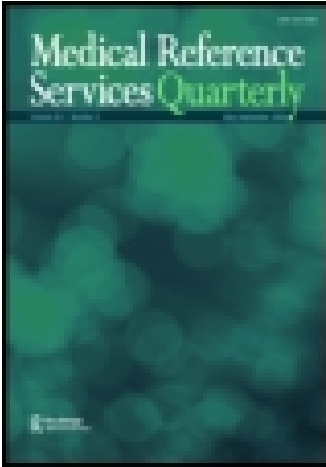


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### Autism Spectrum Disorders: Wading Through the Controversies on the Web

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## NAVIGATE THE NET

*Dawn Littleton, Column Editor*

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### **Autism Spectrum Disorders: Wading Through the Controversies on the Web**

HEATHER COATES

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*Autism is one of three developmental disorders in the group known as the autism spectrum disorders (ASDs). This spectrum of disorders has an estimated prevalence of one in 150 children. Increased awareness and diagnosis has led to an explosion of information available about the disorder. This explosion has made scientific research more readily available, along with inaccurate and spurious information. Autism is a disorder without a known cause or cure and few treatments with sufficient evidence to indicate effectiveness. Due to the variable presentation of autism, there is no single intervention that is effective for all individuals. The complexity of the disorder is addressed by research and practice across several disciplines, including education, psychology, psychiatry, neurology, genetics, and internal medicine. This resource guide will introduce the range of autism spectrum disorders, its various perspectives and treatments, and will point librarians and patrons to introductory resources to provide links for further learning.*

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*KEYWORDS* Asperger's disorder, autism, autism spectrum disorders, Internet, pervasive development disorder—not otherwise specified

## INTRODUCTION

We hear about autism frequently these days, particularly warnings that its prevalence is increasing. Autism Speaks states that one in 150 children have autism.<sup>1</sup> Other claims are more nebulous and come from friends, family, co-workers, and the Internet. Often these statements are powerful, easy to remember, and seemingly straightforward. "Autism is an epidemic." "Autism is caused by the toxins in MMR vaccines." "People with autism don't have feelings." "Kids grow out of it." "Autism can be cured" . . . with medication, a carefully controlled diet, hyperbaric chambers, music therapy, hippotherapy, and so on.

Distinguishing popular opinion from statements supported by scientific evidence is particularly challenging in the case of autism. The most significant challenge for professionals and patients alike is not the lack of understanding about the cause of autism. Rather, it is the abundance of conflicting information, even research data, from the various fields studying autism and the organizations that stand to benefit from perpetuating inaccuracies. There are many misconceptions about autism, which is why finding quality, scientifically based information is particularly difficult for this topic. One of the most challenging misconceptions is that "autism" is a single disorder; another is to consider those diagnosed with ASD as a homogeneous group when discussing treatments.

Autism is just one of a group of disorders known as Autism Spectrum Disorders (ASDs). This group contains three disorders distinct from other developmental disabilities due to the impairment in social relating skills. The autism spectrum includes three distinct disorders: autistic disorder (what is typically called autism), Asperger's Disorder, and Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS). ASDs are designated as a spectrum of disorders because of the wide range of signs and symptoms that can be displayed, ranging from relatively mild to severe. This designation is partly due to the lack of a known cause; in fact, it is likely that autism spectrum disorders are caused by a complex confluence of environmental exposure and genetic susceptibility. Although there is no causative evidence, the prevalence of autism in people with other medical conditions such as Fragile X Syndrome is higher than expected.<sup>2</sup> However, there is insufficient scientific evidence to suggest that the MMR vaccine causes autism, either due to the vaccine itself, the presence of thimerosal (no longer in the MMR vaccine), or the simultaneous administration of multiple vaccines.<sup>3</sup>

Autism is a developmental disorder characterized by significant impairments in social interaction, communication, and restricted or repetitive behaviors or interests<sup>4</sup> to the extent that they interfere with the functioning of the individual. A medical diagnosis is (always, according to the DSM-IV criteria) made based on the individual's development and functioning between birth and three years of age. This narrow window for direct observation by a clinician can present significant challenges in the diagnostic process. If a child is not evaluated prior to age three, the diagnosis is made using medical records, school records, and parent report, among other documents. Many pediatricians and family physicians are not comfortable making a diagnosis due to lack of training; subsequently, ASD diagnosis is often made by a psychiatrist or clinical psychologist. In the school system, the classification is made by a team, usually consisting of the teacher of record, school psychologist, autism consultant, speech therapist, and occupational therapist. In both the medical and educational systems, diagnosis (medical) or classification (school system) is required for an individual to receive services. These lengthy and difficult processes are exacerbated by the lack of appropriately trained providers available.

