



## **Some elements about the prevalence of Autism Spectrum Disorders (ASD) in the European Union**

Autism is a developmental disorder characterized by disturbance in language, perception and socialization. A variety of biochemical, anatomical and neuroradiographical studies imply a disturbance of brain energy metabolism in autistic patients. The underlying aetiology of the disturbed bioenergetics metabolism in autism is still unknown<sup>1</sup>. The autism (sometimes called “classical autism”) is the most common condition in a group of developmental disorders known as the autism spectrum disorders (ASD).

There are three distinctive behaviours that characterize autism. Autistic children have difficulties with social interaction, problems with verbal and nonverbal communication, and repetitive behaviours or narrow, obsessive interests. These behaviours can range in impact from mild to disabling.

The hallmark feature of autism is impaired social interaction. Parents are usually the first to notice symptoms of autism in their child. As early as infancy, a baby with autism may be unresponsive to people, or focus intently on one item to the exclusion of others for long periods of time. A child with autism may appear to develop normally and then withdraw and become indifferent to social engagement. Many children with autism have a reduced sensitivity to pain, but are abnormally sensitive to sensations such as sound, touch, or other sensory stimulation. These unusual sensitivities may contribute to behavioural symptoms such as a resistance to being cuddled or hugged<sup>2</sup>.

### **Subgroups and Related Disorders**

Other ASDs<sup>3</sup> include Asperger syndrome, Fragile X Syndrome, Landau-Kleffner Syndrome, Rett syndrome, childhood disintegrative disorder, and PDD-NOS (pervasive developmental disorder not otherwise specified). In the last five years, research has shown that many people with autistic behaviours have related but distinct disorders:

- Asperger Syndrome is characterized by concrete and literal thinking, obsession with certain topics, excellent memories, and being 'eccentric.' These individuals are considered high-functioning and are capable of holding a job and of living independently.
- Fragile X Syndrome is a form of mental retardation in which the long arm on the X chromosome is constricted. Approximately 15% of people with Fragile X Syndrome exhibit autistic behaviours. These behaviours include: delay in speech/language, hyperactivity, poor eye contact, and hand-flapping. The majority of these individuals function at a mild to moderate level. As they grow older, their unique physical facial features may become more prominent (e.g., elongated face and ears), and they may develop heart problems.
- People with Landau-Kleffner Syndrome also exhibit many autistic behaviors, such as social withdrawal, insistence on sameness, and language problems. These individuals are often thought of as having 'regressive' autism because they appear to be normal until sometime between ages 3 and 7. They often have good language skills in early childhood but gradually lose their ability to talk. They also have abnormal brain wave patterns which can be diagnosed by analyzing their EEG pattern during an extended sleep period.

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<sup>1</sup> See <http://www.orpha.net>.

<sup>2</sup> See <http://www.nimh.nih.gov/Publicat/autism.cfm>.

<sup>3</sup> See [http://people.sca.uqam.ca/~sqa/dsm4\\_e.html](http://people.sca.uqam.ca/~sqa/dsm4_e.html).

- Rett Syndrome is a degenerative disorder which affects mostly females and usually develops between six months to 1 and a half years of age. Some of their characteristic behaviors include: loss of speech, repetitive hand-wringing, body rocking, and social withdrawal. Those individuals suffering from this disorder may be severely to profoundly mentally retarded.
- Williams Syndrome is characterized by several autistic behaviours including: developmental and language delays, sound sensitivity, attention deficits, and social problems. In contrast to many autistic individuals, those with Williams Syndrome are quite sociable and have heart problems.
- Childhood disintegrative disorder (CDD) its condition occurring in 3 to 4 year olds which is characterized by deterioration, over several months, of intellectual, social, and language functioning. Also known as disintegrative psychosis or Heller's syndrome. This rather rare condition was described many years before autism but has only recently been 'officially' recognized. With CDD children develop a condition which resembles autism but only after a relatively prolonged period of clearly normal development. Although apparently rare the condition probably has frequently been incorrectly diagnosed. CDD is usually associated with severe mental retardation. There also appears to be an increased frequency of EEG abnormalities and seizure disorder.
- Pervasive Developmental Disorder, Not Otherwise Specified (PDD-NOS) is a 'subthreshold' condition in which some - but not all - features of autism or another explicitly identified. PDD-NOS is often incorrectly referred to as simply 'PDD' The term PDD refers to the class of conditions to which autism belongs. PDD is not itself a diagnosis, while PDD-NOS is a diagnosis. The term PDD-NOS; also referred to as 'atypical personality development', 'atypical PDD' or 'atypical autism', is included in DSM-IV to encompass cases where there is marked impairment of social interaction, communication, and/or stereotyped behavior patterns or interest, but when full features for autism or another explicitly defined PDD are not met.

