

Autism in the United States: a Perspective

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ABSTRACT

Once rare, autism has reached epidemic proportions in the United States. The increase cannot be attributed to changes in diagnostic criteria, which have actually become more restrictive. Already a heavy burden on educational facilities, the increasing number of patients afflicted with this serious disability will have an enormous effect on the economy as the affected children reach adulthood. Studies of all possible causes of the epidemic are urgently needed. To date, studies of a potential relationship to childhood vaccines have been limited and flawed.

Historical Background

The important historical observation about autism is that it was unknown in ancient cultures, or even in medieval times, and that it just “appeared” some 60 years ago.

Leo Kanner, while at Johns Hopkins, was first to describe autism in 1943. His article *Autistic Disturbances of Affective Contact* described 11 children who had an apparently rare syndrome of “extreme autistic aloneness.”¹ Because these children’s symptoms started early, Kanner’s Syndrome was also known as “infantile autism.” In 1944, Hans Asperger also described a group of children with similar symptoms who were “highly recognizable.”² In the same year, Bruno Bettelheim theorized that children developed autism because their “refrigerator mothers” raised them in a non-stimulating environment, with resulting damage to their social, language and general development. Bettelheim’s credentials were questionable,³ and his theory has been discredited.

Bernard Rimland, Ph.D., founder of the Autism Society of America and founding president of the Autism Research Institute (ARI), has thoroughly analyzed the ARI database of more than 30,000 entries and reported two clear trends:

First, the incidence of autism has increased remarkably, becoming “an explosion” in recent years⁴ and second, a distinct shift in the time of onset of autistic symptoms has become evident. “Late onset autism (starting in the second year) was almost unheard of in the 1950s, ’60s, and ’70s; today such cases outnumber early onset cases five to one.”⁵

Parents in increasing numbers are reporting similar stories. A child, most often a boy who is developmentally, socially, and verbally on par for his age, suddenly stops acquiring new words

and skills in the second year of life and then regresses, losing speech, cognitive abilities, and social dexterity. Children in this group are said to have regressive autism. Further, overwhelmed parents may drift apart, and siblings’ stress may be manifested as behavior problems.⁶

Suggesting that a sudden and exponential increase in autistic disorders is not real, and results only from better diagnosis, amounts to denial. Similarly, though some affected children have Fragile-X Syndrome or a family history of autism, it does not seem reasonable to insist that the present autism outbreak is solely caused by hereditary factors. Genetic disorders have never presented as epidemics, and investing the scant available resources solely in genetic research diverts them from the scientific exploration of more plausible environmental etiological factors.

Official U.S. Statistics

The Individuals with Disabilities Education Act (IDEA) of 1975 was intended to ensure equal educational opportunities for children with disabilities. State and local education districts must provide a “free appropriate public education” based upon an “individualized education program” geared to each student’s needs. The U.S. Department of Education is mandated to report yearly to Congress in accordance with IDEA.

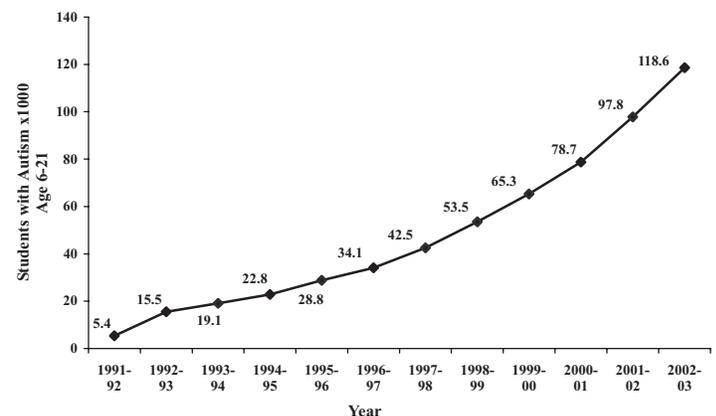


Figure 1. Children with a Diagnosis of Autism Attending U.S. Schools
Source: U.S. Department of Education Annual Reports to Congress (IDEA)

Earlier in the program, cases of autism in U.S. schools were few. As they steadily increased, a decision was made to list autism as a separate entity starting in 1991. As shown in Figure 1, the number of children aged 6 to 21 with autism in U.S. schools rose steadily from 5,415 in 1991-1992 to 118,602 in the latest published Department of Education report for the 2001-2002 school year.⁷

