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# Autism Spectrum Disorder

## *A Guide to the Latest Resources*

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Since the early 1990s there has been a steady escalation in the numbers of children diagnosed with autism spectrum disorder (ASD)—today it is considered the fastest growing developmental disability in the United States. In 2010, it was estimated that 1 in 68 children were affected by autism spectrum disorder. This is an increase of approximately 120 percent from the data collected ten years earlier.<sup>1</sup> Identifying it as one of six neurodevelopmental disorders, the American Psychiatric Association's *Diagnostic and Statistical Manual of Mental Disorders (DSM-5)* describes autism spectrum disorder as “a series of developmental disabilities characterized by impaired social communication and interaction skills, accompanied by the existence of repetitive behaviors or activities, such as rocking movements, hand clapping or obsessively arranging personal belongings.”<sup>2</sup>

Attributed to Dr. Stephen Shore, author and educator who lives with autism and asperger, there is a well-known expression among those in the autism community: “If you meet one person with autism, you’ve met one person with autism.”<sup>3</sup> This comment speaks to the varying degrees of autism spectrum disorder, as every autistic individual is affected in a different way. Some individuals with autism have severe impairments requiring around the clock care, while some are able to lead a relatively normal life, including holding down a full-time job and raising a family. Despite decades of immense research efforts, the precise cause of autism is still unknown. And although a cure has eluded researchers, there are several interventions that have been relatively successful in treating the disability.

Accompanying the surge in autism diagnoses, and the subsequent heightened awareness of the disorder, is the deluge of resources available to researchers, practitioners, and those living with the disability. In truth, the vast number of resources available on autism spectrum disorder are overwhelming. The resources presented in this guide are merely a small sampling of what is available. Print publications, with the exception of periodicals, have been narrowed to those published within the last ten years. Moreover, the resources introduced here are appropriate for a variety of users, including parents, educators, practitioners, and researchers.

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### REFERENCE SOURCES

Some of the reference sources and books were selected after consulting book review sources such as *CHOICE: Reviews for Academic Libraries*. Others were located through searches of the library catalog and electronic databases such as

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## THE ALERT COLLECTOR

*PsycINFO*. Reference sources and books are listed in alphabetical order by author.

Myles, Brenda Smith, et al, eds. *Autism Spectrum Disorders: A Handbook for Parents and Professionals*. Westport, CT: Praeger, 2007 (ISBN: 978-031-333632-4).

This two-volume, A-to-Z reference set provides a diverse collection of entries from dozens of professionals in the fields of education, psychology, and medicine. Also included are four invaluable appendixes listing relevant newsletters, journals, organizations, and personal perspectives. A comprehensive index enhances the usability of this set.

Stillman, William. *The Autism Answer Book: More than 300 of the Top Questions Parents Ask*. Naperville, IL: Sourcebooks, 2007 (ISBN: 978-140-220977-2).

This easy to use book is an indispensable reference source for families living with autism. Each one of the twelve chapters focuses on a particular issues, such as communication skills, physical well-being, school success, and guidance on how to discipline a child with autism. Three appendixes are included.

Volkmar, Fred R., ed. *Encyclopedia of Autism Spectrum Disorders*. New York: Springer, 2013 (ISBN: 978-144-191697-6).

Edited by Fred Volkmar, director of the Yale University Child Study Center at the Yale University Medical Center, this comprehensive, five volume reference guide to autism contains entries by hundreds of experts from the fields of education, psychology, medicine, and social work. More than 1,000 entries address topics such as child and school psychology, neuropsychology, psychiatry, and social work. The reference entries are supported by dozens of illustrations and tables.

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## BOOKS

Conn, Carmel. *Autism and the Social World of Childhood: a Sociocultural Perspective on Theory and Practice*. New York: Routledge, 2014 (ISBN: 978-041-583833-7).

Focusing specifically on children in the primary grades, Conn explores the social interactions, friendships, and play of children. Part one examines the theoretical issues surrounding the social interaction of children with and without autism. Part two focuses on the practical aspects of inclusiveness in educational settings. The author shares multiple real life accounts of children's experiences and provides guidance on educational methods for supporting the development of play in children with autism. Each chapter concludes with a brief summary.