### **Treatments and interventions**

There is no cure for ASD. For many children, ASD symptoms improve with treatment and with age. Some children with autism grow up to lead normal or near-normal lives. Therapies and behavioural interventions are designed to remedy specific symptoms and can bring about substantial improvement. In contrast to 20 years ago when many autistic individuals were institutionalized, there are now many flexible living arrangements. Usually, only the most severe individuals live in institutions. In adulthood, some people with autism live at home with their parents; some live in residential facilities; some live semi-independently (such as in a group home); and others live independently. Therapists use highly structured and intensive skill-oriented training sessions to help children develop social and language skills. Doctors often prescribe an antidepressant medication to handle symptoms of anxiety, depression, or obsessive-compulsive disorder. Anti-psychotic medications are used to treat severe behavioural problems. Seizures can be treated with one or more of the anticonvulsant drugs. Stimulant drugs, such as those used for children with attention deficit disorder are sometimes used effectively to help decrease impulsivity and hyperactivity. The ideal treatment plan coordinates therapies and interventions that target the core symptoms of autism: impaired social interaction, problems with verbal and nonverbal communication, and obsessive or repetitive routines and interests. Most professionals agree that the earlier the intervention, the better.

Over the years, families have tried various types of traditional and non-traditional treatments to reduce autistic behaviors and to increase appropriate behaviors. Although some individuals are given medications to improve general well-being, there is no primary drug which has been shown to be consistently effective in treating symptoms of autism. The most widely prescribed medication for autistic children is *Ritalin*, (a stimulant used to treat Attention Deficit/Hyperactivity Disorder). However, there are no double-blind controlled studies to demonstrate its effectiveness for those with

autism. The two treatments which have received the most empirical support are Applied Behaviour Analysis (ABA; behaviour modification) and the use of vitamin B6 with magnesium supplements or Di-methylglycine (DMG). Behaviour modification involves a variety of strategies, (e.g. positive reinforcement, time-out), to increase appropriate behaviors, such as communication and social behaviour, and to decrease inappropriate behaviors, such as self-stimulatory and self-injurious behaviour.

### **Causes of ASD**

Although there is no known unique cause of ASD, there is growing evidence that autism can be caused by a variety of problems. There is some indication of a genetic influence in autism. For example, there is a greater likelihood that two monozygotic twins (i.e., identical twins) will have autism than two dizygotic twins (i.e., fraternal twins). In the case of monozygotic twins, there is a 100% overlap in genes; whereas in dizygotic twins, there is a 50% overlap in genes, the same overlap as in non-twin siblings. Currently, a great deal of research has focused on locating the 'autism gene' however, many researchers speculate that three to five genes will likely be associated with autism. There is also evidence that the genetic link to autism may be a weakened or compromised immune system. Other research has shown that depression and/or dyslexia are quite common in one or both sides of the family when autism is present.

There is also evidence that a virus can cause autism. There is an increased risk in having an autistic child after exposure to rubella during the first trimester of the pregnancy. *Cytomegalovirus* has also been associated with autism. There is growing concern that toxins and pollution in the environment can also lead to autism. There is growing evidence that the gut or intestinal tract of autism children is impaired. Researchers have documented yeast overgrowths (*candida albicans*), low levels of phenyl sulfur transferase, and measles virus in their intestinal tract.

It has been a certain concern that viruses associated with vaccinations, such as the measles component of the MMR vaccine and the pertussis component of the DPT shot may cause autism. A large study<sup>4</sup> conducted by the Danish Epidemiology Science Center and other partners on a large Danish sample of 2 129 864 person-years with a total of 537 303 children included in the cohort a total of follow-up of 5 811 children still December 1999. Results show diagnosis of autistic disorder (in 316 children), other autistic-spectrum disorders (in 422), tuberous sclerosis (in 35), congenital rubella (in 2), or the fragile X or Angelman's syndrome (in 8). For children who received MMR vaccine, there were 1 647 504 person-years of follow-up. This study provides three strong arguments against a causal relation between MMR vaccination and autism. First, the risk of autism was similar in vaccinated and unvaccinated children, in both age-adjusted and fully adjusted analyses. Second, there was no temporal clustering of cases of autism at any time after immunization. Third, neither autistic disorder nor other autistic-spectrum disorders were associated with MMR vaccination. Furthermore, the results were derived from a nationwide cohort study with nearly complete follow-up data. According to this, as well as other available international studies, the WHO has declared<sup>5</sup> no to be '*aware of any scientific evidence that meets the criteria laid out by the Committee (The Global Advisory Committee on Vaccine Safety) that might substantiate an association between autism and MMR vaccines*'.

