


Autism Speaks Toolkits: Resources for Busy Physicians

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Abstract

Given the increased prevalence of autism spectrum disorders (ASD), it is likely that busy primary care providers (PCP) are providing care to individuals with ASD in their practice. Autism Speaks provides a wealth of educational, medical, and treatment/intervention information resources for PCPs and families, including at least 32 toolkits. This article serves to familiarize PCPs and families on the different toolkits that are available on the Autism Speaks website. This article is intended to increase physicians' knowledge on the issues that families with children with ASD frequently encounter, to increase their ability to share evidence-based information to guide treatment and care for affected families in their practice.

Keywords

autism toolkits, Autism Speaks, autism, physician education, toolkits

Autism spectrum disorders (ASD) have increased in prevalence and in public awareness with the most recent estimates cited as 1 in 68 in the general population and 1 in 42 boys.¹ Research has also shown that persons with ASD experience increased prevalence of medical comorbidities, such as gastrointestinal problems,² seizures,³ feeding difficulties,⁴ sleep problems,⁵ and mental health diagnoses.⁶ We also know that for many children with ASD there are a myriad of behavioral issues and challenges in daily routine and schooling that can be overwhelming for families. The November 2012 supplement of *Pediatrics* is devoted to the above issues.⁷

Given this increasing prevalence, it is a certainty that primary care providers (especially pediatricians) will encounter children with ASD and associated comorbidities in their practices. Primary care providers need to be knowledgeable about medical and behavioral challenges common in children with ASD, provide management for medically related issues, and assist families in accessing services and interventions. At this time, the medical management of medical and behavioral co-morbidities in children with ASD is the same for typical children. Though the principles are the same, primary care providers often report that they lack training in managing medical and behavior issues for children with ASD.⁸ This perception of being inexperienced may arise from difficulties in implementing treatment plans due to the child's behaviors, a typicality, or developmental ability.

Autism Speaks is focused on supporting research into the causes, prevention, treatments and a cure for autism;

on increasing awareness of ASD; and on advocating for the needs of individuals with autism and their families.⁹ Autism Speaks has developed toolkits that provide evidence-based information and treatment suggestions on some of the most common issues facing individuals with autism.¹⁰ These toolkits are accessible and downloadable by the public at no cost through the Autism Speaks website (<http://www.autismspeaks.org>). Many of these toolkits provide specific recommendations on how to design and implement treatment plans. Other toolkits are more informative and are directed to parents, teachers, and other caregivers of children with ASD. This article will summarize these toolkits to provide a quick reference when this information is needed.

For ease of discussion, the toolkits have been classified into 6 main topics for this article.

Toolkits to Assist the Physician in Treating the Child With ASD

There are 3 toolkits written for providers on how to approach and initiate a conversation with a parent when there are concerns of a possible ASD in their child.

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Another helpful toolkit is one designed for professionals on how to give feedback to families when diagnosing an ASD. While originally intended for psychology trainees, it can be helpful for all medical and allied health members of your team.

As mentioned above, individuals with ASD have an increased likelihood to have seizure disorders, as well as sleep, gastrointestinal, and feeding difficulties. Toolkits have been created for each of these specific issues, such as sleep problems for children and teens, feeding problems, including pica behaviors (ingesting nonfood items), toileting, and for constipation.

Other medically related toolkits have been created to help professionals and parents as they navigate the medical/adaptive behavior procedures that could potentially be stressful for children. Toolkits on how to prepare a child for laboratory blood draws, dental appointments, eye examinations, and haircuts are also available on the Autism Speaks website.

The *Medical Decision Toolkit* and the *Safe and Careful Use of Medication in ASD Toolkit* can guide families as they weigh the possible benefits and risks of a medication intervention in the treatment of their child. Although not a toolkit, the *Complementary and Alternative Treatment* article on the Autism Speaks website reviews evidence-based information about commonly used complementary medicine treatment and gives links to research information on several treatments. Given that families with children with ASD may be recruited to participate in research studies, information in the *Participants Guide to Autism Drug Research Toolkit* may be useful in helping them understand common practices in ASD research.

Educational Information About ASD and Evidence-Based Treatment Options

Through an informal survey of Arkansas families with a child with ASD conducted in 2012, a majority of respondents indicated that information and education about ASD was a need.¹¹ *The First 100 Days Toolkit* (also available in Spanish) pertains to the first 100 days after a child is given a diagnosis of ASD. This toolkit provides families with information and guides them in the subsequent steps for the next several months. There are also toolkits designed for extended family (siblings, grandparents, and friends of individuals with ASD) to help increase their knowledge and understanding of ASD.