Feinstein, Adam. *A History of Autism: Conversations with the Pioneers*. Chichester, West Sussex, United Kingdom: Wiley-Blackwell, 2010 (ISBN: 978-140-518653-7).

In an effort to address many of the long-standing misconceptions about autism spectrum disorders, the author

examines the history of autism research beginning with the work of pioneers Leo Kanner and Hans Asperger. Feinstein's study traces the evolution of autism studies from an era in which autistic children were considered emotionless shells and parents were blamed for the disability to one in which millions of dollars are poured into autism research and advocacy groups flourish. The last chapter of Feinstein's study examines autism in developing nations and finds that services and advocacy for autism spectrum disorders are indeed becoming more widespread. The author concludes that despite the forward progression in autism research, there are still mountains to climb in seeking a cause and a cure.

Fitzpatrick, Michael. *Defeating Autism: A Damaging Delusion*. London: Routledge, 2009 (ISBN: 978-041-544981-6).

For hundreds of years quackery and unorthodox treatments have claimed to cure just about every malady and disorder known to man. Autism has proven to be a consistently profitable business in the realm of questionable therapies. As a practicing physician and father of an autistic child, Fitzpatrick has witnessed the effects of risky and expensive alternative or biomedical treatments reported to cure autism. His book sets out to investigate and discredit the biomedical movement and its "defeat autism" mentality. In the last chapter he urges desperate parents to be appropriately critical of "too good to be true" therapies and provides guidance with a series of questions they must ask of doctors, scientists and advocacy groups who claim to offer a cure.

Goldstein, Sam, Jack A. Naglieri, and Sally Ozonoff, eds. *Assessment of Autism Spectrum Disorders*. New York: The Guilford Press, 2009 (ISBN: 978-159-385983-1).

According to its editors, this book is the first one dedicated to examining dependable methods of evaluation of autism spectrum disorders. Following a historical perspective and overview are chapters devoted to the discussions of developments in autism assessment, and the instruments used in specific fields of autism research, such as social behavior, speech, language and communication, and neuropsychological functioning.

Gallo-Lopez, Loretta and Lawrence C. Rubin, eds. *Play-based Interventions for Children and Adolescents with Autism Spectrum Disorders*. New York: Routledge, 2012 (ISBN: 978-041-589075-5).

Written for practitioners, this book is a compilation of articles fusing theory and practice in the use of play-based therapies. Following an initial section that illustrates the significance of play-based therapies, the remainder of this volume addresses three types of play-based interventions: individualized, programmatic, and expressive or creative. Multiple treatments and therapies are profiled throughout the articles, including canine, art, music, and dance therapy.

Grinker, Roy Richard. *Unstrange Minds: Remapping the World of Autism*. New York: Basic Books, 2007 (ISBN: 978-046-502764-4).

Grinker, an anthropologist and the father of a child with autism, illustrates the way culture affects how we see autism spectrum disorders. Part one traces the growth of autism research, from its infancy in the 1940s, to the stigma associated with the disorder, to current research and philanthropy. Part two examines the attitudes about autism spectrum disorders in several other countries, some of which have no word for autism and continue to label it as a disease. This book was a finalist for the 2007 Victor Turner Prize.

Hanbury, Martin. *Positive Behaviour Strategies to Support Children and Young People with Autism*. London: Paul Chapman Publishing, 2007 (ISBN: 978-141-292911-0).

This work, geared toward parents and teachers working with children and young adults on the autism spectrum, offers proactive strategies to deal with challenging behaviors. For the purpose of this study, the author defines challenging behaviors as those that are destructive, disruptive, violent, and those that cause self-injury. Hanbury provides detailed guidance on understanding behavior support and creating a healthy, calming environment for those with autism. Peppered with case studies, this book also includes an appendix of training materials and a glossary.

Kalyva, Efrosini. *Autism: Educational and Therapeutic Approaches*. Los Angeles: SAGE, 2011 (ISBN: 978-085-702488-6).