With respect to biochemistry, many autistic individuals have elevated levels of serotonin in their blood and cerebral spinal fluid, whereas others have relatively low levels of serotonin. It should be mentioned that other disorders, such as Down syndrome, attention deficit/hyperactivity disorder, and unipolar depression are also associated with abnormal levels of serotonin. There is also evidence that some autistic individuals have elevated levels of beta-endorphins, an endogenous opiate-like substance in the body. It is felt that those individuals who have an increased pain tolerance may likely be due to elevated levels of beta-endorphins.

A dysfunctional immune system has also been associated with autism. It is thought that a viral infection or an environmental toxin may be responsible for damaging the immune system. As

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<sup>4</sup> A population-based study of measles, mumps, and rubella vaccination and autism, The New England Journal of Medicine, 2002

<sup>5</sup> See <http://www.who.int/vaccines-diseases/mmrautism.shtml>

mentioned above, there is also evidence of a genetic association to a compromised immune system. Researchers have found that many autistic individuals have a decreased number of helper t-cells which help the immune system fight infection.

### **Case definition of ASD**

One of the main difficulties to give estimations about prevalence of ASD, in a historical perspective, is the fact that our understanding of autism has changed over the past decade. One of the changes has been the appreciation that several closely-related disorders exist; they share the same essential features but differ on specific symptoms, age of onset, or natural history. These disorders mentioned above are now conceptualised as ASD. This explains why, according to recently published British estimates, the current rates of autism are 16 per 10 000 but in fact these rates increase to 63 per 10 000 when all forms of ASD are included. Debate remains about the validity and usefulness of a broad definition of autism.

After the introduction of the DSM-IV criteria a dramatic increase in the prevalence of autism could be observed. This variation in the definition of autism is one of the factors that may account for differences in reported prevalence rates, the criteria historically used are summarised as follows:

- ***Kanner's Criteria:*** A profound lack of affective contact and repetitive, ritualistic behaviour, which must be of an elaborate kind. They considered that, if these two features were present, the rest of the typical clinical picture would also be found. Lotter used the two features in his final identification of autistic children and in the division into 'nuclear' and 'non-nuclear' groups. He operationalised the criteria and gave examples of the behaviour (Lotter, 1967). He did not include age of onset as essential.
- ***Rutter's Criteria:*** Impaired social development which has a number of special characteristics out of keeping with the child's intellectual level, delayed and deviant language development that also has certain defined features and is out of keeping with the child's intellectual level, 'insistence on sameness' as shown by stereo-typed play patterns, abnormal preoccupations or resistance to change, and onset before 30 months.
- ***DSM-III Criteria:*** In this, the term 'pervasive developmental disorder' was used for the general category of autism and related conditions. A subgroup labelled 'infantile autism' was defined by: lack of responsiveness to others; language absence or abnormalities; resistance to change or attachment to objects; the absence of schizophrenic features; and onset before 30 months. DSM-III also has categories for childhood onset (after 30 months and before 12 years) and for atypical pervasive developmental disorder.
- ***DSM-III-R Criteria:*** The definitions in the section on pervasive developmental disorders in the revised version of DSM-III, referred to as DSM-III-R (American Psychiatric Association, 1987) have moved to a diagnosis requiring: impairment in reciprocal social interaction (at least two from a list of 5 items, comprising specified clinical examples); impairment in verbal and non-verbal communication (at least one from a list of 6 items); markedly restricted repertoire of activities and interests (at least one from a list of 5 items), and a grand total of at least eight from among the 16 items listed.
- ***Ishii and Takahashi Criteria:*** Disturbed inter-personal relationships (defined by a list of clinical examples comprising 9 items); absence or deviance in speech and language development (8 items); insistence on the preservation of sameness or resistance to change (6 items), and abnormal responses to sensory stimuli or motility disturbance (10 items).
- ***DSM-IV Criteria:*** The new Diagnostic and Statistical Manual of Mental Disorders, 4th edition (DSM-IV) came out in the summer of 1994. There have been numerous changes which affect the diagnoses of Autism and related disorders. In order for a diagnosis of Autism to be made, the person still needs to evidence problems in three broad areas: social interaction, communication, and stereotyped patterns of behaviour. However, the number of symptoms