Even after diagnosis, individuals with an ASD and their families face many challenges in obtaining appropriate treatment. The complex and variable nature of the spectrum combined with significant impairments in social relating skills means that successful interventions are multifaceted, long-term, and expensive. The research bases of education and psychology provide some clues to the types of programs that have significant empirical support. However, it is important to keep in mind that no single program is effective for all individuals with an ASD.<sup>5</sup> The components of successful programs include structured treatment using principles of Applied Behavior Analysis (ABA); parent involvement in all areas; early intervention; intensive treatment; programming for generalization; specific curricula that emphasize social and communication skills; and integration with peers when possible.<sup>5</sup> Currently, there is only one FDA-approved medication, Risperdal<sup>TM</sup>, for symptoms of irritability associated with autism.<sup>6</sup>

#### SITE SELECTION CRITERIA

Each site listed here was selected because it met the following criteria.

- A significant portion of the information provided is based on scientific research
- Does not advocate or propose a "cure"
- Does not advocate expensive treatments or treatments that may cause harm
- Does not advocate one treatment for all individuals on the spectrum
- Recognition of the individuality of presentation of the disorder across people and growth throughout the lifespan.

The preponderance of government sites is due to relative uncertainty regarding the cause of and most appropriate treatments for ASDs. Research examining the physiological mechanisms of autism have begun relatively recently and still have far to go. The controversy over possible causes and treatments is reflected in the endorsements of many parent groups and non-profit organizations. The intense desire for a cure often leads parent groups and non-profit organizations to endorse treatments without sufficient evidence of effectiveness. The sites selected for this guide may be overly conservative when considering treatment options, but the information and conclusions are based firmly on scientific evidence.

## WEB RESOURCES

The sites are broadly organized according to common questions faced by individuals with an ASD and those who care for them. Due to the enormous variety of intervention approaches from multiple disciplines, this guide cannot be considered comprehensive. Instead, the topics and resources included should be considered starting points for those learning about autism spectrum disorders.

General Information, Diagnosis, and Screening

### **CDC Autism Information Center**

<<http://www.cdc.gov/ncbddd/autism/>>

The CDC Autism Information Center serves as a portal for information from National Centers and several NIH departments. A wide array of topics includes an introductory overview, screening and diagnosis, treatment and therapy, FAQ, relevant CDC activities, recent publications and news alerts, and tools. This site is an excellent place to begin learning about ASDs due to the quality, current information for parents, educators, clinicians, and researchers. A particularly useful feature on this portal are the links to relevant Congressional and CDC activities, which provide current and historical information. The CDC activities link will direct users to the “Learn the Signs. Act Early.” campaign page, from which users can request information packets on developmental milestones at no cost.

### **CDC: Immunization Safety and Autism: Thimerosal and Autism Research Agenda**

<[http://www.cdc.gov/ncbddd/autism/documents/vaccine\\_studies.pdf](http://www.cdc.gov/ncbddd/autism/documents/vaccine_studies.pdf)>

As of January 2009, this document summarizes the vaccine studies completed or being conducted by the CDC. A brief description of each study, estimated publication date, and focus area are provided.

**MedlinePlus HealthTopics: Autism**

<<http://www.nlm.nih.gov/medlineplus/autism.html>>

The MedlinePlus site provides information in consumer-friendly language: “Children with autism might have problems talking with you, or they might not look you in the eye when you talk to them. They may have to line up their pencils before they can pay attention, or they may say the same sentence again and again to calm themselves down. They may flap their arms to tell you they are happy, or they might hurt themselves to tell you they are not. Some people with autism never learn how to talk.”

The scope is primarily medical and health information related to ASDs, with significant coverage of current research including full text of open access journal articles. A special feature is the option of viewing the content in several languages, including Spanish, Russian, and Somali.

**NICHD Autism Overview: What We Know**

<[http://www.nichd.nih.gov/publications/pubs/upload/autism\\_overview\\_2005.pdf](http://www.nichd.nih.gov/publications/pubs/upload/autism_overview_2005.pdf)>

Designed primarily for parents, this booklet, published by the National Institute of Child Health and Human Development in 2005, includes a list of references for health care professionals. The organization of content into common questions is consumer-friendly, and the glossary is well-written, for example: “This fact sheet offers broad information about autism and answers some of the more common questions that parents and families often have about the disorder. You can get more detailed information on these topics from the sources listed in the References section. Keep in mind that the articles listed are geared toward scientists and researchers, so the information is more technical than what is presented here.”

**National Institute of Mental Health (NIMH): Autism Spectrum Disorders**

<<http://www.nimh.nih.gov/health/publications/autism/nimhautismspectrum.pdf>>

This NIMH booklet provides a broad overview of ASDs, including the history of the disorder, description of the spectrum disorders, the diagnostic process, treatment options, and other relevant topics for parents. Several sections provide direct recommendations to parents. The language may be somewhat challenging for individuals with low literacy. For example: “There is no single best treatment package for all children with ASD. One point that most professionals agree on is that early intervention is important; another is that most individuals with ASD respond well to highly structured, specialized programs. Before you make decisions on your child’s treatment, you will want to gather information about the various options available.

Learn as much as you can, look at all the options, and make your decision on your child's treatment based on your child's needs. You may want to visit public schools in your area to see the type of program they offer to special needs children."