Table 1. States with the Largest Increases in the Number of Students with Autism, Ages 6 to 21 [1992-93 to 2002-03]

	1992-1993	2002-2003
Illinois	5	5,080
Maryland	28	2,962
Mississippi	0	537
Nebraska	4	481
Nevada	5	684
New Hampshire	0	491
Ohio	22	4,017
Oregon	37	3,339
Wisconsin	18	2,739
DC	0	179

Source: U.S. Department of Education Annual Reports to Congress (IDEA)

Every state in the U.S. has recorded an increase in the number of students with the diagnosis of autism. Nine states and the District of Columbia, which recorded the highest increases, are shown in Table 1.

It is likely that the number of children with autism will continue to increase as more affected children enter first grade (see Figure 2). According to the New Jersey Department of Education, there were 14 students of age 21 with autism in the state in the last reported school year, 2001-2002, compared to 514 students who were age 6. Other states are reporting the same trend: an increase in the number of younger children needing services, more programs being organized to handle the influx, and an ever increasing number of specially trained therapists hired.

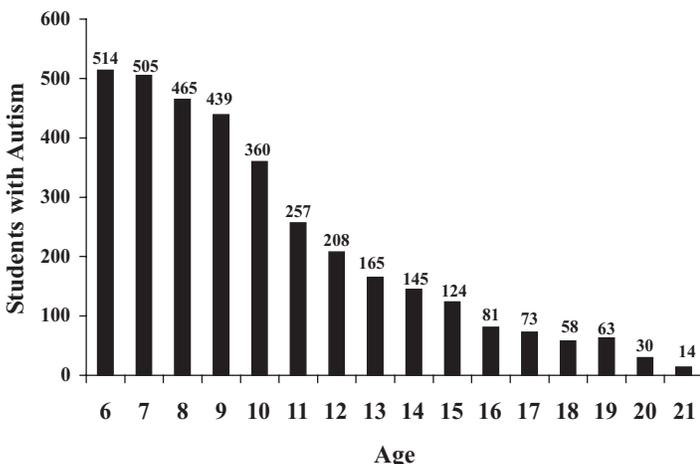


Figure 2. Children with Autism by Age in New Jersey Schools 2001-2002
Source: New Jersey Department of Education

In the last 10 years, the number of children with autism between 6 and 21 years of age attending school in the U.S. rose at a much faster rate than the number of children with disabilities in general (see Table 2).

When IDEA passed in 1975, Congress promised to provide 40 percent of the costs associated with the legislation. However, it has never actually funded more than 15 percent.⁸ State governments have also provided a decreasing proportion of the school budgets as state funds become scarce nationwide. Federal and state contributions vary greatly from state to state (see Table 3).

In addition, state contributions are not evenly distributed, and cities usually receive proportionately more state dollars than suburban communities, though the latter may have a higher

concentration of affected children.⁹ Local taxpayers usually end up bearing the spiraling cost of educating the increasing number of affected children.

Special services are often provided through most of the summer, and each child with autism can cost the school system \$30,000 a year or more. If an acceptable program is not locally available, the affected child has to be transported to a collaborative or regional center, where the yearly tuition may be higher. In rural areas, the cost of providing therapy and educating a single child with autism may be considerable.¹⁰

Lastly, as autism is diagnosed earlier, services must be made available starting at age 3, and affected children must be enrolled in early intervention programs, which are also expensive to start and maintain.

For a child to receive services in any program, a firm diagnosis of autism must first be made by a physician. Each case is then thoroughly reviewed by the special education department in the school district, which may request more information or turn down the recommendation. Autism is not a diagnosis that parents accept readily, physicians make lightly, or that school authorities approve easily. In fact, it is probable that autism in U.S. schools is actually underdiagnosed and that many less severe cases are labeled behavior and communication disorders, in order to avoid the stigma and/or the added cost.

In spite of all of the above, some “experts” still claim that the spectacular increases in autism reported lately are simply the result of more liberal or less stringent diagnostic criteria.

Diagnostic Criteria for Autism in the U.S.

As technical recognition of autism increased along with the number of cases, accurate comparisons in prevalence and incidence rates became difficult, if not impossible.

