

## Internet Resources about Autism:

- [www.familyvillage.wisc.edu](http://www.familyvillage.wisc.edu)

The Waisman Center's Family Village is a global community of resources for individuals with disabilities, their families, and their friends and allies. Visitors to the site will find resources and information for a wide range of disabilities, including autism and other developmental disabilities, organized in a directory. The site features links to message boards, parent groups, adaptive products and assistive technology, as well as information about education services, legal issues, and living with a disability.

- [www.mchlibrary.info/KnowledgePaths/kp\\_autism.html](http://www.mchlibrary.info/KnowledgePaths/kp_autism.html)

As part of the Maternal and Child Health Library, this web-site is an extensive collection of links that offer a wealth of information for families and professionals, ranging from fact sheets describing general characteristics associated with autism spectrum disorders to information from cutting-edge genetic studies. In addition to links to autism-related websites, there are links to electronic publications that can be downloaded and printed, books and other printed resources, and on-line discussion groups. Every link has been summarized so that you know the kind of information that can be found in each location.

- <http://www.waisman.wisc.edu/family/autism-study-info.html>

This site is the homepage for Lifespan Family Research being conducted at the Waisman Center and includes detailed reports from the study on families of adolescents and adults with autism. The most recent report was added in February of 2006 and is entitled *Health-Related Needs for Adolescents and Adults with Autism and Their Parents*.

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## research & resources

• WAISMAN CENTER NEWS FOR FAMILIES •  
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# research & resources

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## Autism Research at the Waisman Center

The Waisman Center is an interdisciplinary research facility that is dedicated to the advancement of knowledge about human development, developmental disabilities, and neurodegenerative diseases. Autism is one developmental disability that Waisman Center researchers and staff members are strongly committed to, both in the realm of research and in the provision of top-quality clinical services to individuals and families.

Because our researchers are affiliated with 26 different academic departments at the UW-Madison, Waisman Center studies on autism focus on many different aspects of the condition, including neurological, social, psychological, physiological, and genetic components. This inter-disciplinary approach is enabling the Waisman Center to make great advances in the understanding of autism. Below are just some of the research projects on autism.

- **Animal Models of Social Behavior:** Garet Lahvis, Ph.D., of the Department of Surgery, is conducting research with mice in order to increase our understanding of the genetic bases of social behavior and social challenges in humans. Because mice are very social animals who tend to live in large groups in the wild and whose complex social behaviors are easily observable in the laboratory, the genes involved in mouse behavior may have much in common with those of humans, which would

provide insights into the genetic components of the social challenges associated with autism spectrum disorders.

- **Families of Adolescents and Adults with Autism:** Waisman Center Director Marsha M. Seltzer, Ph.D., and Waisman investigators Jan Greenberg, Ph.D., and Sandra Magaña, Ph.D., of the School of Social Work, in collaboration with investigators from Brandeis University, are evaluating how autism is manifested in adolescents and adults and affects their families. The study follows 405 individuals with autism and their families over a five-year period to answer questions regarding how symptoms of autism change as the individual gets older, how parents cope with the unique challenges of caring for a child with autism, how siblings are affected, and how treatment and service needs of individuals with autism change over the life-span.

Recent findings from this project have indicated that, although autism is a life-long condition, many symptoms become less severe as individuals grow older; children's overall level of language ability tends to improve with age; characteristics that persist over time include difficulty forming friendships, having overly focused and unusual interests, and asking socially inappropriate questions; and that mothers of children with autism are at greater risk of experiencing symptoms of depression than mothers of individuals with Down syndrome

or fragile X syndrome.

Visit [www.waisman.wisc.edu/family/autism-study-info.html](http://www.waisman.wisc.edu/family/autism-study-info.html) to view reports that provide more details about the findings from the investigation thus far.