Using the most recent scientific evidence, the author documents the most effective therapies available to children and adults with autism spectrum disorder. Among the interventions discussed are cognitive-behavioral approaches, sensorimotor approaches, and biochemical approaches. Stating that this is not simply a blueprint of therapies, Kalyva encourages parents, educators, and practitioners to think critically about the effectiveness of chosen treatments and adjust them to the needs of the individual. Each chapter includes a series of questions for discussion.

Offit, Paul A. *Autism's False Prophets: Bad Science, Risky Medicine, and the Search for a Cure*. New York: Columbia University Press, 2008 (ISBN: 978-023-114636-4).

This book, written by the Director of the Vaccine Education Center at Children's Hospital of Philadelphia, tackles the misconceptions surrounding the relationship between childhood vaccines and autism. The author also chronicles the succession of fraudulent therapies for autism promoted by well-meaning doctors, their supporters, and the media. This book was selected as a CHOICE Outstanding Title in 2008.

Volkmar, Fred. *A Practical Guide to Autism: What Every Parent, Family Member, and Teacher Needs to Know*. Hoboken, NJ: Wiley, 2009 (ISBN: 978-047-039473-1).

The goal of this comprehensive guide is to provide family members and educators with the tools needed to

cope with all aspects of autism spectrum disorder. Topics addressed include how to go about finding services and appropriate educational interventions, managing medical issues, dealing with behavior problems, and understanding alternative and complimentary treatments. Each chapter concludes with a brief summary, suggestions for further reading, and a series of questions and answers relevant to that chapter's topic.

Waterhouse, Lynn. *Rethinking Autism: Variation and Complexity*. London: Elsevier, 2013 (ISBN: 978-012-415961-7).

Best suited for researchers and clinicians, this book suggests that autism is not simply one disorder or even a spectrum of disorders, but is instead a symptom (much like a fever) of multiple brain abnormalities. Waterhouse believes that the continued diagnoses of autism as a single disorder hinders the efforts of researchers who should instead be focused on the heterogeneity of autism and the developmental brain disturbances that cause the disorder.

Williams, Betty Fry, and Randy Lee Williams. *Effective Programs for Treating Autism Spectrum Disorder: Applied Behavior Analysis Models*. New York: Routledge, 2011 (ISBN: 978-041-599931-1).

With an emphasis on applied behavior analysis, the authors provide an overview of the most successful evidence-based therapies for autism spectrum disorder. Their thorough examination of applied behavior analysis includes a review of the behavioral principles of learning, followed by several procedures based upon these principles. Comprising the bulk of this volume, the third section is an assessment of the features, services, and research efforts of eight effective treatment programs.

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## PEER-REVIEWED JOURNALS

*UlrichsWeb Global Serials Directory* and the Thomson Reuters database *Journal Citation Reports* were consulted for peer-reviewed journals on autism or journals in which autism topics are plentiful. The following journals were selected for inclusion. They are all appropriate for academic and research libraries. They are listed in descending order by impact factor. The impact factor is the average number of citations an article in a given journal receives. The impact factor gives the user some indication of how influential a journal is.

*Autism Research*. Hoboken, New Jersey: Wiley, 2008– (ISSN: 1939-3806).

This journal publishes original, empirical articles that focus on a developmental approach to the biology and psychology of autism. *Wiley Online Library* provides full-text access to this journal. Indexed and abstracted in *SCOPUS*, *MEDLINE*, and *Social Sciences Citation Index*, this journal has an impact factor of 4.330.

*Autism: The International Journal of Research and Practice.* London: SAGE, Ltd, 1997–. Bi-monthly (ISSN: 1362-3613).

This journal is published in association with the National Autistic Society in the United Kingdom. It publishes original articles in the fields of psychiatry, neurology, and psychology in an effort to improve the quality of life for those with autism spectrum disorder. This title is available full-text in the *HighWire Press* database and the *SAGE Health Sciences* and *Clinical Medicine* packages. Multiple *EBSCO* databases, *Scopus*, and *Web of Science* index and abstract this journal. It has an impact factor 3.639.

