide is a primer on autism research and meant to serve as a reference for parents. It includes a glossary of terms and information on how to determine if a particular study is pertinent to a child.

**ATN/AIR-P Dental Professionals' Tool Kit** (Autism Speaks)

This kit provides dental providers with strategies to reduce children's anxiety levels and increase compliance while receiving dental services.

**Big Red Safety Toolkit for Caregivers and First Responders by Autism Wandering Awareness Alerts Response Education** (AWAARE) (Supported by AutismOne, Autism Speaks, Doug Flutie Jr. Foundation for Autism, HollyRod Foundation, National Autism Association, and Talk About Curing Autism)

The Caregiver toolkit provides information for caregivers of children and adults on the autism spectrum to help minimize wandering behavior and how to respond when elopement occurs. The First Responder toolkit provides information on autism spectrum disorder and wandering behaviors to first responders to improve their efficiency in locating and securing the missing person.

[**Investigative Checklist for Law Enforcement When Responding to Missing Children with Special Needs**](#)
(National Center for Missing and Exploited Children)

This Checklist is meant to enhance the response measures taken by law enforcement to safely recover missing children with special needs and is to be used in conjunction with the Missing Children With Special Needs addendum and Missing Children With Special Needs Lost-Person Questionnaire.

## Health and Medical Toolkits for Adults:

[**AASPIRE Healthcare Toolkit Project by Academic Autistic Spectrum Partnership in Research and Education (AASPIRE)**](#) (Supported by National Institute of Mental Health (NIMH) grant R34MH092503)

This is a study to develop a toolkit that improves healthcare access and quality for patients on the autism spectrum. After interviewing patients and caregivers about their experiences in the healthcare system, AASPIRE has developed a program to help individuals on the autism spectrum create a customized letter to communicate their needs and preferences to healthcare providers. They are now evaluating how providing this letter to a provider has affected healthcare services received by autistic patients.

## Health and Medical Resources for All:

[**Research Autism, UK: Database of Interventions, Treatments and Therapies for Autism**](#)

This database provides information about a wide range of interventions, including what they are, what they are supposed to achieve and whether there is any supporting scientific evidence behind them. It aims to provide a periodically-updated objective evaluation by experts of the scientific evidence behind the most commonly used interventions.  The database serves as a tool that individuals and families can use to help them understand the evidence supporting ASD interventions.

[**National Standards Report**](#) (National Autism Center, 2009)

This report provides comprehensive information about the level of scientific evidence that exists in support of the many educational and behavioral treatments currently available for individuals with Autism Spectrum Disorders (ASD). It aims to provide the strength of evidence supporting educational and behavioral treatments that target the core characteristics of these neurological disorders; describe the age, diagnosis, and skills/behaviors targeted for improvement associated; with treatment options; identify the limitations of the current body of research on autism treatment; and offer recommendations for engaging in evidence-based practice for ASD.

[Autism Spectrum Disorders: Guide to Evidence Based Interventions](#) (Missouri Department of Mental Health, Missouri Autism Guidelines Initiative, 2012)

This guide, produced by the Missouri Autism Guidelines Initiative, describes evidence based interventions for individuals with autism spectrum disorders (ASDs) based on six recent nationally recognized systematic research reviews. The document provides information and tools to support individuals with ASDs and their families and to assist healthcare professionals, educators, and other community-based service providers in making informed decisions about selection, implementation, and monitoring of ASD interventions.

# Transition, Employment and Housing Toolkits and Resources:

[Transition Tool Kit](#) (Autism Speaks)

This kit addresses the broad range of issues faced by autistic adolescents transitioning to adult life. It covers self-advocacy, employment, housing, healthcare and safety.

[A Guide for Transition to Adulthood](#) (Organization for Autism Research)

This guide encourages early planning for a transition to adulthood for a person with autism. It emphasizes collaboration and involvement in a community to establish a plan for an independent adulthood.

[Supported Employment Evidence-Based Practices (EBP) Kit by Substance Abuse & Mental Health Services Administration](#) (Substance Abuse and Mental Health Services Administration (SAMHSA))

This toolkit provides information regarding implementation of evidence-based practices in workplaces to support employment of those with serious mental illnesses. It includes information on training staff and evaluating the effectiveness of a supported employment program.

[Employment Tool Kit](#) (Autism Speaks)

This kit helps adults on the autism spectrum research, find and keep employment. The resources have been compiled from a variety of people including other adults with autism.

[**Housing and Residential Supports**](#) (Autism Speaks)

In transitioning from childhood to adult life, securing housing for adults with autism spectrum disorders can be challenging. This kit provides information on housing options and other supports and services needed by adults with autism.

## **Toolkits and Guides for Daily Living:**

[**ATN/AIR-P Parent's Guide to Toilet Training in Autism**](#) (Autism Speaks, HRSA)

This kit addresses the added challenges that children with an autism spectrum disorder may face when learning toilet training. It provides advice on schedules and routines and promoting visual supports.

[**ATN/AIR-P Sleep Tool Kit-Parent Booklet and Quick Tips**](#) (Autism Speaks, HRSA)

This kit provides parents with strategies to improve sleep in their children. The suggestions are based both on research as well as clinical experience of sleep experts.

[**Challenging Behaviors Tool Kit**](#) (Autism Speaks)

Sometimes individuals with autism will display challenging behaviors that are hard for parents and caregivers to understand and address. This kit provides strategies and resources to address these behaviors and ways to support the autistic individual as well as the family.

