

## Comprehensive Autism Resources for the Beginner and the Researcher

### *Topic Area Description*

For this pathfinder I've developed a detailed collection of print, audio-visual, database and Internet resources to aid both the beginner and the researcher in learning more about Autism.

Autism is a developmental disorder that appears in the first 3 years of life, and affects the brain's normal development of social and communication skills. Autism is a physical condition linked to abnormal biology and chemistry in the brain. The exact causes of these abnormalities remain unknown, but this is a very active area of research. There are probably combinations of factors that lead to autism. (MedlinePlus)

The disorder has affected many lives and families. Though there is no cure for the disorder, intensive treatment of affected children at a very early age has often lead to improved and higher-level functioning as affected individuals progress through life.

There is a very focused nationwide movement aimed at curing Autism with assistance and awareness coming from many different areas - media, medical, industry and so on.

Given the near daily advances in the analysis, diagnosis, and cures for the disorder, the most up to date information will be found in either the Authoritative Internet Resources or Database Resources. That's not to say that print sources aren't viable - they are - but the researcher and user who wants the most up to date information would probably be more inclined to start their research online before moving to print resources.

Not being an expert on Autism, my research included several conversations with employees of the Autism Society, National Library of Medicine, and Autism Speaks. I relied on their expertise in direction on some of the resources, especially the Audio-Visual materials.

### **Authoritative Internet Resources**

- **Autism Speaks** - Autism Speaks is the nation's largest autism science and advocacy organization, dedicated to funding research into the causes, prevention, treatments and a cure for autism; increasing awareness of autism spectrum disorders; and advocating for the needs of individuals with autism and their families. We are proud of what we've been able to accomplish and look forward to continued successes in the years ahead.  
<http://www.autismspeaks.org/>  
Autism Speaks. (November 2010). Autism Speaks. Retrieved 11 27, 2010, from Autism Speaks: <http://www.autismspeaks.org/>
- **Autism Society of America** - The Autism Society, the nation's leading grassroots autism organization, exists to improve the lives of all affected by autism. They do this by increasing public awareness about the day-to-day issues faced by people

on the spectrum, advocating for appropriate services for individuals across the lifespan, and providing the latest information regarding treatment, education, research and advocacy.

<http://www.autism-society.org>

Autism Society of America. (November 2010). Autism Society of America. Retrieved 11 27, 2010, from Autism Society of America: <http://www.autism-society.org>

- **Autism Fact Sheet: National Institute of Neurological Disorders (NINDS)** – The mission of the National Institute of Neurological Disorders and Stroke is to reduce the burden of neurological disease - a burden borne by every age group, by every segment of society, by people all over the world. NINDS is part of the National Institutes of Health (NIH).  
[http://www.ninds.nih.gov/disorders/autism/detail\\_autism.htm](http://www.ninds.nih.gov/disorders/autism/detail_autism.htm)  
National Institute of Neurological Disorders. (November 2010). Autism Fact Sheet: National Institute of Neurological Disorders. Retrieved 11 27, 2010, from National Institute of Neurological Disorders: [http://www.ninds.nih.gov/disorders/autism/detail\\_autism.htm](http://www.ninds.nih.gov/disorders/autism/detail_autism.htm)
- **Autism: MedlinePlus** - MedlinePlus is the National Institutes of Health's Web site for patients and their families and friends. Produced by the National Library of Medicine, it brings you information about diseases, conditions, and wellness issues in language you can understand. MedlinePlus offers reliable, up-to-date health information, anytime, anywhere, and for free.  
<http://www.nlm.nih.gov/medlineplus/autism.html>  
MedlinePlus. (November 2010). Autism: MedlinePlus. Retrieved 11 27, 2010, from MedlinePlus: <http://www.nlm.nih.gov/medlineplus/autism.html>
- **Autism Research Institute The Autism Research Institute (ARI)** is the hub of a worldwide network of parents and professionals concerned with autism. ARI was founded in 1967 to conduct and foster scientific research designed to improve the methods of diagnosing, treating, and preventing autism. ARI also disseminates research findings to parents and others worldwide seeking help. The ARI data bank, the world's largest, contains over 40,000 detailed case histories of autistic children from over 60 countries. ARI publishes the Autism Research Review International, a quarterly newsletter covering biomedical and educational advances in autism research.  
<http://www.autism.com>  
Autism Research Institute. (November 2010). Autism Research Institute. Retrieved from Autism Research Institute: [www.autism.com](http://www.autism.com)
- **Global Autism Collaboration** - The mission of the Global Autism Collaboration is to network and collaborate with autism organizations worldwide to generate necessary legal and social change to deal with the global autism health crisis. (Global Autism Collaboration)  
<http://www.autismwebsite.com/gac>  
Global Autism Collaboration. (November 2010). Global Autism Collaboration. Retrieved 11 27, 2010, from Global Autism Collaboration: <http://www.autismwebsite.com/gac>