*Journal of Autism and Developmental Disorders.* New York: Springer, 1971–. Monthly (ISSN: 0162-3257).

Focusing on all aspects of research on autism spectrum disorder and its related developmental disabilities, the mission of this journal is to promote the understanding of autism and its causes. It includes original experimental articles and case studies examining behavioral, biological and educational interventions. Full-text articles may be found in the *SpringerLINK* database. Indexes and abstracts of this journal are found in multiple *EBSCO* and *ProQuest* databases, and *Web of Science*. This journal has an impact factor of 3.665.

*Research in Autism Spectrum Disorders.* Philadelphia: Elsevier, 2007–. Monthly (ISSN: 1750-9467).

With a focus on applied topics, this journal publishes empirical articles on the assessment of subjects with autism and the educational and psychological interventions used in treating them. Full-text access is available in the *ScienceDirect Freedom Collection* database. *ERIC* provides abstracting and indexing for this journal. Its impact factor is 2.212.

*Focus on Autism and Other Developmental Disabilities.* Thousand Oaks, CA: SAGE, 1986–. Quarterly (ISSN: 1088-3576).

This journal publishes articles that are appropriate for the practitioner involved in the education and treatment of children with autism and pervasive developmental disorders. Full-text access is available in the *HighWire Press* database, and *SAGE Premier* databases. Indexes and abstracts are available in *ERIC*, *Gale Academic ASAP*, and multiple *EBSCO* databases. It has an impact factor of 1.265.

*Journal of Applied Behavior Analysis.* Wiley-Blackwell, 1968–. Quarterly (ISSN: 0021-8855).

The goal of this psychology journal, a publication of the *Society for the Experimental Analysis of Behavior*, is to publish original research articles about experimental applications of applied behavior analysis. Full-text access to this journal is available in *LexisNexis* and multiple *EBSCO* databases. Indexes and abstracts may be found in *Gale's Professional Collection* and *Psychology Collection* databases, and *PubMed*. This journal has an impact factor of 1.088.

## WEBSITES

A recent Google search for autism returned more than 68 million results. Combing the Internet for reliable sources takes time and patience. The websites listed here are the official online faces of various organizations and institutes dedicated to the research, study, and advocacy of autism spectrum disorders.

Autism Research Institute, [www.autism.com](http://www.autism.com)

Founded in the late 1960s by one of the pioneers of autism research, Dr. Bernard Rimland, the Autism Research Institute believes that autism is indeed treatable through various methods such as behavioral therapy, diet and nutrition, and medical and sensory interventions. The institute's website provides parents and professionals with the tools necessary to support individuals with autism. Noteworthy resources at this site include a series of free webinars and conference proceedings conducted by leading experts in the field of autism research. An archive of past webinars and conference proceedings is also accessible.

Autism Science Foundation, <http://autismsciencefoundation.org>

In an effort to find the causes of autism spectrum disorder and to develop innovative and effective therapies, the Autism Science Foundation funds the latest and most advanced scientific research. Founded in 2009, this nonprofit organization has funded over one million dollars in autism research grants. Its website provides an extensive list of resources and funding opportunities for researchers, including funding calendars, applications for fellowships, research mini-grants, and undergraduate research grants. Users can also view current and previous grantees of ASF funded research, and grant outcomes reports.

Autism Speaks, <https://www.autismspeaks.org/site-wide/autism-spectrum-disorder>

This nonprofit organization was founded in 2005 by the grandparents of an autistic child. Its website is a gold mine of information for families of autistic children, adults with autism, educators, and researchers. Among the resources available here is a guide to the services offered by the Autism Speaks Autism Treatment Network (ATN), and free downloadable tool kits addressing a variety of topics. This site is unique in offering access to a team of individuals called the Autism Response Team (ART). Located throughout the United States, this group of dedicated men and women provide personalized support and information (via email and telephone) to families and individuals living with autism.