The *Applied Behavior Analysis* and *Visual Schedules Toolkits* give step-by-step directions on how to introduce some evidence-based therapeutic techniques in the home and classroom. In both *The First 100 Days* and the

Asperger/High Functioning Autism Toolkits there are excellent descriptions of evidence-based interventions for ASD (ie, speech therapy, occupational therapy, applied behavior analysis, use of visual supports, social stories, social skills, and cognitive behavioral therapy). There is also a toolkit to assist families with improving quality-of-life titled *Leading the Way: Autism-Friendly Youth Organization*.

One novel link on the Autism Speaks website lists software applications (“apps”) that might be helpful to persons with ASD. The information about Apps is not a toolkit specifically, but included under a specific tab on the AS website, at <http://www.autismspeaks.org/autism-apps>. The list of apps included there is quite long, and not all apps included have proven effectiveness; however, this growing list can provide families some initial information regarding a rapidly changing category of intervention/assistance for persons with ASD. In addition to the name of the app, AS has provided additional information about each app. This additional information helps families understand what skills are being targeted for intervention, what devices can download and use the app, the targeted age for the app, research on the app and any ratings given to the app.

Managing Challenging Behavior Toolkits

The primary care provider is often the first-line professional that a family approaches for help in managing challenging behavior of children and adolescents with ASD. Providers will benefit from reviewing the *Challenging Behavior Toolkit*. This toolkit is a 74-page download that also includes a link to videos of professionals discussing frequently asked questions about challenging behaviors from a legal and a clinical perspective. The *Intro to Behavioral Health Treatments Toolkit* provides caregivers/parents with an overview of in-home strategies they can use to manage difficult behaviors.

Accessing Appropriate Support in the School Setting

Through several toolkits, Autism Speaks provides excellent information about the IEP (Individualized Educational Plan) process. The *IEP Toolkit* gives information about Individuals with Disabilities Education Act (IDEA) and a student’s rights to a free and appropriate education. This toolkit includes links that show sample letters that a family may write to school personnel to initiate the IEP process. Important information to help parents become educated consumers such as the prescribed timeline of completion of the IEP process is also found in this toolkit. The *School*

Table 1. Toolkits to Help the Physician in Treating the Child With Autism Spectrum Disorders (ASD).

Name of Toolkit	Link to Toolkit
Talking to parents	
Talking to Parents about Autism	http://www.autismspeaks.org/what-autism/learn-signs/talking-parents-about-autism-action-kit
First Concern to Action	http://www.autismspeaks.org/early-access-care/first-concern-action
Guide on providing feedback to families affected by autism	http://www.autismspeaks.org/science/find-resources-programs/autism-treatment-network/tools-you-can-use/atn-air-p-providing-feedback-families
Medical concerns	
Strategies to Improve Sleep in Children with Autism Spectrum Disorders: A Parent's Guide	http://www.autismspeaks.org/science/resources-programs/autism-treatment-network/tools-you-can-use/sleep-tool-kit
Sleep Strategies for Teens with Autism Spectrum Disorder: A Guide for Parents	http://www.autismspeaks.org/science/resources-programs/autism-treatment-network/tools-you-can-use/sleep-tool-kit
Guide to Exploring Feeding Behavior in Autism	http://www.autismspeaks.org/science/find-resources-programs/autism-treatment-network/tools-you-can-use/atn-air-p-guide-exploring-feeding-behavior
Guides to Pica for Parents and Professionals	http://www.autismspeaks.org/science/resources-programs/autism-treatment-network/atn-air-p-pica-guides
Parent's Guide to Toilet Training in Autism	http://www.autismspeaks.org/science/resources-programs/autism-treatment-network/atn-air-p-toilet-training
Guide for Managing Constipation in Children	http://www.autismspeaks.org/science/find-resources-programs/autism-treatment-network/tools-you-can-use/atn-air-p-guide-managing-constipation-children
Medical procedures	
Blood draw	http://www.autismspeaks.org/science/resources-programs/autism-treatment-network/tools-you-can-use/blood-draw-toolkits
Dental	http://www.autismspeaks.org/family-services/tool-kits/dental-tool-kit
Eye examination	http://www.autismspeaks.org/science/find-resources-programs/autism-treatment-network/tools-you-can-use/atn-air-p-tools-successful-vision-exams
Haircuts	http://www.autismspeaks.org/family-services/tool-kits/tips-successful-haircuts
Medicine/research	
Medical Decision Making	http://www.autismspeaks.org/sites/default/files/documents/atn/medicine-decision-aid.pdf
Safe and Careful Use of Medication in ASD	http://www.autismspeaks.org/science/find-resources-programs/autism-treatment-network/tools-you-can-use/atn-air-p-autism-medication-safe-careful-use
Participants Guide to Autism Drug Research	http://www.autismspeaks.org/science/participate-research/participants-guide-drug-research
Complementary and Alternative Treatments for ASD	https://www.autismspeaks.org/what-autism/treatment/complementary-treatments-autism

Table 2. Educational Information on Autism Spectrum Disorders (ASD) and Evidence-Based Treatment Options.