which fall under these three broad areas have been reduced from 16 to 12 to make this diagnostic category more homogeneous. The individual needs to evidence 6 symptoms spanning the three broad areas with at least two symptoms indicating social interaction deficits, and one symptom in each of the communication and stereotyped patterns of behaviour categories. The symptoms which fall under the social interaction category are: marked impairment in the use of multiple nonverbal behaviours; failure to develop age-appropriate peer relationships; lack of spontaneous seeking to share interests and achievements with others; and lack of social or emotional reciprocity. The symptoms which fall under the communication category are: delay in or lack of spoken language development (with no compensation through alternative modes of communication); in verbal persons, marked impairment in conversational skills; stereotyped and repetitive use of language; and lack of spontaneous age-appropriate make-believe or social imitative play. The symptoms which fall under the stereotyped patterns of behavior category are: preoccupation with at least one stereotyped and restricted patterns of interest to an abnormal degree; inflexible adherence to non-functional routines or rituals; stereotyped and repetitive motor mannerisms; and preoccupation with parts of objects. Besides at least 6 of these symptoms, there also needs to be delays in social interaction, social communication, or symbolic or imaginative play. Another change is that the age of onset of these symptoms has to occur prior to age 3. Some new disorders are now included in this DSM system: Rett's Disorder, Childhood Disintegrative Disorder, Pervasive Developmental Disorders, Asperger's Disorder.

### **Studies on the general prevalence of ASD**

To try to answer questions about ASD prevalence is extremely difficult. The usual health information sources (health surveys, hospital discharges, and registers) are difficult or not existing for being used to contribute to establish prevalence of ASD. The treatment of ASD is not normally a hospital treatment. The figures available for England or France gives practically the same figure (3 500 hospital discharges in the year 2002 for the ICD-10 codes F80-89 Disorders of psychological development) but it could be assumed that these represents only some acute cases or severe episodes of ASD requiring hospitalisation.

It is difficult to measure incidence and prevalence rates for not major conditions using Health Interview Surveys. For conditions as ASD, the sample size required begins to approach the total population size. However, there is a class of diseases for which it is possible, but very expensive, to conduct large population-based surveys but often, even the largest studies produce estimates with very wide confidence intervals.

There is no central recording of ASD cases in any EU Member State and there are very few epidemiological studies on ASD on which to make appropriated predictions. The available studies are infrequent, expensive, problematic and very difficult to compare in a trend time perspective<sup>6</sup>.

The problems arise from three main causes.

1. There are many difficulties in diagnosing people with these disorders. There is no medical test that can determine in an absolute way whether or not a person has autism. Diagnostic criteria are in terms of descriptions of behaviour. The earliest criteria, suggested by Kanner, were very narrow. The current standard classification systems (ICD-10 and DSM-IV) are much wider, even for the sub-group of 'childhood autism' (or 'autistic disorder' in DSM-IV). Professionals differ in the way they apply the criteria, even if they are, theoretically, using one of the standard systems. Diagnoses may be recorded in different ways in case notes and centralised data collections.

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<sup>6</sup> From an article of Lorna Wing and David Potter, <http://www.nas.org.uk/nas/jsp/polopoly.jsp?d=364&a=2618>.

2. Diagnostic terms tend to be used in different ways. Sometimes the term 'autism' is used to mean Kanner's original group, sometimes it refers to the wider group called 'childhood autism' in ICD-10 and sometimes the whole autistic spectrum, including the individuals described by Asperger. In any case, there is a very great deal of overlap among all the sub-groups named in ICD-10 and DSM-IV and many individuals fit more than one diagnosis within the spectrum.
3. In epidemiological studies of prevalence, case finding methods vary. Those that involve seeing, assessing and diagnosing every individual in the sample to be examined will tend to find higher numbers than studies that rely on using case notes of individuals who have already been given the diagnosis in local clinics.

For these reasons, it is very difficult to make comparisons among studies done by different workers, at different times, in different places, using different definitions, and different methods of case finding and examination. Thus, the earliest epidemiological studies used Kanner's very narrow criteria and found the often quoted prevalence rate of 4.5 to 5 in 10 000 children. Later studies have used wider criteria arriving to prevalences beyond 60 per 10 000, so it would be inappropriate to calculate a mean prevalence based on results from the earliest and the later studies.

Knowledge about prevalence is, however, vital if effective services are to be planned and provided at the correct points in individuals lives. The expense of making appropriate provision for those people within this population makes it the more surprising that governments have not been willing to fund new epidemiological research, covering individuals of all levels of ability, using soundly based scientific methods, which would enable accurate planning.

The available figures (Table 1) from the scarce epidemiological studies around the world tend to confirm this approach. Changes on the criteria used increases the prevalence per 10 000. Studies between 1967-1982 using Kanner's criteria provide prevalence's on a range of 4.5 to 5.0, using the Rutter's criteria the range 5.6 to 10.8, etc. When large DSM-IV criteria are used, in the most recent studies, prevalence's founded could be on a range of 57.0 to 67.0.