CDC Autism Spectrum Disorders, [www.cdc.gov/ncbddd/autism/index.html](http://www.cdc.gov/ncbddd/autism/index.html)

Maintained by the Centers for Disease Control and Prevention, this site boasts a vast collection of resources appropriate for experienced professionals or those with little

understanding of autism spectrum disorders. The information here includes basic facts, resources on screening and diagnosis, data and statistics. In addition, the most recently published CDC-authored articles, including those from the Autism and Developmental Disabilities Monitoring Network, are available in full-text. The website's collection of free materials include fact sheets and resource kits.

National Autism Center, [www.nationalautismcenter.org](http://www.nationalautismcenter.org)

Serving as the prestigious May Institute's Center for the Promotion of Evidence-based Practice, the National Autism Center is a nonprofit organization whose mission is to provide evidence-based information on autism therapies. Among the most significant resources available on this site are the results of the National Standards Project. This aim of this project is to provide guidance on decision-making about autism interventions. First published in 2009, phase one of the project examines autism spectrum disorders and interventions in children and adolescents under the age of 22. The recently released second phase explores interventions for adults aged 22 and over.

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## VISUAL MEDIA

There is an abundance of outstanding visual media resources available on autism spectrum disorder. This list includes documentary films only.

*The Autism Enigma*. Directed by Marion Gruner and Christopher Sumpton. Produced by Christopher Sumpton, Marion Gruner and Robin Bengier. PBS, 2012.

This short documentary chronicles the efforts of two families as they work with doctors to find effective therapies for their autistic children. The doctors profiled in this film theorize that diet and antibiotic use are the primary causes of autism spectrum disorders. They illustrate how particular intestinal microbes affect the brains of children with autism, and speculate that replacing abnormal microbial ecosystems with healthy microbial ecosystems may alleviate symptoms of autism.

*Autism: The Musical*. Directed by Tricia Regan. Produced by Tricia Regan, Sasha Alpert and Perrin Chiles. BMP Films, 2008.

This inspirational Emmy Award winning film documents the story of Elaine Hall, an acting coach who leads five autistic children and their families to participate in a 22 week program called the Miracle Project. Through this program the group writes and stages a theatrical production and in the process learns communication skills and experiences the joys of self-expression.

*Best Kept Secret*. Directed by Samantha Buck. Produced by Danielle Di Giacomo. BKS Films, 2013.

Filmed in 2011 at Newark, New Jersey's John F. Kennedy High School, this documentary film chronicles teacher Janet Mino's efforts to prepare her entire class of low-functioning autistic students for graduation and transition into the adult world. This film illuminates the difficulties that low income families face in finding appropriate assistance programs for loved ones with autism. This film won the prestigious Peabody Award in 2013.

*Loving Lampposts: Living Autistic*. Directed by Todd Drezner. Produced by Lauren Silver. Cinema Libre, 2011.

As the father of an autistic son, director Todd Drezner has created a thought provoking look at the experience of having a child diagnosed with autism, the subsequent negativity attached to the diagnosis, and the search for a miracle cure. Drezner suggests that instead of viewing autism as medical disorder, it should simply be regarded as a different way of looking at the world. This notion of "neurodiversity" proposes that instead of being stigmatized, individuals with autism should be embraced and accepted as just as other disabled people are. This film won the Best Feature Documentary at the 2011 Peace on Earth Film Festival.

*Neurotypical*. Directed by Adam Larsen. Produced by Ronald Sigurd Larsen. Create Space Films, 2013.

Neurotypical is the term used by those who are autistic to describe those who are not autistic. This film is unique in that it is filmed from the perspectives of several adults with autism. Through interviews with many individuals, we find that those with autism have various ways or systems of "passing" for normal in the neurotypical world. The conclusion is that most of these individuals, after years of undergoing interventions to make them normal, are happy with themselves and have no desire to be neurotypical.

## References

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2. American Psychiatric Association, *Diagnostic and Statistical Manual of Mental Disorders*, 5th ed. (Washington, DC: American Psychiatric Association, 2013), 31.
3. "Who are You—Living with Autism," US Autism and Asperger Association, accessed June 17, 2015, [www.usautism.org/who\\_are\\_you\\_autism.html](http://www.usautism.org/who_are_you_autism.html).