ASD. One objective of the center is to increase the number of highly qualified personnel serving children with ASD. Technical assistance in conducting needs assessment of resources for individuals with ASD will also be available to participating states. In addition, consultation will be provided to identify and meet the child, family, and community needs at systems level. The directors of the Waisman Center site of the project are Leonard Abbeduto, PhD, and Linda Tuchman-Ginsberg, PhD.

SERVICES AND OUTREACH

Inclusive Preschool

The Waisman Early Childhood Program is a model preschool that demonstrates how to include children with disabilities, including children with autism, in regular classroom settings. Directed by Joan Enns, PhD, the WECPC provides a supportive learning environment that fosters the emotional, social/play, cognitive, language/communication, and physical development of children of all ability levels. Approximately 100 children attend year-round and 40 participate in part-time special programs. Each year, about five children with autism are enrolled in the preschool. These children receive individualized supports and interventions that help them learn the skills needed for school participation, learning and relating to others.

Clinics

• The Waisman Center’s Child Development and Neurodevelopmental Disabilities Clinic provides diagnostic and treat ment planning assessments to children and adults with a variety of developmental disorders, including autism. Approximately 150 children and adolescents are seen each year, of whom roughly 50% have an autism spectrum disorder. The DD Clinic uses a team approach to its developmental assessment, involving professionals from several health disciplines including medicine, occupational and speech therapy, audiology, psychology, and social work.

• The Waisman Center’s Early Autism and Communication Research Clinic provides developmental, communicative, and diagnostic evaluation services to children between ages 2 and 3 years old who have been characterized as having ASD. The clinic and Toddler Talk Project are directed by Susan Ellis Weisman, PhD, a Waisman Center investigator and professor of communicative disorders.

Community Outreach

The Waisman Community TIES (Training, Intervention and Evaluations Services) program is an outreach program for children and adults with developmental disabilities who present various challenging behaviors, including withdrawal, aggression, and self-injury. The mission of Waisman Community TIES is to address behavioral, psychological, and emotional needs using therapeutic approaches that ensure continued participation in the community. TIES provides counseling, crisis response, psychiatric consultation, parent education and support, and training for personnel and personal consultation in local human service agencies. Directed by Paul White, MA, and funded by Dane County, this program maintains an active caseload of about 250 children and adults residing in Dane County. Individuals with autism spectrum disorders represent approximately 30% of this caseload.

National Medical Home Autism Initiative (NMHAI)

The National Medical Home Autism Initiative is a technical assistance, resource, and advocacy project designed to promote methods that will improve the capacity of the medical home and early intervention community to identify, appropriately serve, and integrate children with autism into their communities.

The project team for this initiative includes principal investigators William Schwab MD, UW-Madison Department of Family Medicine, and pediatric consultant Mark Rosenberg, MD, Illinois, and Waisman Center co-investigators Dan Bier, MHA, MPH, and Linda Tuchman, PhD, coordinator of early intervention programs.

The primary goal of the project is to establish medical home partnerships that will provide particular attention to developmental surveillance and service strategies for individuals with ASD. The project team works collaboratively with the Waisman Resource Center and others to provide technical assistance and training opportunities for medical practices and families and will participate in a variety of national efforts designed to promote public awareness of autism and/or developmental surveillance of all children.

NMHAI is funded as a cooperative agreement with the Division of Services for Children with Special Health Care Needs in the federal Maternal and Child Health Bureau, Health Resource and Service Administration, U.S. Department of Health and Human Services.

Waisman Resource Center

Centrally located within the clinical services area on the first floor of the Waisman Center, the Waisman Resource Center provides free and confidential information and assistance to families whose children have autism or other special needs. The center is staffed full time by professionals with degrees in social work and education, with experience in a variety of disability-related areas. They assist families by identifying resources and supports in the community; answering questions about health insurance and coverage; problem-solving with families based on their situations and experiences; and connecting families and providers with a variety of family supports, list serves, newsletters, and training opportunities.