### Audio Visual Resources - Web-based Videos and DVDS

- Autism Key >> Autism Key Video Library - These 'home made' videos provide the most update, direct and personal views and insights on Autism. (Autism Key)

[http://www.autismkey.com/autism\\_videos/](http://www.autismkey.com/autism_videos/)

Autism Key. (November 2010). Autism Key Video Library. Retrieved 11 27, 2010, from Autism Key: [http://www.autismkey.com/autism\\_videos/](http://www.autismkey.com/autism_videos/)

- **Autism: Now What Do I Do?** [VHS] - A good reference for information on medical treatments once a parent finds out their child has autism.  
Freeman, S. (Director). (2006). Autism: Now what do I do? [VHS] International Documentary Television Corp., & SKF Books.
- **Being Responsive: You and Your Child with Autism** [DVD] - This is an Australian video for parents of young children with autism focused on developing and creating interaction times with their child.  
Matthews, V. (Director). (2006). Being responsive: you and your child with autism [DVD]. Australia.
- **Autism Spectrum Disorder: Screening, Diagnosing, Thinking About Genetic Aspects** [DVD] - A topical, medical overview of autism.  
Bodurtha, J. (Producer), & Oswald, D. (Director). (2008). Autism spectrum disorder: Screening, diagnosing, thinking about genetic aspects [DVD]. Richmond, Va.: VCU Health System.
- **About Me and You. Watch Me Learn.** [DVD] - This DVD is part of a comprehensive learning system aimed to compliment school and therapy teaching.  
Palo, M. (Director). (2008). About me and you. Watch me learn. [DVD]. Greenlawn, NY: Watch Me Learn, Inc.
- **Two Worlds, One Planet** [DVD] - This video provides a look inside a private K-12 day school specializing in youth with Autism and other disorders.  
Levin, G. (Producer), & Reinking, A. (Director). (2008). Two worlds, one planet [DVD]. Boston, MA: Faces of Autism, LLC.
- **Understanding Autism** [DVD] - This video is ideal for those with family members or loved ones affected by autism spectrum disorders, helps to identify and diagnose quirks/behaviors in the autistic.  
Sydney, N.S.W: SBS. (Director). (2006). Understanding autism [DVD].
- **Autism and Applied Behavioral Analysis: ABA** [DVD] - This is an ABC Nightline News program on autism.  
Wolfe, P. (Director). (2006). Autism and applied behavioral analysis: ABA [DVD].

## Print Resources

- **The Autism Answer Book: More Than 300 of the Top Questions Parents Ask** by William Stillman - William Stillman, a noted autism expert and author, delivers an Autism Q&A style book for parents and concerned family members.  
Stillman, W. (2007). The autism answer book: More than 300 of the top questions parents ask. Naperville, Ill: Sourcebooks.
- **The Autism Book: Answers to Your Most Pressing Questions** by S. Johanna Robledo, Dawn Ham-Kucharski - A popular question and answer book written parents of autistic children.  
Robledo, S., & Ham-Kucharski, D. (2005). The autism book: Answers to your most pressing questions. New York: Avery.