[**Dental Tool Kit**](#) (Autism Speaks)

Good oral hygiene habits may be difficult for some children with autism to establish. This kit provides a dental guide and tips for improving oral hygiene at home.

[**Tips for Successful Haircuts**](#) (Autism Speaks)

Haircuts can provoke anxiety in people with autism due to sensory issues or fear of an unknown process. This kit provides information as well as a video for families and stylists to make the haircut experience more positive.

# Education Toolkits

**Talking to Parents About Autism Kit** (Autism Speaks)

It is possible that an educator may be the first to notice signs of developmental delay in a child. This kit provides materials to help educators initiate a conversation with parents about the possibility of autism.

**School Community Tool Kit** (Autism Speaks)

This kit provides teachers and school administrators helpful information about students with autism. These tools and strategies can improve interactions and benefit the learning environment for all members of the community.

**An Educator's Guide to Autism** (Organization for Autism Research)

This guide is targeted to educators who are preparing to teach a child with autism in their classroom. It outlines six steps 1) educate yourself 2) reach out to parents 3) prepare the classroom 4) educate peers and set social goals 5) collaborate on the implementation of an educational program and 6) manage behavioral challenges.

**An Educator's Guide to Asperger Syndrome** (Organization for Autism Research)

This guide provides educators with basic information about Asperger Syndrome as well as strategies to better facilitate learning.

**Individualized Education Program (IEP) Guide and Other School Resources** (Autism Speaks)

This guide offers a timeline of an IEP and describes the steps necessary throughout the IEP process. The advice is provided by a team of lawyers at Goodwin Procter LLP.

**Navigating the Special Education System** (Organization for Autism Research)

This guide explains the special education system in the United States including the laws and regulations surrounding special education. It also details Individualized Education Programs and how to best advocate for a child with autism.

[Shouldn't School be Safe? Working Together to Keep Every Child Safe from Restraint and Seclusion in School](#) (TASH)

Shouldn't School Be Safe? is a free resource developed for parents and by parents that offers insight and advice to respond to and prevent restraint and seclusion.


[Roadmap to Seclusion and Restraint Free Mental Health Services](#) (CD) (SAMHSA)

Supports the training of direct-care staff in strategies for the prevention and elimination of seclusion and restraint in the treatment of people with serious mental illness or children with serious emotional disturbances. Uses approaches focused on consumer well-being.


[Restraint and Seclusion Resource Document](#)  (U.S. Dept. of Education)

The goal of this resource document is to help ensure that schools are safe and healthy environments where all students can learn, develop and participate in instructional programs that promote high levels of academic achievement.  This publication outlines principles for educators, parents and other stakeholders to consider when developing or refining policies and procedures to support positive behavioral interventions and avoid the use of restraint and seclusion.


# Comprehensive Services Reports, Studies and Resources:

**State of the States Project (Centers for Medicare and Medicaid Services)**

The State of the States project is broadly reviewing existing State programs and supports provided to autism spectrum disorder (ASD) people and their families across all 50 States and the District of Columbia. The project addresses 3 central questions:  1) What type of publicly funded services and supports are available for people with ASD?  2) How many people receive the supports?  and 3) How are States improving diagnosis and services for people with ASD, regardless of payment source?  Using quantitative and qualitative research methodologies, the project is collecting  information on how many people access ASD-related supports and services in a variety of service systems, including Social Security, the educational system, early intervention and employment services, institutional services, and Home and Community-Based Services. The content of service provision will be assessed by interviews with both State agencies and ASD stakeholders designed to address the types of services/supports available, extent of insurance coverage for those service/supports, leisure/recreational opportunities offered, staff training, and overall State policy infrastructure, among others. The results will provide the first comprehensive analysis of ASD services and supports available through State and Federal programs.

[Report on State Services to Individuals with Autism Spectrum Disorders (ASD)](#) (CMS)

This report, released on April 1, 2011, assesses the implementation of evidence-based/promising practices through the lens of state experience, summarizing the current state of ASD-related services in Arizona, California, Connecticut, Indiana, Maine, Missouri, New Mexico, Pennsylvania, and Wisconsin. The report describes the types of services and supports provided by state and local governments; the sources of funding for programs; and the policy, staffing and implementation issues to be addressed to effectively serve people with ASD.

[Autism Spectrum Disorders (ASD) Services Final Report on Environmental Scan](#)

In 2010, CMS issued this report, which is the result of a comprehensive review of scientific evidence regarding the efficacy, effectiveness, safety, and availability of ASD-related psychosocial services and supports for children, transitioning youth, and adults with ASD, including data on the evidence based interventions for people with ASD across the lifespan and data on the costs associated with providing services to people with ASD.

[AutismNOW](#) (Supported by Administration on Intellectual and Developmental Disabilities/Administration for Community Living)

This website is a comprehensive resource for both families and persons with autism. It has basic information about the disease as well as information relevant to all stages of life including employment, education, and community support.

[Madison House/Johns Hopkins University Project: Blueprint for a Nation](#)

MHAF is working with Johns Hopkins University School of Education on a multi-faceted study of the prevalence, issues, challenges, barriers and opportunities facing adults with autism and their families in the United States.  A renowned scholar will be appointed early in 2013 and will work collaboratively with JHU Schools of medicine, economics, public policy, public health and Kennedy Krieger Brain Institute. The first year's work will culminate with a whitepaper serving as a national blueprint for non-profits, federal and local governments, and private sector partners.  Experts across the country will be invited to share and contribute at key points in the study.