In Kanner’s conception, children with autism were affected early and had poor or absent speech; an obsessive desire for preservation of sameness; lack of affective contact; difficulty with interpersonal communication; and a fascination with specific objects.¹¹

Table 2. Increase in Autism and All Disabilities in U.S. Schools 1991-92 to 2001-02

	1991-1992	2001-2002	% Increase
Autism	5,315	97,847	1,700
All Disabilities	4,499,924	5,853,830	30

Source: U.S. Department of Education Annual Reports to Congress (IDEA)

Table 3. Federal, State and Local Contributions to Education (U.S., Calif., R.I.) in 2000

	Federal		State		Local	
National Average	\$18,581,511,000	6.80%	\$127,719,673,000	46.80%	\$119,538,243,000	43.8%
California	\$3,443,221,000	8.60%	\$23,736,295,000	59.30%	\$12,379,999,000	30.90%
Rhode Island	\$73,870,000	5.60%	\$548,776,000	41.60%	\$679,478,000	51.50%

Source: National Association of State Boards of Education (NASBE)

Table 4. DSM-IV Criteria for Diagnosis of Autism 299.00

(I) A total of six or more items from (A), (B), and (C), with at least two from (A), and one each from (B) and (C):

(A) Qualitative impairment in social interaction, as manifested by at least two of the following:

1. Marked impairments in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body posture, and gestures to regulate social interaction
2. Failure to develop peer relationships appropriate to developmental level
3. Lack of spontaneous seeking to share enjoyment, interests, or achievements with other people, (e.g., by a lack of showing, bringing, or pointing out objects of interest to other people)
4. Lack of social or emotional reciprocity (note: in the description, it gives the following as examples: not actively participating in simple social play or games, preferring solitary activities, or involving others in activities only as tools or "mechanical" aids)

(B) Qualitative impairments in communication as manifested by at least one of the following:

1. Delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime)
2. In individuals with adequate speech, marked impairment in ability to initiate or sustain conversation with others
3. Stereotyped and repetitive use of language, or idiosyncratic language
4. Lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level

(C) Restricted repetitive and stereotyped patterns of behavior, interests and activities, as manifested by at least two of the following:

1. Encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
2. Apparently inflexible adherence to specific, nonfunctional routines or rituals
3. Stereotyped and repetitive motor mannerisms (e.g. hand or finger flapping or twisting, or complex whole-body movements)
4. Persistent preoccupation with parts of objects

(II) Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years:

- (A) Social interaction
- (B) Language as used in social communication
- (C) Symbolic or imaginative play

(III) The disturbance is not better accounted for by Rett's disorder or childhood disintegrative disorder.

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In 1956, Kanner and Eisenberg¹² proposed that just *two* essential features were required to make a diagnosis of autism: profound lack of affective contact and repetitive, ritualistic, elaborate behavior.

In 1978, Rutter¹³ proposed that a definition of autism in children required *four* criteria: (1) Impaired social development out of keeping with the child's intellectual level; (2) impaired language

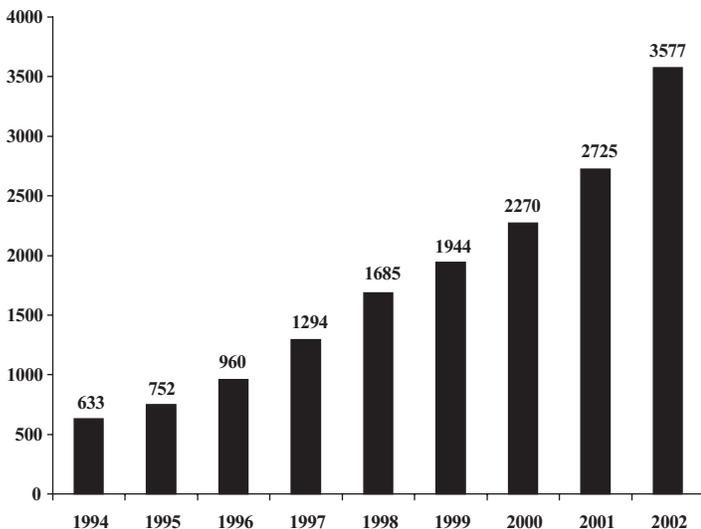


Figure 4. New Cases of Type I Autism in California
Source: California Department of Developmental Services

development out of keeping with the child's intellectual level; (3) stereotyped play patterns, abnormal preoccupations, and resistance to change; and (4) onset before the age of 30 months.