The reason for tightening the criteria for Autism and for adding Rett's Disorder, CDD, and Asperger's Disorder to DSM-IV are to recognize that Autism is a disorder with many possible symptom variants. Because of this, individuals diagnosed with Autism in the past have been heterogeneous. This has made it difficult to conduct research to determine the aetiology, prognosis, and appropriate treatment for individuals with Autism. Hopefully, as the DSM-IV system recognizes the variability of Autistic-like behaviours across individuals, researchers can determine the aetiologies and treatments for each of these related disorders. One question that remains unanswered, due to this refinement in the DSM system, is how the public services will recognize the need for services for individuals in all four of these diagnostic categories, not just for those diagnosed with Autism.

*Table 1: Overview on reports of studies that provide disease frequency statistics on autism, autistic spectrum disorders (ASDs), and related disorders.*

<i>Area</i>	<i>Year</i>	<i>Total children in age range</i>	<i>Criteria used</i>	<i>Age range</i>	<i>Total rate per 10 000</i>
Middlesex (UK)	1967	77 800	Kanner	8-10	4.5
Aarhus (DK)	1972	46 500	Kanner	2-14	4.3
Camberwell (UK)	1979	34 700	Kanner	3-17	4.9
Fukushima (JP)	1982	217 600	Kanner	4-10	5.0
Västerbotten (S)	1983	69 600	Rutter	0-20	5.6
Rhône (F)	1989	103 700	Rutter	5-9	10.8
Iceland	1996	38 746	Rutter	4-12	8.8
Kurume (JP)	1987	32 800	DSM III	4-12	15.5
Ibaraki (JP)	1988	95 400	DSM III	7	13.8
Nagoya (JP)	1989	12 300	DSM III	3-5	13.0
Utah (US)	1989	184 800	DSM III	8-12	4.0
North Dakota (US)	1987	181 000	DSM III	2-18	3.3
Göteborg1 (S)	1984	128 600	DSM III	4-18	4.0
Göteborg2 (S)	1986	42 900	DSM III	0-10	7.5
Nova Scotia (CA)	1988	20 800	DSM III - R	6-14	10.1
Nord-Trondelag (NO)	1998	n.a.	DSM-IV	3-14	3.8
Göteborg3 (S)	1991	40 700	DSM III - R	4-13	11.5
Toyota (JP)	1983	35 000	Ishii	6-12	16.0
Northern Finland (FI)	1997	152 732	DSM III – R / DSM-IV	5-7	20.7
Ireland East (IRL)	1997	549 255	DSM III / DSM III - R	0-25	4.94
Atlanta (US)	1996	289 456	DSM-IV	3-10	34.0
Brick Township, New Jersey (US)	1998	7 117	DSM-IV	3-10	67.0
Cambridgeshire (UK)	1999	34 262	DSM-IV	5-11	57.0

The most important ASD studies on cross-survey comparisons<sup>7</sup> conclude in similar approaches. The cross-survey comparisons have correlated reported prevalence estimates with the years in which the selected surveys were published showed an increase in autism rates over time, but the correlation was not statistically significant. The later analyses showed a rising trend that reached statistical significance. In each case, however, the studies attributed any positive trend in reported prevalence rates to methodological changes. Until recently, this was a reasonable inference to draw from the literature. Reviewers have emphasized the difficulty of assessing trends against a background of regular changes in diagnostic criteria. When dates of publication are used in a meta-analysis, an analysis of time trends will reveal little beyond an apparent effect of changes in diagnostic standards.

An assessment (not shown) of all published prevalence studies by diagnostic criteria set reveals that prevalence was relatively stable until the most recent set of diagnostic criteria was introduced. Relying on the date of publication can obscure large differences in the study populations observed. For example, three Scandinavian studies published in a three-year period used markedly different populations: a Swedish study published in 1997 measured the prevalence of autism in a 3- to 6-year-old population born from 1988 through 1991; another Swedish study published two years later, in 1999, focused on 7-year-olds who were born in 1985, several years before the children in the first group; while a Norwegian study published between the two covered a wide range of age cohorts and measured prevalence rates going back as far as 1978. In addition, combining surveys from locations as widely separated as Yokohama, California, and Goteburg greatly increases the potential for non-comparability. None of the three meta-analyses chose surveys based on country groupings, therefore risking the introduction of confounding environmental factors that are geographically specific. With the publication since 1999 of six U.S. studies and seven U.K. studies, the opportunity for useful geographic comparison has improved greatly.

