

The Autism Epidemic in California Background Paper

What is Autism?

According to the National Institute of Child Health and Human Development, autism is a complex biological disorder that generally lasts throughout a person's life. It is called a developmental disability because it starts before age three, in the developmental period, and causes delays or problems in different ways in which a person develops or grows. In most cases, autism causes problems with:

- Communication, both verbal and nonverbal;
- Social interactions with other people, both physical (such as hugging or holding) and verbal (such as having a conversation);
- Routines or repetitive behaviors, like repeating words or actions over and over, obsessively following routines or schedules for their actions, or having very specific ways of arranging their belongings.

The symptoms of the disorder cut off people with autism from the world around them. Children with autism may not want their mothers to hold them. Adults with autism may not look others in the eye. Some people with autism never learn how to talk. These behaviors not only make life difficult for people who have autism, but also make life hard for their families, their health care providers, their teachers, and anyone who comes in contact with them.

Because autism affects people differently and the symptoms range from mild to severe, the word autism is used to describe several conditions that fall within the term "autism spectrum disorder" (ASD). ASD currently includes the following conditions:

- Autistic disorder (sometimes called "classic" autism);

- Asperger syndrome;
- Childhood disintegrative disorder;
- Rett syndrome; and
- Pervasive Developmental Disorder Not Otherwise Specified, or atypical autism.

Depending on his or her specific symptoms, a person with autism can be in any one of these categories.

What causes autism?

No one knows the exact cause or causes of autism. Many scientists now believe that autism has its beginnings before a person is even born, and are focusing efforts on possible genetic causes of autism. Past research, as cited by the National Institute of Child Health and Human Development, has suggested a link between autism and genes, including research comparing identical and fraternal twins. When autism occurs in *identical twins*, both members of the set have the condition 60 percent of the time. When autism occurs in *fraternal twins*, both members of the set have the condition only 3-to-6 percent of the time. Because identical twins come from a single egg that splits in two, they share 100 percent of their genes. Fraternal twins come from two separate eggs, so they are genetically different. If autism was not caused in part by genes, then the number of identical twins with autism would not be any higher than the number of fraternal twins with the same condition. Researchers believe some people have an error in their genes that makes them more likely to develop autism.

While it is generally agreed that genes are involved in the cause of autism, it is also clear, based at least in part on the documented increase in autism cases, that something else, perhaps an environmental factor, also contributes to the development of autism. Some people have suggested that childhood vaccines might play a role in causing autism, and some believe that the Measles, Mumps and Rubella (MMR) vaccine is specifically to blame. Many parents have reported that their child "regressed" into autism after a period of normal development, shortly after receiving an MMR vaccination. This is an area of significant controversy, and the majority of medical experts do not believe that vaccines are to blame. Earlier this month, the New England Journal of Medicine released a study by Danish researchers that specifically looked at whether MMR vaccination caused autism. This study, which looked at the records

of every child born in Denmark from 1991 through 1998, found no link between MMR vaccination and autism.

What is the Prevalence of autism?

In the past, ASDs were thought to be relatively rare, occurring in approximately one in every 2,000 children. Since 1985, however, studies have found that as many as 2 to 6 out of every 1,000 children have an ASD. Autistic disorder, or classic autism, occurs less frequently, but it is still estimated to be as high as 1 in 500. In 1999, the Department of Developmental Studies issued a report titled "Changes in the Population of Persons with Autism and Pervasive Developmental Disorders in California's Developmental Services System: 1987 through 1998." This report documented an increase of 273 percent in reported cases of autism in California over this time period. The Legislature responded to this report by requesting the Medical Investigations of Neurological Disorders (M.I.N.D.) Institute conduct a comprehensive pilot study to examine factors associated with this increase, and appropriated \$1 million to the M.I.N.D. Institute for this purpose. This pilot study, titled "The Epidemiology of Autism in California: A Comprehensive Pilot Study," substantiated this increase in autism by finding that there was no significant difference in the criteria for diagnosis, and that people are not moving into California in significant numbers to receive services for their autistic children.

According to the National Institutes of Health, boys are four times as likely to be affected by autism as girls. Additionally, a younger sibling of an autistic child is much more likely to be affected by autism as well – a risk 45 to 90 times higher than that of the general population.

The U.C. Davis M.I.N.D. Institute

The U.C. Davis Medical Investigation of Neurodevelopmental Disorders (M.I.N.D.) Institute was envisioned in 1997 by four Sacramento fathers of children with autism, and launched at U.C. Davis in 1998 as a unique interdisciplinary institute to conduct research and provide clinical programs focused on autism and autism spectrum disorders, fragile X syndrome, Tourette's Syndrome, mental retardation, and other learning, developmental delay, and communication disorders. The Institute receives approximately \$6 million per year in

annual state funding (though this was reduced by 10 percent in the current budget year), augmented by a one-time appropriation of \$28 million in 2000. The Institute also receives private donations, and is nearing completion of a new 150,000 square foot research and clinical complex at U.C. Davis, which is scheduled to open in April of 2003. The Institute has numerous studies underway, and recently released a report conducted at the request of the Legislature on "The Epidemiology of Autism in California: A Comprehensive Pilot Study."

The Regional Center System in California

In 1969, the Lanterman Mental Retardation Services Act established regional coordination of care for persons with mental retardation. In 1973, this act was extended to serve persons with cerebral palsy, epilepsy, autism and other conditions similar in severity to mental retardation. In 1976, the act, now known as the Lanterman Developmental Disabilities Services Act (Lanterman Act), was amended to establish the right to treatment and habilitation services for persons with developmental disabilities. The Lanterman Act establishes an entitlement to services and supports for persons with developmental disabilities and their families throughout their lifetime. However, not all children with an autism spectrum disorder qualify for services. The child must be diagnosed with autistic disorder (classic autism), or otherwise be disabled to such an extent that similar treatment is necessary.

The Department of Developmental Services is responsible for designing and coordinating a wide array of services for California residents with developmental disabilities. These services are provided through a statewide system of 21 locally-based regional centers. Regional centers are nonprofit private corporations that have offices throughout California to provide a local resource to help find and access the many services available to individuals with developmental disabilities and their families. There is generally no cost to families. Services provided by regional centers include the following:

- Information and referral;
- Assessment and diagnosis;
- Counseling;
- Lifelong individualized planning and service coordination;
- Purchase of necessary services included in the individual program plan;
- Resource development;

- Outreach;
- Assistance in finding and using community and other resources;
- Advocacy for the protection of legal, civil and service rights;
- Early intervention services for at risk infants and their families;
- Genetic counseling;
- Family support;
- Planning, placement, and monitoring for 24-hour out-of-home care;
- Training and educational opportunities for individuals and families; and
- Community education about developmental disabilities.

California's Regional Center System has compiled over 20 years of data from annual assessments of individuals who qualify for service. The Client Development Evaluation Report (CDER) is the assessment instrument that is administered to each client at intake, and yearly thereafter, to determine developmental and functional status. The types of information collected on the CDER form include developmental diagnostic information (documentation of mental retardation, cerebral palsy, autism, seizure disorder, and/or other), mental disorders, chronic major medical conditions, medications, and categorization of deficits in use of muscles, independent living, social, emotional, cognitive, and communication skills. The CDER database is what was used in the recent M.I.N.D. Institute study on the epidemiology of autism.