In 1980, DSM III (*Diagnostic and Statistical Manual of Mental Disorders*, Third Edition),^{11,14} was introduced, and its classification of infantile autism required *five* criteria: (1) Lack of responsiveness to others; (2) language absence or abnormalities; (3) resistance to change or attachment to objects; (4) absence of schizophrenic features; and (4) onset before 30 months.

In 1987, the diagnostic criteria for autism were revised (DSM III-R), and a definition of pervasive developmental disorders was introduced.¹¹ Other countries had their own sets of criteria.

Since 1994, the required criteria for Autistic Disorder 299.00 have been those established in the DSM IV, shown in Table 4.¹⁵ Similarly, detailed and strict criteria were outlined for Asperger's Syndrome (AS) and Pervasive Developmental Disorder, Not Otherwise Specified (PDD-NOS) 299.80.

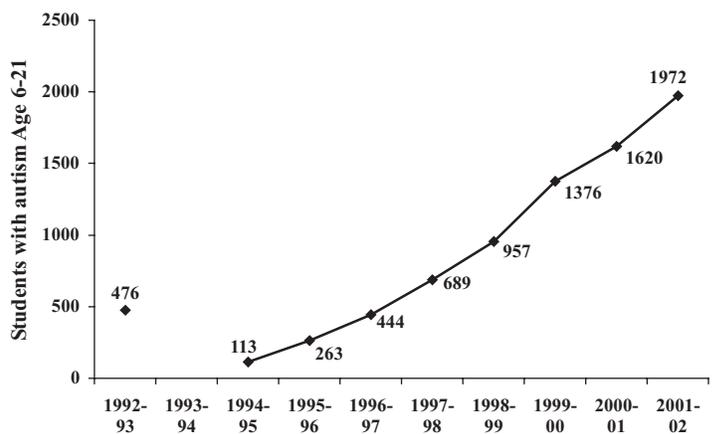


Figure 3. Students with Autism Attending School in Washington State
Source: U.S. Department of Education Annual Reports to Congress (IDEA)

Clearly, DSM IV criteria are more restrictive. In fact, in certain states such as Washington, the number of cases of autism (IDEA) actually *decreased* immediately after the introduction of DSM IV (Figure 3). The subsequent steady rise in the number of affected students clearly points to a true increase, as the criteria have remained uniform, and in all probability the diagnosis in each case has been accepted by the same medical, educational, and developmental teams.

The Impact of Autism

The autism explosion since 1994 and DSM IV is best documented in California, where the Department of Developmental Services (DDS)¹⁶ regularly reports all new cases of the disorder introduced in the system (Figure 4). As shown, there were 633 *new* cases of DSM IV autism in 1994. Within 5 years (1999), the number of new cases had risen to 1,944 or 6 new cases a day, 7 days a week. There were 2,725 confirmed new cases of autism added to the system in 2001 and 3,577 more in 2002 or ten

Table 5. Autism, Behavior Disorders, and All Disabilities in Rhode Island (6/30/2001-6/30/2002)

	6/30/2001	6/30/2002	% Increase
Autism	407	498	23.35
Behavior Disorders	2,583	2,848	10.25
All Disabilities	31,793	32,789	3.13

Source: Rhode Island Department of Education

children a day.¹⁷ That one-year increase of 31 percent was the highest in the 33-year history of the department. Children with autism under age 3 and those with PDD-NOS and Asperger’s Syndrome were not included.

Autism has become the predominant disability for which services are accessed in California. According to the most recent California Autism Report released in March 2003, cases of Type I autism increased by 97 percent in the last four years compared to 16 percent for cerebral palsy and 29 percent for mental retardation.

The same is true in other states and is well documented recently in Rhode Island, where proportionately, the one-year increase in autism was substantially greater than the increase in behavior disorders and all disabilities combined (see Table 5).

The only reasonable conclusion from this review is that the recent increase in autism in the U.S. is real and significant. There is also every reason to believe that more children will be “developing” autism in the coming years. Educational programs will have great difficulty coping with the flow of newly diagnosed children. In addition, when autistic children become adults and their parents are not there, the impact on society will be even greater and the burden on the national economy will mount into the trillions of dollars.