We can examine results from some of the most significant EU studies. The authors of the Cambridgeshire study (1999)<sup>8</sup> conclude: *'Results from this study of the broader autism spectrum in 5-11 year old children in Cambridgeshire, UK, demonstrate that the numbers of children with autism spectrum disorders in this age range may be significantly greater than previously recorded, and support recent other research demonstrating higher prevalence figures nationally and internationally. It is not possible from this data to establish whether there has been an increase in incidence of autism, thus leading to greater prevalence figures overall, or whether changes in prevalence are in fact due to widening of diagnostic boundaries and better professional awareness. However, our conservative figures support the recent findings of Baird et al. (2000) and the Brick Township report (2000), and suggest that further more detailed epidemiological research is much needed to fully address such questions regarding incidence and presentation of the broader autism spectrum'*.

The authors of the Northern Finland (1997) study<sup>9</sup> conclude: *'the total prevalence ( $\pm$  5% CI) of AD in Northern Finland was 13.9 (12.0–15.7)/10 000. ... The age specific prevalence's obtained in this study showed the prevalence to be lowest, 6.1 per 10 000, in the oldest age group of 15- to 18-year-old children, and highest, 20.7 per 10 000, in the age group of 5–7 years, when the criteria of ICD-10 and DSM-IV were used. According to this study, we have about three- to fourfold prevalence of AD in Northern Finland now compared to 16 years ago. Associated medical disorders or associated disorders of known or suspected genetic origin were found in 12.3%, including tuberous sclerosis, Down syndrome, fragile-Xsyndrome, Klinefelter syndrome, XYY syndrome, chromosome 17 deletion, and mitochondriopathy. Other associated medical disorders were epilepsy, hydrocephalus, foetal alcohol syndrome and cerebral palsy. Severe impairment of vision was found in 3.7% of the individuals with autistic disorder. Epilepsy was found in 34 (18.2%), cerebral palsy in 8 (4.3%) and other associated neurological disorders (such as hydrocephalus, foetal alcoholic syndrome, Sotos syndrome, neonatal meningitis/encephalitis). Medical disorders seem to have a special impact on the genesis of autistic disorder and need to be thoroughly examined in each child with autistic disorder'*.

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<sup>7</sup> See articles of Eric Fombonne, Lorna Wing, and Mark F. Blaxil in the references

<sup>8</sup> Autism Research Centre, University of Cambridge,

<sup>9</sup> 'Autism in Northern Finland: A prevalence, follow-up and descriptive study of children and adolescents with autistic disorder' **Marko Kiellinen**, Faculty of Medicine,



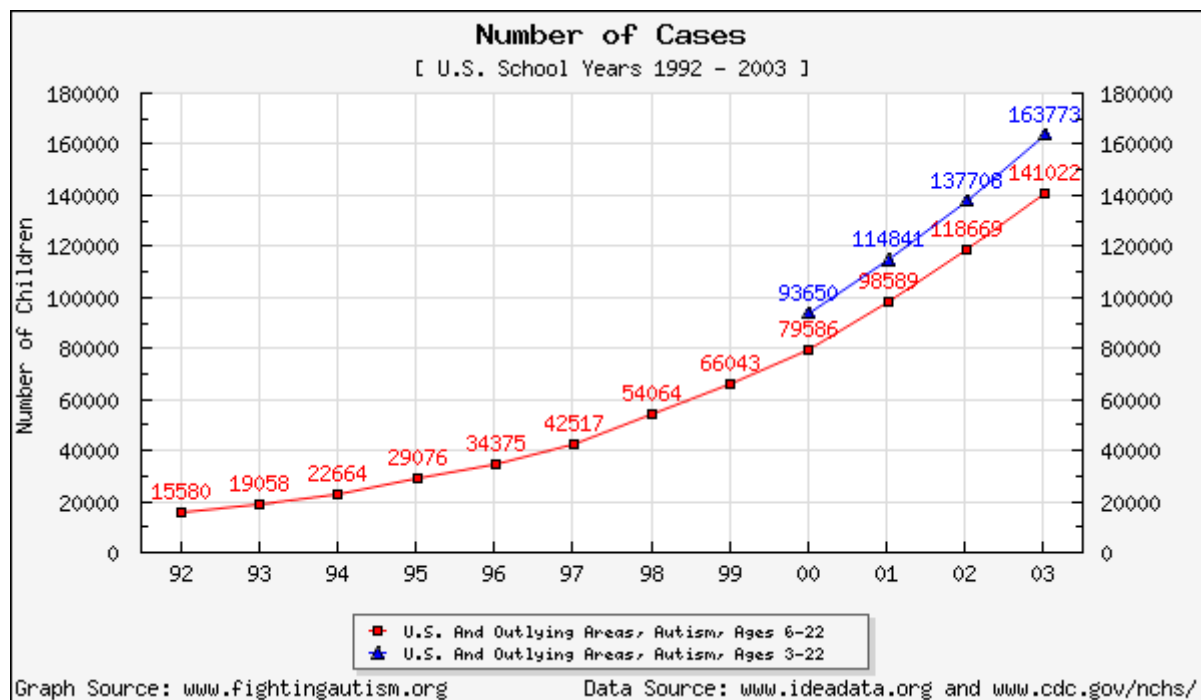
Other cross-survey studies suggest that the evidence<sup>10</sup> supporting an increasing rate of autism in the UK and the US has gathered strength. Although both the nomenclature and the criteria set used to define autism have changed over the years, these changes are not so great as to prevent comparative analysis and do not explain major differences in reported prevalence over time. The largest stable source of variability in reported autism rates comes from incomplete ascertainment in young age cohorts, which limits the ability to detect an underlying and rising secular trend. Reviews that have downplayed the rising trend have overemphasized unimportant methodological problems and failed to take into account the most relevant biases in survey methodologies. Point prevalence comparisons made within and across surveys conducted in specific geographic areas, using year of birth as a reference for trend assessment, provide the best basis for inferring disease frequency trends from multiple surveys.