Name of Toolkit	Link to Toolkit
First 100 Days	http://www.autismspeaks.org/family-services/tool-kits/100-day-kit
First 100 Days (Spanish version)	http://www.autismspeaks.org/family-services/tool-kits/manual-de-los-100-d%C3%ADas
Asperger Syndrome and High Functioning Autism	http://www.autismspeaks.org/family-services/tool-kits/asperger-syndrome-and-high-functioning-autism-tool-kit
Info for Extended family	http://www.autismspeaks.org/family-services/tool-kits/family-support-tool-kits
Family Support	http://family-services/tool-kits/family-support-tool-kits
Parent's Guide to Applied Behavior Analysis	http://www.autismspeaks.org/science/resources-programs/autism-treatment-network/atn-air-p-applied-behavior-analysis
Visual Supports	http://www.autismspeaks.org/science/resources-programs/autism-treatment-network/tools-you-can-use/visual-supports
Leading the Way: Autism-Friendly Youth Organizations	http://www.autismspeaks.org/family-services/youth-organizations

Table 3. Managing Challenging Behaviors Toolkits.

Name of Toolkit	Link to Toolkit
Managing Challenging Behaviors	http://www.autismspeaks.org/family-services/tool-kits/challenging-behaviors-tool-kit
Introduction to Behavioral Health Treatments	http://www.autismspeaks.org/science/resources-programs/autism-treatment-network-atn-air-p-behavioral-health-treatments

Table 4. Toolkits on Accessing Appropriate Support in the School Setting.

Name of Toolkit	Link to Toolkit
IEP (Individualized Educational Plan) Guide	http://www.autismspeaks.org/family-services/tool-kits/iep-guide
Bullying	http://specialneeds.thebullyproject.com/
School Community	http://www.autismspeaks.org/family-services/tool-kits/school-community-tool-kit

Table 5. Toolkits to Assist With Transition to Adulthood.

Name of Toolkit	Link to Toolkit
Employment	http://www.autismspeaks.org/family-services/tool-kits/employment
Community-Based Skills Assessment	https://www.autismspeaks.org/family-services/community-based-skills-assessment
Transition to Adulthood	http://www.autismspeaks.org/family-services/tool-kits/transition-tool-kit
Housing and Community Living	http://www.autismspeaks.org/family-services/housing-and-community-living
Postsecondary Education	http://www.autismspeaks.org/family-services/tool-kits/postsecondary

Table 6. Toolkits on Advocacy and Autism Awareness.

Name of Toolkit	Link to Toolkit
Advocacy Tool Kit	http://www.autismspeaks.org/family-services/tool-kits/advocacy
Puzzle Piece Project and Autism Awareness Month	http://www.autismspeaks.org/family-services/tool-kits/puzzle-piece-project-tool-kit

Community Toolkit provides a wealth of information such as printable handouts about ASD for bus drivers and other school workers as well as best practice teaching strategies for the classroom teacher. Although not a toolkit, if you go to the Family Services section of the Autism Speaks website and click on *Combating Bullying*, you will be directed to a website for an antibullying toolkit.

Toolkits to Assist With Transition Into Adulthood

Transitioning into adult services and into the postsecondary or work force can be a daunting task for parents and the professionals who work with individuals with ASD. These toolkits (Employment, Community Skills Based Assessment, Transition to Adulthood, Housing and Community Living, and Postsecondary Education)

can give the teen with ASD and their support team a good overview of how to proceed as they approach high school graduation.

Toolkits on Advocacy and Autism Awareness

The Advocacy Toolkit provides pointers on how to advocate successfully for a child in the school and in the community. There is also a toolkit that shares ideas on ways information about autism can be shared within a community during Autism Awareness Month.

By going to the Autism Speaks website, you can access all of this information easily by clicking on Family Services, Resource Guide or Tool Kits. Links for each toolkit individually is provided in Tables 1-6. There is a host of additional information on the website that

can be excellent resources for your practice if you work with individuals on the autism spectrum. New toolkits are being developed constantly, so this it will be important to regularly visit the Autism Speaks website to see what new resources will be available in the future.

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JB had the concept for the article and wrote the majority of the content. ML and JJF contributed on content, construction of tables, and editing.

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