- **The Autism Encyclopedia** by John T. Neisworth, Pamela S. Wolfe - an updated and exhaustive resource including 22 pages of references including ones from all four editions of the Diagnostic and Statistical Manual of Mental Disorders. Neisworth, J., & Wolfe, P. (2005). The autism encyclopedia. Baltimore, Md: Paul H. Brookes Pub. Co.
- **Autism Journey Guide by Talk About Curing Autism (TACA)** - This 300 page guide is a collection of best practices in autism care and development based on experiences the Talk About Curing Autism (TACA) Foundation has had with families. Talk About Curing Autism. (2009). Autism journey guide. Autism Journey Guide. Costa Mesa, CA, USA: Talk About Curing Autism.
- **Autism Spectrum Disorders from A to Z: Assessment, Diagnosis...& More!** By Emily Doyle and, Barbara T. Doyle - A comprehensive book covering all aspects of Autism and written in a very accessible and user-friendly format. Doyle, B., & and, E. (2004). Autism spectrum disorders from A to Z: Assessment, diagnosis - & more! Arlington, TX: Future Horizons Inc.
- **The Official Autism 101 Manual: Everything You Need To Know About Autism From Experts Who Know and Care** by Karen L. Simmons - An exhaustive resource for parents and professionals. With over 40 contributors, this book provides a wide- ranging overview of all aspects of autism. Simmons, K. (2006). The official autism 101 manual. Alta., Canada: Autism Today.
- **Pervasive Developmental Disorder: An Altered Perspective** by Barbara Quinn, Anthony Malone - The authors describe the symptoms of PDD, what a diagnosis means, how a child fits into the umbrella term used to cover the whole family of autistic spectrum disorders including autism and Asperger Syndrome. Quinn, B., & Malone, A. (2000). Pervasive developmental disorder: An altered perspective. London: Jessica Kingsley Publishers.
- **Understanding Autism Spectrum Disorders** by The American Academy of Pediatrics (AAP) (2006) - This booklet will help parents identify early signs, symptoms, and the behavioral differences in their children so that an intervention program can be started as soon as possible. American Academy of Pediatrics. (2006). Understanding autism spectrum disorders. American Academy of Pediatrics.
- **Understanding Autism: From Basic Neuroscience to Treatment** by Steve Moldin, John Rubenstein - This reference book reviews state-of-the-art research on the diagnosis, treatment, and prevention of autism includes a discussion of the economic cost of autism. Moldin, S. O., & Rubenstein, J. L. (2006). Understanding autism: From basic neuroscience to treatment. Boca Raton, Fla.: CRC Press.
- **Understanding Autism** by Susan Dodd - Provides information to assist parents in developing their understanding of how autistic children think and respond. Dodd, S. (2005). Understanding autism. Marrickville, N.S.W, Australia: Elsevier.

### Database Resources

- **NDAR** - The NIH has developed the National Database for Autism Research (NDAR) as a secure bioinformatics platform for scientific collaboration around

autism spectrum disorder (ASD). Its objectives are to facilitate data sharing and scientific collaboration, provide bioinformatics solutions to address community-Wide needs, and enable the effective communication of detailed research data, tools, and information. NDAR is a robust resource designed to help the ASD research community to accelerate discoveries that will improve the lives of people with autism and their families.

<http://ndar.nih.gov/ndarpublicWeb/>

National Institutes of Health. (November 2010). National Database for Autism Research. Retrieved 11 27, 2010, from National Database for Autism Research: The NIH has developed the (NDAR) <http://ndar.nih.gov/ndarpublicweb/>

- **DIRLINE** is a directory database of addresses, phone numbers and information about health and biomedicine organizations, research resources, projects, and databases.  
<http://dirline.nlm.nih.gov/>  
U.S. National Library of Medicine, National Institutes of Health, Department of Health & Human Services. (n.d.). DIRLINE - U.S. National Library of Medicine. Retrieved 11 29, 2010, from DIRLINE - U.S. National Library of Medicine: <http://dirline.nlm.nih.gov/>
- **PubMed** searches MEDLINE (and OLDMEDLINE 1951-1965).  
<http://www.nlm.nih.gov/services/usemedline.html>  
U.S. National Library of Medicine, the National Institutes of Health. (n.d.). FAQ: Finding Medical Information in MEDLINE. Retrieved 11 29, 2010, from U.S. National Library of Medicine, the National Institutes of Health: <http://www.nlm.nih.gov/services/usemedline.html>
- **LocatorPlus** - an online catalog of all the books, journals, and other materials owned by NLM to identify materials on autism.  
<http://locatorplus.gov/>  
U.S. National Library of Medicine, National Institutes of Health. (n.d.). LocatorPlus. Retrieved 11 25, 2010, from LocatorPlus: <http://locatorplus.gov/>
- **Autism Society's Resource Database** is searchable by location or service type, and provides resource listings throughout the United States. Listings include: Autism Society Local Chapters, government agencies, physicians, medical and diagnostic centers, day schools, information and support groups, early intervention, community services for adults, service providers, legal and advocacy services, consultants, camps, research centers, and more. The resource database was created in 2004 and now contains well over 25,000 individual listings.  
<http://www.autismsource.org>  
Autism Source. (n.d.). Autism Source. Retrieved 11 28, 2010, from Autism Source: <http://www.autismsource.org/>

### Sources for Ready Reference

- **The Autism Answer Book: More Than 300 of the Top Questions Parents Ask by William Stillman** - William Stillman, a noted autism expert and author, delivers an Autism Q&A style book for parents and concerned family members. Stillman, W. (2007). The autism answer book: More than 300 of the top questions parents ask. Naperville, Ill: Sourcebooks.
- **The Autism Book: Answers to Your Most Pressing Questions** by S. Jhoanna Robledo, Dawn Ham-Kucharski - A popular question and answer book written parents of autistic children.