A comparison of UK and US surveys, taking into consideration changing definitions, ascertainment bias, and case-finding methods, provides strong support for a conclusion of rising disease frequency. The rate of autism in the US, once reported as <3 per 10 000, has now risen to >30 per 10 000, a 10-fold increase. The rate of autism in the UK, once reported as >10 per 10 000, has risen to roughly 30 per 10 000. Reported rates for ASDs in both countries have risen from the 5 to 10 per 10 000 range to the 50 to 80 per 10 000 range. This review has found little evidence that systematic changes in survey methods can explain these increases, although better ascertainment may still account for part of the observed changes. A precautionary approach therefore suggests that increased rates of autism and related disorders be accepted as an urgent public health concern.

### **The debate on the ASD prevalence in the USA**

Last years, a lot of articles have been published in the USA about a so called 'epidemic of autism'. The existence of this 'epidemic' has never been officially admitted by the US health authority, the CDC.

The origin of the polemics is a study, of the US Department of Education, for children with autism aged 6-21, who are given Special Education services under IDEA (the Individuals with Disabilities Education Act). From these figures it appears that on 1992 a total of 15 580 children (6-22 years of age) were supported for autistic disorders and on 2003 the number of children supported were 141 022 (an increase of 924%)<sup>11</sup>. The graph on the evolution of number of cases is presented here.



<sup>10</sup> 'What's Going On? The Question of Time Trends in Autism' Mark F. Blaxill.

<sup>11</sup> See <http://www.namisc.org/newsletters/April02/autism.htm>

However, these figures could not be considered in itself as ‘clinical diagnosis figures’. As analysed by Gabriels and Noland<sup>12</sup>, it is a big distinction between an educational diagnosis of autism using the IDEA ’97 definition as interpreted by each state (the US Federal law IDEA ’97 must be interpreted and enacted by each state) and a clinical diagnosis provided by a medical doctor or a clinical psychologist using the DSM-IV criteria:

- Children must meet requirements under the IDEA ’97 and state interpretations for educationally defined disabilities in order to receive special education and related services.
- Even though a child may not yet have received a clinical diagnosis from a professional in the general medical or mental health community, he or she may still qualify for special education services according to the federal and state autism disability definition.
- When educational personnel are called upon to make a diagnosis under the guidelines of the federal and state definitions, they should exercise caution and only operate within the boundaries of their training and supervision.

The educational disabilities are, in general, much more broadly defined than the criteria provided by the DSM-IV and school personnel are not expected to delineate among various autism spectrum disorders, but instead to simply identify that a child has a disability that falls within the autism spectrum.

According to the CDC<sup>13</sup> it’s known that in the USA during the 2000-2001 school year, more than 15 000 children 3 through 5 years of age and more than 78 000 children and adults 6 through 21 years of age were classified as having autism under the Individuals with Disabilities Education Act (IDEA). IDEA is the federal law that supports special education and related services for children and youth with disabilities. However, there are more children with ASDs who are classified under IDEA (which is an educational needs classification not a tool for medical diagnosis) in a disability category other than autism. There are, however, some children with ASDs who are not included in these counts, such as children who are in regular education classes, who attend private school, or who are home schooled<sup>14</sup>.

The results of the Atlanta (1996) and specially the Brick Town (1998) ASD studies (see Table 1) have been mentioned as a big concern. For the CDC the number of children with ASDs and four other disabilities through the Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP) in 1996 leads to state that 34 of every 10 000 children (3 through 10 years of age) in metropolitan Atlanta had at least one ASD. In Brick Township, 67 of every 10 000 children (3 through 10 years of age) had at least one ASD. The CDC is now working with several states to learn how many children in other parts of the country have ASDs. These states are developing or improving programs that track the number of children in their areas with ASDs. The programs began gathering information in 2002, and the CDC expects that they will start reporting findings in late 2003 (not yet published).