- **Imaging Studies of Brain Development and Functioning:** Using advanced MRI (magnetic resonance imaging) techniques, Andrew Alexander, Ph.D., Departments of Medical Physics and Psychiatry, is studying how the brains of children with autism spectrum disorders develop over time. This study has already documented differences in the structural organization of white matter in the brain between individuals with autism and the general population, and has noted that these differences correlate with clinical and behavioral measures of autism.

Mariana Lazar, Ph.D. is investigating the structure and organization of major white matter pathways using the innovative imaging techniques of diffusion tensor imaging and white matter tractography. Brains of individuals with autism and those of typically developing individuals will be studied and compared, in order to determine if communication pathways between brain regions differ between the two groups.

- **Research on Twins with Autism:** H. Hill Goldsmith, Ph.D., and Morton Ann Gernsbacher, Ph.D., both of the Department of Psychology, are conduct-

ing the first population-based twin study of autism spectrum disorder (ASD). Diagnostic and behavioral assessments are conducted to estimate the importance of genetic factors as a cause for ASD, to separate the roles of other medical conditions as genetic influences on ASD, and to characterize behavioral problems that are sometimes associated with ASD, such as anxiety, aggression, and sensory defensiveness. The project is also examining language development, family functioning, and brain structure and function.

This study is currently recruiting twins, one or both of whom have an autism spectrum diagnosis and live anywhere in Wisconsin or adjoining states. To participate or for more information, contact Hill Goldsmith or one of his research staff at (608) 265-2674 or via e-mail, [wisconsintwins@waisman.wisc.edu](mailto:wisconsintwins@waisman.wisc.edu) or see their web site at <http://psych.wisc.edu/lang/autism/autism.html>

• **Speech and Motor Development:**

In addition to their research with twins who have autism, H. Hill Goldsmith, Ph.D., and Morton Ann Gernsbacher, Ph.D. are studying individuals with autism who cannot use spoken language to communicate. This project seeks to determine if there is a distinct sub-type of autism that is characterized by a lack of oral motor and manual speech production, if there are unique aspects of oral and motor development that distinguish children with autism from typically developing children, and what the neurological and genetic foundations are for these speech impairments. Preliminary results suggest that, among children who are eventually diagnosed with an autism spectrum disorder, early impairments in both manual and oral motor control are significant predictors of the child's level of speech.

Susan Ellis Weismer, Ph.D., of the Department of Communicative Disorders, is working in collaboration with Morton Ann Gernsbacher, Ph.D., to in-

vestigate the early communication and language skills of toddlers who have an autism spectrum diagnosis. The results from this study will provide valuable information for designing effective language intervention programs. By comparing the early language skills of toddlers with ASD with the skills of both typically developing toddlers and late-talking toddlers without ASD, the results of this project will also have important implications for the early diagnosis of autism.

This study is currently recruiting toddlers under 3 years of age who have an ASD diagnosis (autism, PDD-NOS, Asperger's) OR who are suspected of having ASD. To participate or for more information, contact Chris Hollar at (608) 263-3123 or via e-mail, [chollar@wisc.edu](mailto:chollar@wisc.edu) or see the project's web site at [www.waisman.wisc.edu/lpl/toddler\\_talk.htm](http://www.waisman.wisc.edu/lpl/toddler_talk.htm)

• **Speech Patterns:** Lawrence Shriberg, Ph.D., of the Department of Communicative Disorders is collaborating with investigators from the Yale Child Study Center to examine the unique ways individuals with autism use speech. This study seeks to determine similarities and differences in speech patterns between individuals with high-functioning autism and Asperger syndrome as compared with the general population. The study is also evaluating whether there are aspects of speech, such as rate of speech or stress on words, that are unique to children and adults with autism or Asperger syndrome.

Recent findings from this investigation demonstrate that individuals with Asperger syndrome tend to talk more than individuals with high-functioning autism and the general population, and that individuals with high-functioning autism and Asperger syndrome make more speech distortion errors, have more inappropriate emphasis on words, and use more improper phrasing than individuals in the general population.