- Robledo, S., & Ham-Kucharski, D. (2005). The autism book: Answers to your most pressing questions. New York: Avery.
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### Sources for In-depth Information for the Casual User

- **Understanding Autism: From Basic Neuroscience to Treatment** by Steve Moldin, John Rubenstein - This reference book reviews state-of-the-art research on the diagnosis, treatment, and prevention of autism includes a discussion of the economic cost of autism. Moldin, S. O., & Rubenstein, J. L. (2006). Understanding autism: From basic neuroscience to treatment. Boca Raton, Fla.: CRC Press.

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Dodd, S. (2005). Understanding autism. Marrickville, N.S.W, Australia: Elsevier.
- **Autism Key >> Autism Key Video Library** - These 'home made' videos provide the most update, direct and personal views and insights on Autism. (Autism Key)  
[http://www.autismkey.com/autism\\_videos/](http://www.autismkey.com/autism_videos/)  
Autism Key. (November, 2010). Autism Key Video Library. Retrieved 11 27, 2010, from Autism Key: [http://www.autismkey.com/autism\\_videos/](http://www.autismkey.com/autism_videos/)
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National Institutes of Health. (November, 2010). National Database for Autism Research. Retrieved 11 27, 2010, from National Database for Autism Research: The NIH has developed the (NDAR) <http://ndar.nih.gov/ndarpublicweb/>
- **DIRLINE** is a directory database of addresses, phone numbers and information about health and biomedicine organizations, research resources, projects, and databases.  
<http://dirline.nlm.nih.gov/>  
U.S. National Library of Medicine, National Institutes of Health, Department of Health & Human Services. (n.d.) DIRLINE - U.S. National Library of Medicine. Retrieved 11 29, 2010, from DIRLINE - U.S. National Library of Medicine: <http://dirline.nlm.nih.gov/>
- **PubMed** searches MEDLINE (and OLDMEDLINE 1951-1965).  
<http://www.nlm.nih.gov/services/usemedline.html>  
U.S. National Library of Medicine, the National Institutes of Health. (n.d.). FAQ: Finding Medical Information in MEDLINE. Retrieved 11 29, 2010, from U.S. National Library of Medicine, the National Institutes of Health: <http://www.nlm.nih.gov/services/usemedline.html>
- **LocatorPlus** - an online catalog of all the books, journals, and other materials owned by NLM to identify materials on autism.  
<http://locatorplus.gov/>  
U.S. National Library of Medicine, National Institutes of Health. (n.d.). LocatorPlus. Retrieved 11 25, 2010, from LocatorPlus: <http://locatorplus.gov/>
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Bodurtha, J. (Producer), & Oswald, D. (Director). (2008). Autism Spectrum Disorder: Screening, Diagnosing, Thinking About Genetic Aspects [DVD]. Richmond, Va.: VCU Health System.
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[http://www.ninds.nih.gov/disorders/autism/detail\\_autism.htm](http://www.ninds.nih.gov/disorders/autism/detail_autism.htm)  
National Institute of Neurological Disorders. (November 2010). Autism Fact Sheet: National Institute of Neurological Disorders, Retrieved 11 27, 2010, from National Institute of Neurological Disorders: <http://www.ninds.nih.gov/disorders/autism/detailgautism.htm>
- **Autism: MedlinePlus** - MedlinePlus is the National Institutes of Health's Web site for patients and their families and friends. Produced by the National Library of Medicine, it brings you information about diseases, conditions, and wellness issues in language you can understand. MedlinePlus offers reliable, up-to-date health information, anytime, anywhere, for free.  
<http://www.nlm.nih.gov/medlineplus/autism.html>  
MedlinePlus. (November 2010). Autism: MedlinePlus. Retrieved 11 27, 2010, from MedlinePlus: <http://www.nlm.nih.gov/medlineplus/autism.html>
- **The Autism Research Institute (ARI)** is the hub of a worldwide network of parents and professionals concerned with autism. ARI was founded in 1967 to conduct and foster scientific research designed to improve the methods of diagnosing, treating, and preventing autism. ARI also disseminates research findings to parents and others worldwide seeking help. The ARI data bank, the world's largest, contains over 40,000 detailed case histories of autistic children from over 60 countries. ARI publishes the Autism Research Review International, a quarterly newsletter covering biomedical and educational advances in autism research.  
<http://www.autism.com>  
Autism Research Institute. (November 2010). Autism Research Institute. Retrieved from Autism Research Institute: <http://www.autism.com>

## References

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- Jochum, R. (2010, 11 29). Response from the autism society [Electronic mail list message]. Bethesda, Maryland, USA.
- Layman, E. (2010, 11 20). Re: student research question [Electronic mail list message]. Bethesda, Maryland, USA.