AUTISM-RELATED ACTIVITIES AT THE WAISMAN CENTER

INTRODUCTION

Autism is a neurodevelopmental disorder that affects social interaction, communication, and behavior. Public concern about autism has grown in recent years as research has shown it to be more prevalent than once thought—occurring in about one out of every 150-200 people. The Waisman Center is strongly committed to solving the autism puzzle and providing high quality services to people with autism and their families.

This document describes the Waisman Center’s current activities related to autism. The scope of these endeavors will continue to expand as the Center actively pursues the development of more research into the causes, consequences, and treatments of this complex disorder. The Waisman Center is uniquely positioned to make major advances in the understanding of autism because of its multi-disciplinary approach and ability to conduct research, training, service, and outreach programs under one roof.

RESEARCH

Twins who have Autism

Waisman Center investigator Hill Goldsmith, PhD, Department of Psychology, is conducting the first population-based twin study of autism spectrum disorders (ASD) supported by the National Institutes of Health. He and his collaborators are identifying a sample of virtually all twins aged 2-16 years old in Wisconsin, one or both of whom have been characterized as having ASD. Full diagnostic and behavioral assessments are conducted for all twins, with the goals of:

• estimating the role of genetic factors as a cause of ASD
• clarifying the roles of other medical conditions, such as cerebral palsy or seizure disorders, as genetic influences on ASD
• characterizing behavioral problems, such as anxiety, sleep problems, sensory sensitivities, or aggression, that accompany ASD in some cases
• determining whether twins are at increased risk for ASD

Early results from the project do implicate genetic factors, but several cases of genetically identical twin pairs, only one of whom has ASD, have been identified. The project also assesses language development, family functioning, and brain structure and function. Besides Goldsmith and his co-principal investigator Mortom Gerberuch, PhD, other Waisman investigators involved in the twin project include Professors Davidson, Durkin, and Seltzer.

Wisconsin Surveillance of Autism and Other Developmental Disabilities

In collaboration with the Department of Health and Human Services, Maureen Durkin, PhD, DrPH, from the UW-Madison Department of Population Health Sciences, is leading an investigation into the prevalence and health needs of Wisconsin children with autism and other developmental disabilities. The program is funded by the Centers for Disease Control and is part of a nationwide network of state-level programs aimed at tracking the number of new cases of autism and other developmental disabilities, as well as improving the ability of health care providers to detect autism and other developmental disabilities as early as possible. This will be accomplished through a series of training programs targeted at physicians, nurses, psychologists, and other allied health personnel.

Families of Adolescents and Adults

Waisman Center director Martha Mailick Seltzer, PhD, and Waisman investigator Jan Greenberg, PhD, both from the School of Social Work, are breaking new
ground in our understanding of how autism affects the lives of adolescents and adults with autism and their families. This research is supported by a grant from the National Institutes of Health and is conducted in collaboration with the Waisman Center at the University of Wisconsin-Madison. By following a group of 405 individuals with autism and their families over a 12-year period, this project is helping to answer the following questions:

- How do the symptoms of autism change through adolescence and adulthood?
- How do parents cope with the unique challenges of caring for their son or daughter with autism?
- How are siblings affected?
- How do treatment and service needs of people with autism change throughout the life-span?

Some of the recent findings from this investigation are as follows:

- Although autism is a lifelong condition, there are substantial changes over time, with many symptoms becoming less severe as individuals grow older.

Waisman investigator Lawrence D. Shriberg, PhD, has recently launched a study focusing on advanced MRI methods to study longitudinal brain development, including autism. One of his current projects focuses on using advanced MRI methods to study longitudinal brain development in children with autism spectrum disorders. He has documented differences in the structural organization of brain white matter between those with autism, as well as the correlation between brain differences and clinical and cognitive measures of autism. He also has collected data from the National Institutes of Health.