• **STAART Center (Studies to Advance Autism Research and Treatment):**

The Waisman Center is part of a network of eight centers in the nation that are investigating the underlying neuro-biological mechanisms of autism, how children with the disorder develop, how a family is affected when a child has autism, and the effectiveness of various interventions to improve the symptoms of autism. Richard J. Davidson, Ph.D., Departments of Psychology and Psychiatry, is leading the primary project in the Wisconsin component of the STAART Center, which uses functional magnetic resonance imaging (fMRI) to study the brain circuitry underlying emotion in individuals with autism. Results from the study will provide a better understanding of the neurological processes behind symptoms of autism such as gaze aversion, anxiety, shyness, and social withdrawal.

This study is currently recruiting two groups of participants: individuals who are typically developing (ages 10-17) and individuals with autism (ages 10-35). Braces or permanent retainers make an individual ineligible for this study. To participate or for more information, contact Kim Dalton at (608) 263-8913 or via email at [kmdalton@wisc.edu](mailto:kmdalton@wisc.edu), or visit <http://tezpur.keck.waisman.wisc.edu>

Other investigators are participating in the STAART Center, including Waisman Center Director Marsha M. Seltzer, Ph.D., H. Hill Goldsmith, Ph.D., Morton Ann Gernsbacher, Ph.D., and Leonard Abbeduto, Ph.D.

• **Wisconsin Surveillance of Autism and Other Developmental Disabilities:**

Maureen Durkin, Ph.D., DrPH, from the Department of Population Health Sciences, is examining the prevalence and health needs of Wisconsin children with autism and other developmental disabilities. The study is part of a state-level program that tracks the well-being of children with autism, with the goal of increasing early detection of autism and other developmental disabilities through the specialized training of health care providers.

## New Study to Begin with Latino Families Who Have Children with Autism

To date, very few research projects have explored the experiences of Latino children with autism and their families. We are excited to announce a new interview-based pilot study for Latino parents who have children with an autism spectrum diagnosis between 3 and 21 years old. Interviews will be conducted in the language of preference (Spanish or English). The study aims to understand the strengths and challenges these families face in caring for a child with autism. The study will also look at how Latino children are diagnosed with an autism spectrum disorder, and how families learn about and receive services. If you are interested in helping to recruit Latino families, or want to participate, call Sandy Magaña at 263-0270 or contact the Research Participation Core at their toll free number, 1-800-965-9205.

## Autism Services at the Waisman Center

In addition to conducting ground-breaking research to advance knowledge about autism, the Waisman Center also provides an array of services and contains a wealth of resources for individuals with autism and their families.

• **Inclusive Preschool:** Directed by Joan Ershler, Ph.D., the Waisman Early Childhood Program (WECP) is an exemplary program that includes children with disabilities, both physical and developmental, in regular classroom settings. WECP's enriching and supportive environment promotes the emotional, social/play, cognitive, language/communication, and physical development of its students of all ability levels. Several children with autism are enrolled in the preschool each year and each receives individualized supports and interventions to help him or her learn skills necessary for school participation, learning, and relating to others.

• **Clinics:** Under the direction of Lewis Leavitt, M.D., the Waisman Center's Developmental Disabilities (DD) Clinic provides diagnostic and treatment planning assessments to individuals with a variety of developmental disabilities, including autism. Using a team approach to assessment, the DD Clinic involves professionals from several health care disciplines, including medicine, occupational and speech therapy, audiology, psychology, and social work. The Child Development Clinic, directed by Tina Iyama, M.D., specializes in developmental pediatric assessment of young children who have autism and other developmental delays. Most of the children seen in this clinic each year are referred for concerns regarding possible autism spectrum disorders.