## Clinical Treatment and Research

### **ClinicalTrials.gov**

<<http://clinicaltrials.gov>>

"ClinicalTrials.gov is a registry of federally and privately supported clinical trials conducted in the United States and worldwide. ClinicalTrials.gov gives you information about a trial's purpose, who may participate, locations, and phone numbers for more details. This information should be used in conjunction with advice from health care professionals." This site includes many clinical studies conducted on autism spectrum disorders.

### **Interactive Autism Network (IAN)**

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

A unique site, IAN states its purpose is to bring patients and researchers together to advance the pace of research: "IAN, the Interactive Autism Network, is an innovative online project designed to accelerate the pace of autism research by linking researchers and families. Anyone impacted by an Autism Spectrum Disorder (ASD) can become part of IAN's online community to stay informed about autism research, provide feedback, and make their voices heard."

## Early and School-based Intervention

### **The Council for Exceptional Children**

<<http://www.cec.sped.org/>>

In special education, as in other fields, the definition of evidence-based practices is still being determined. CEC is an international organization that advocates for appropriate policies and standards to support those educating individuals with disabilities and exceptional talents. While the evidence-based practice discussion continues, CEC is assisting educators in selecting practices that are empirically supported: "CEC is taking a leading role in defining and presenting evidence-based practices for the field. CEC's Professional Standards & Practice Committee has developed a comprehensive proposal for evidence-based practices. The proposal will select criteria to identify evidence-based practices and develop a process by which CEC would identify these practices."

**Interagency Autism Coordinating Committee (IACC)**

<<http://iacc.hhs.gov/reports/>>

The IACC was established to comply with the Combating Autism Act of 2006. Several seminal reports have been issued that are directly affecting both practice and research of ASD-related issues. From the site: “The EWG is a diverse group comprising of members with special ASD expertise—service providers, educators, community program coordinators, researchers, individuals with ASD, and family members of individuals with ASD. The EWG was asked to review the state of the field and identify principles of best practices, challenges, and recommendations to provide the blueprint for a national public and private implementation plan for expanding and improving ASD services.”

**Autism Society of America (ASA): Individualized Education Plan**

<[http://www.autism-society.org/site/PageServer?pagename=life\\_edu\\_IEP](http://www.autism-society.org/site/PageServer?pagename=life_edu_IEP)>

Generally, ASA is an advocacy group that also provides information to parents. This page describes the basic purpose and guidelines of an Individualized Education Plan, as mandated by the Individuals with Disabilities Education Improvement Act (IDEIA). In describing the relevant federal statutes (IDEA, IDEIA, and NCLB), this article describes in plain language the basic educational rights of students and their caregivers. The process of developing the IEP, elements, and relevant inputs are described generally. The IEP is a federally mandated tool for individualizing education for students with special needs; this article provides a clear and simple introduction.

**Laws and Legal Rights**

Fortunately, there are federal laws that mandate Free and Appropriate Education (FAPE) for individuals with certain disabilities. The relevant federal education laws are the Individuals with Disabilities Education Act (IDEA), the Individuals with Disabilities Education Improvement Act (IDEIA), and No Child Left Behind (NCLB). In addition, individuals with disabilities are covered more generally in the Americans with Disabilities Act (ADA).

**ED.gov: Individuals with Disabilities Education Act (IDEA) 2004**

<<http://idea.ed.gov/>>

This is the official site for IDEA by the U.S. Department of Education. “The Individuals with Disabilities Education Act is a law ensuring services to children with disabilities throughout the nation. IDEA governs how states and public agencies provide early intervention, special education and related services to more than 6.5 million eligible infants, toddlers, children, and youth with disabilities.”



**No Child Left Behind (NCLB)**

<<http://www.ed.gov/nclb/landing.jhtml>>

This is the official site of the NCLB. There are many tools available for parents and professionals, but navigating the site may be challenging.

**Americans with Disabilities Act (ADA)**

<<http://www.ada.gov/cguide.htm>>

This is a guide for consumers to the ADA on the official ADA site. Relevant topics to ASDs include employment, public transportation, and accommodations. “The ADA prohibits discrimination on the basis of disability in employment, state and local government, public accommodations, commercial facilities, transportation, and telecommunications. It also applies to the United States Congress. To be protected by the ADA, one must have a disability or have a relationship or association with an individual with a disability. An individual with a disability is defined by the ADA as a person who has a physical or mental impairment that substantially limits one or more major life activities, a person who has a history or record of such as impairment, or a person who is perceived by others as having such an impairment. The ADA does not specifically name all of the impairments that are covered.”

## CONCLUSION

Autism is a developmental disorder distinguished from others by significant impairments in social relating skills. An individual with an ASD can make progress if appropriate goals are set but will never outgrow their disorder. Research indicates that early intervention offers significant positive differences when compared to later interventions.<sup>7</sup> As research continues to shed light on the causes of and effective treatments for ASDs, the information available will converge; until that time, it is necessary to exercise caution when searching for information. This guide should enable both librarians and consumers who are new to the area to find relevant, empirically supported information that addresses specific needs.

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