Possible Etiologies

Control of epidemics is the responsibility of public health authorities. The Centers for Disease Control and Prevention (CDC), the central agency in charge of the nation’s health, has previously played a vital role in a variety of national and international crises and programs ranging from chemical explosions in Texas City, Texas, in 1947, to family planning (1967), famine relief in Nigeria (1968), birth defects monitoring (1970), occupational safety (1973), ship sanitation (1975), and the health complications from the Mount St. Helens volcanic eruption in 1980.¹⁸

Since the 1980s, the agency has become increasingly involved in promotion and regulation of vaccines. However, the CDC has done little to control the autism epidemic or discover its causes. So far it has funded only three studies, and all three were epidemiologic. In the first two, both conducted in the U.S., serious increases in autism were reported.

In one, the investigators concluded that there were “high rates of autistic disorder and ASD in Brick Township, New Jersey, relative to rates from previously published studies. The rates from the majority of recent studies are several fold lower than the rate in Brick Township.”¹⁹

In the second, examining autistic syndromes in the area near Atlanta, Ga., the authors commented, “The overall rate (of autism) is *10 times higher* than rates from three other U.S. studies ... in the 1980s and early 1990s.”²⁰

The primary purpose of the third study, from Denmark,²¹ appears to be exoneration of the measles-mumps-rubella (MMR) vaccine.²²⁻²⁵ Several methodological problems marred the research and, despite the fact that there was a higher prevalence of autism among the children who had received the MMR vaccine, the authors asserted that there was no MMR-autism connection. Moreover, the study is not relevant to the situation in the U.S. Vaccines in Denmark have not contained thimerosal since 1992, and Danish children only received six doses of vaccine in the first year of life. In the U.S., children received 12 or more doses of vaccine before their first birthday, and many of those vaccines contained thimerosal, including one administered in the nursery.

So far, though the CDC does not know what causes autism and its neurological, endocrine, gastrointestinal, and immune symptoms, it appears determined, without a single clinical study of its own, to deny the potential role of MMR vaccination and mercury preservatives. The possibility that mercury may affect the immune system²⁶⁻²⁸ of certain genetically predisposed children and trigger autism upon their exposure to MMR²⁹⁻³² has never been conclusively ruled out.

The decision to remove thimerosal from pediatric vaccines in 1999 was wise. It is difficult to believe that, to assure sterility, a known poison had been added for more than 60 years to products intended for infants. Safer “preservatives” should have been used.

Serious independent research is urgently needed. It cannot be expected from people with financial ties to the vaccine industry and the vaccine authorities.

Research should not be restricted to looking at epidemiologic data on computer spreadsheets. It must include parents’ interviews and a careful examination and evaluation of the affected children. Endoscopies and colonoscopies should be carefully performed, and biopsies of the gut wall should be tested for evidence of measles.

It was revealed at the December 10, 2002, hearing of the House Government Reform Committee that Arthur Krigsman, M.D., had performed some 250 colonoscopies on children with autism and had identified pathological and histological findings similar to those described by Andrew Wakefield in England. Unfortunately, his hospital did not allow him to have the specimens further tested, or specifically tested for evidence of measles.

A committee member, Representative Dave Weldon, M.D., of Florida’s District 15, requested from Dr. Stephen Foote of NIH, who was present, to find a way to have these specimens tested promptly. It is not known whether this was done.

A complete cerebrospinal spinal fluid examination including serology is needed. Serum specimens should be carefully obtained and tested for antibodies to myelin basic protein (MBP) and neuron-axon filament proteins (NAFP). Antibody levels of measles virus (MV) and human herpesvirus-6 (HHV-6) should be

determined; evaluation of serotonin, serotonin receptor antibody, interleukin-12 (IL-12), and interferon-gamma (IFN-g) levels would also be helpful.

Testing for urinary indolyl-acryloylglycine (IAG) and polypeptides is of value both diagnostically and therapeutically, as it identifies those children who would benefit from diet restrictions. Checking for heavy metals is always indicated. Other appropriate testing should be individualized.

Conclusions

There has been a true and significant increase in autism in the U.S. To date, the CDC and other governmental health authorities have not given enough attention to this serious epidemic and its present and future impact. They must face their responsibility now.

Emerging evidence suggests some relationship between MMR and thimerosal-containing vaccines and regressive autism. Additional independent and unbiased clinical studies must be conducted in order to determine all causes involved.

Information about the autism epidemic and its potential causes should be widely disseminated.

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Competing interests: Dr. Yazbak is the grandfather of a boy with regressive autism, typical "autistic" enterocolitis, and evidence of measles genomic RNA in the gut wall.

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