• **Community Outreach:** Paul White, M.A., is the director of Waisman Community TIES (Training, Intervention and Evaluations Services), which is an outreach program for individuals with developmental disabilities who present various challenging behaviors such as withdrawal, self injury, or aggression. TIES addresses behavioral, psychological, and emotional needs, and provides counseling, crisis response, psychiatric consultation, and parent support and education in order to insure continued participation in the community.

• **National Medical Home Autism Initiative (NMHAI):** The National Medical Home Autism Initiative is a technical assistance, resource, and advocacy project designed to improve the early identification of, provision of services to, and integration of children with autism within communities. The project team includes William Schwab, M.D., of the Department of Family Medicine, Dan Bier, M.P.A., M.S.W., Linda Tuchman, Ph.D., and Christine Breunig, in collaboration with investigators in Illinois. The goals of the project are to establish medical home partnerships that will focus on developmental surveillance and service strategies for individuals with ASD, to work collaboratively with other organizations to provide technical assistance and training opportunities for medical practices and families, and to promote public awareness of autism.

## Autism and Fragile X Syndrome: Is There a Connection?

Fragile X syndrome is the most common inherited cause of mental impairment and is caused by a mutation in the gene known as FMR1, which prevents the production of a protein that is important for brain development. Fragile X syndrome is characterized by learning disabilities or mental retardation, attention deficit and hyperactivity, anxiety and unstable mood, and certain physical characteristics including long face, large ears, and hyper-extensible joints. Seizures occur in about 25% of individuals with fragile X syndrome. Some individuals with fragile X syndrome exhibit behaviors and symptoms commonly seen in individuals with autism, including social anxiety, perseverative speech, tactile defensiveness, hand flapping, and cognitive disability. It is estimated that between 15% and 33% of individuals with fragile X syndrome also meet the diagnostic criteria for autism. These shared characteristics of fragile X syndrome and autism have lead researchers to investigate the relationship between the two developmental disorders. Fragile X syndrome is another condition that is being researched by Waisman Center investigators. Several projects are currently being conducted and are recruiting participants who have both fragile X syndrome and autism:

- **Fragile X Syndrome: Language and Communication in Adolescents**

Leonard Abbeduto, Ph.D. of the Department of Educational Psychology, is investigating the biological, environmental and psychological factors that affect the development of communication skills and seeks to determine whether there are developmental challenges specific to fragile X syndrome. Participants should be adolescents between the ages of 11 and 15 who have fragile X syndrome.

**Contact:** Leonard Abbeduto, Ph.D. (608) 263-1770 or [abbeduto@waisman.wisc.edu](mailto:abbeduto@waisman.wisc.edu)

- **Fragile X & Autism: Brain Structure and Function**

Led by Richard Davidson, Ph.D. of the Departments of Psychology and Psychiatry, this study uses functional magnetic resonance imaging (fMRI) and records eye movements to determine if individuals with fragile X or autism scan or focus on different areas of pictures of faces differently than non-diagnosed individuals. Participants who are between the ages of 13-35 years and who have fragile X syndrome are eligible to participate.

**Contact:** Kim Dalton, Ph.D. (608) 263-8913 or [kmdalton@wisc.edu](mailto:kmdalton@wisc.edu)

- **Mothers of Individuals with Fragile X Syndrome: A Study of Psychological Well-Being**

Dr. Leonard Abbeduto, Ph.D., and his research team are seeking biological mothers of a 11 to 21 year old son or daughter who has fragile X syndrome, to participate in a study designed to investigate the psychological well-being of women who have a son or daughter with fragile X syndrome.

**Contact:** Dr. Len Abbeduto at (608) 263-1737 or [abbeduto@waisman.wisc.edu](mailto:abbeduto@waisman.wisc.edu)

- **Fragile X Syndrome and Social Anxiety**

Laura Holsen, Ph.D., and Richard Davidson, Ph.D., would like to invite individuals with fragile X syndrome, ages 8 to 35, to participate in a study that uses fMRI techniques to better understand the development of processes within the brain that may be associated with social anxiety.