Kim Dalton, PhD, is focusing on underlying brain structure and function associated with autism and related developmental differences/disabilities such as fragile X. She is also looking at brain structure and function in unaffected siblings of individuals with developmental differences. She is conducting research in collaboration with Richard Davidson, PhD, in the Waisman Laboratory for Brain Imaging & Behavior. They have completed five in a series of studies investigating the underlying brain mechanisms associated with discrimination of facial expressions of emotions, facial recognition, and social cognition in children with autism spectrum disorders. This research is particularly timely given that early development followed by loss of purposeful use of the hands, distinctive hand movements, slowed brain development, increased head circumference, and mental retardation. Caused by mutations in the X-linked MECP2 gene, RTT affects one in 10,000-15,000 girls. The goal of Chang’s research is to elucidate the molecular mechanism of RTT’s origin and development, key information on the path to developing effective treatments or a cure. Since there is considerable overlap in clinical features between RTT and autistic spectrum disorders, the lessons learned studying RTT may also advance our general understanding of autism.

### Training

**Graduate and Post-doctoral Training Program**

- The NICHD-funded post-doctoral training program in Developmental Disabilities Research supports post-doctoral fellows each year who receive research training related to various types of developmental disabilities, including autism. The program is directed by Leonard Abbeduto, PhD, Department of Educational Psychology.
- The Interdisciplinary Leadership Education Program in Neurodevelopmental and Related Disabilities (LEND) trains approximately 10 to 20 students each year about developmental disorders. Much of the clinical and classroom training is focused on autism.

**Parent Leadership Training**

Parents as Leaders, funded by the Wisconsin Department of Health and Family Services and the National Professional Development Center on Autism Spectrum Disorders, offers training on state-of-the-science early screening, identification and diagnosis of autism-related activities at the Waisman Center

**Potential Clues to Autism through the Study of Other Neurodevelopmental Disorders**

- **Fragile X**: Waisman investigator and associate director for behavioral sciences, Leonard Abbeduto, PhD, has recently launched a study designed to understand the association between autism and fragile X syndrome. Fragile X syndrome is caused by a mutation in a single gene of the X chromosome and is the leading inherited cause of intellectual disabilities. Between 25% and 50% of individuals with the fragile X syndrome also meet criteria for autism spectrum disorders. The National Institutes of Health is currently funding, and at least in some cases, Abbeduto and others have argue that fragile X syndrome may offer insights into the autism spectrum more generally. In this project, which is funded by the National Institutes of Health, Abbeduto and colleagues at the University of California at Davis are investigating the impact of social impairments on language learning in children with fragile X syndrome and children with autism due to other causes.
- **Rett Syndrome**: Waisman Center investigator Qiang Chang, PhD, is focusing on understanding Rett Syndrome (RTT), a severe childhood neurodevelopmental disorder characterized by early-onset and inactivation of a gene on the X chromosome. RTT is characterized by early development followed by loss of purposeful use of the hands, distinctive hand movements, slowed brain development, increased head circumference, and mental retardation. Caused by mutations in the X-linked MECP2 gene, RTT affects one in 10,000-15,000 girls. The goal of Chang’s research is to elucidate the molecular mechanism of RTT’s origin and development, key information on the path to developing effective treatments or a cure. Since there is considerable overlap in clinical features between RTT and autistic spectrum disorders, the lessons learned studying RTT may also advance our general understanding of autism.

**National Professional Development Center on Autism Spectrum Disorders**

The Waisman Center is a member of this multi-university center that includes collaborators at the University of North Carolina-Chapel Hill and the University of California at Davis. Funded by the U.S. Department of Education, Office of Special Education Programs, this project promotes the use of evidence-based practices for intervention and education for infants, children, and youth with autism spectrum disorders (ASD) and their families. Services provided include family support services and professional development activities, including the use of five fingers to focus on state-of-the-science early screening, identification and diagnosis of autism-related activities at the Waisman Center