**Contact:** Donna Schaan (608) 890-0233 or [dmschaan@wisc.edu](mailto:dmschaan@wisc.edu)

Visit the following websites for more information about Fragile X syndrome:

- [www.fragilex.org](http://www.fragilex.org) (Homepage of the National Fragile X Foundation)
- [www.fpg.unc.edu/~fxic/](http://www.fpg.unc.edu/~fxic/) (Fragile X Information Center, part of the Carolina Fragile X Project at the University of North Carolina at Chapel Hill)
- [www.fraxa.org](http://www.fraxa.org) (Homepage of the Fragile X Research Foundation)

## Autism at a Glance: What We Know Now

### **What is autism?**

Autism is a complex developmental disability that affects the functioning of the brain, causing particular difficulties in communication and social interaction. Autism is a spectrum disorder, which means that the symptoms experienced and the severity of the symptoms differ between affected individuals. The most common characteristics associated with autism include impairments in an individual's verbal and nonverbal communication and the ability to engage in social interactions. Some individuals with autism may insist on sameness in their routine and be resistant to change, engage in unusual play, exhibit repetitive behaviors, and make stereotyped movements. Other symptoms of autism include an over- or under-sensitivity to sensory experiences, avoidance of eye contact, and self-injurious behavior. The differences in development of a child who has autism are usually evident by age 3, if not before.

### **Who does autism affect?**

The Centers for Disease Control estimate that 1 in 166 births are affected by some form of autism. Autism is four times more prevalent in boys than in girls, but the condition has no racial, ethnic, or social boundaries and can affect any child from any family, regardless of lifestyle, education level, or income. The overall incidence of autism is consistent around the world.

### **What causes autism?**

There is no known single, definitive cause for autism. Several theories regarding the basis of the disorder have been put forth, which are debated and researched by the medical and scientific community. It is generally accepted that autism results from differences in brain structure or function, but there is controversy about the specific genetic and environmental factors that are involved. Although there appears to be a pattern of autism and related developmental disabilities within families, a specific causative gene or genes has not been identified.

## How Is Autism Diagnosed?

Two assessments are currently considered the "gold standard" for diagnosing autism in research settings: the Autism Diagnostic Observation Schedule (ADOS) and the Autism Diagnostic Interview- Revised (ADI-R). Both instruments are used by staff at the Waisman Center.

The ADOS is a semi-structured assessment that provides a standard context in which interaction can occur. The assessor and individual being assessed complete play-like tasks, such as having a pretend party and describing a picture, that are designed to evoke certain social and communication behaviors related to the diagnosis of autism spectrum disorders. There are four different modules that make up the ADOS, and the module administered to each person being evaluated is chosen according to the extent of his or her language abilities. This makes the ADOS versatile and useful for a wide range of individuals, whether they are fluent speakers, nonverbal, or somewhere in between. Diagnoses are made based upon the assessor's observations, so training to conduct the ADOS is a rigorous and lengthy process.

The ADI-R is a comprehensive interview that is conducted with a parent or caretaker who is familiar with the current behaviors and developmental history of the individual being evaluated. There are eight content areas that the ADI-R focuses on: background including family, education, other diagnoses, and medications; overview of the individual's behavior; early development and developmental milestones; language acquisition and loss of language or other skills; current functioning in regard to language and communication, social development, play, interests, and behaviors; and clinically relevant behaviors including aggression, self-injury, and seizure activity. The results from the ADI-R are useful to support a diagnosis of autism and to differentiate autism from other developmental disabilities.

Individuals of all ages with an autism diagnosis are needed to help Waisman Center research staff members learn how to administer the ADOS. Because the ADOS is being administered for research training purposes only, participants will not receive any information about clinical impressions from the assessment. To participate or for more information, contact Sara Kover at [kover@wisc.edu](mailto:kover@wisc.edu) or by phone at (608) 263-2251