Other source has received an enormous US and international attention to support the ‘epidemic of autism’: it was a report from the California Department of Developmental Services (DDS). The DDS carries out a systematic following of persons with disability needing special services. From December 1998 to December 2002, the population of persons with ‘autism’ in California’s DSS System nearly doubled<sup>15</sup>. This unprecedented 97% increase in four years did not include children less than three years of age, persons classified with less common forms of autism, or persons who are suspected of having autism but are not yet diagnosed. The total number of persons with autism served state-wide increased from 10 360 in December 1998 to 20 377 in December 2002. Between 1987 and December 2002, the population of persons with autism increased by 634%. For the DDS that means that the average age of persons with autism entering the system has shifted toward much younger children in recent years. The increase in the number of younger children diagnosed with autism means that entitlement services

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<sup>12</sup> See <http://www.cu.edu/ColemanInstitute/Boulder-material/posters/GabrielsNoland.PPT>

<sup>13</sup> See [http://www.cdc.gov/ncbddd/autism/asd\\_common.htm](http://www.cdc.gov/ncbddd/autism/asd_common.htm)

<sup>14</sup> See [http://www.ideadata.org/tables24th/ar\\_aa3.htm](http://www.ideadata.org/tables24th/ar_aa3.htm)

<sup>15</sup> See <http://www.dds.ca.gov/autism/pdf/AutismReport2003.pdf>

required by each individual with autism would occur for a significantly longer duration. This DDS report has been examined very critically by some significant researchers (as Eric Fombonne<sup>16</sup>) concluding: that the report of the DDS apply to numbers rather than rates and fail to account for changes in the size and composition of the Californian underlying population (e.g. ignoring the increase of 25.8% in the 6-14 years population, ignoring positive migration fluxes to California both from within the US and from abroad). Those factors might also be differentially related to the presence of an autistic child in a family. None of these basic epidemiologic concerns were taken up in the report. Second, no attempt was made to control for changes in diagnostic concepts and definitions. The report refers to definitions DSM-IV but ignoring that, in view of the wide age range of the sample and study period (1987-1998), multiple diagnostic systems were in fact used over the years producing heterogeneity in diagnoses in successive birth cohorts (DSM-III in 1980, DSM-III-R in 1987, etc.). As a result the diagnostic categories of Asperger syndrome, Rett syndrome and childhood disintegrative disorder, introduced for the first time in DSM-IV accounts, not surprisingly, for the largest increases in the California report. Finally, in California and elsewhere, autistic children are now diagnosed at a much earlier age. A decreasing mean age at diagnosis will necessarily result in an increased number of reported cases, even assuming a stable prevalence or incidence. Thus, age-specific rates among older children are required to test time trends.

The official position of the USA health authorities on prevalence of autism, via the CDC, is public on [http://www.cdc.gov/ncbddd/autism/asd\\_common.htm](http://www.cdc.gov/ncbddd/autism/asd_common.htm). The official position is 'we don't know' and is related to the uncertainties in the definition used about ASD (autism spectrum disorder).

As a final conclusion of all the available data the CDC states: *'We do not know if ASDs are becoming more common in the United States. We do know that today more children are being identified as having an ASD than in the past. The studies that have looked at how common ASDs are often used different ways to identify children with ASDs, and it are possible that researchers have just gotten better at identifying these children. It is also possible that professionals know more about ASDs now and are therefore more likely to diagnose them correctly. Also, a wider range of people are now being classified as having ASDs, including people with very good language and thinking skills in some areas who have unusual ways of interacting or behaving. Clearly, we have much more to learn. CDC studies in Atlanta and CDC-funded studies in the states will continue over time and will help answer this important question of whether ASDs are truly becoming more common in the United States'*.

### **Some conclusions on the ASD prevalence trend in the European Union**

Taking account of the scarce available data in terms of EU epidemiological studies, the existing debate in the USA, the statistical and health information experience in the EU, as well as the highly qualified existing opinions from experts (see references), the European Commission could establish some conclusions on the ASD prevalence trend in the European Union:

1. Studies indicate that the debate on the hypothesis of an increase in rates of autism or ASD needs to benefit from an acceptance of the methodological limitations of the existing data. No psychiatric case register study has ever allowed for estimating and monitoring the incidence of ASD conditions over a long-time period. The existing cross-sectional surveys hugely differ in their case definition and case identification methods that account for large variations in prevalence estimates both over time and across areas, avoiding a meaningful analysis of time trends.
2. The rates in recent surveys are substantially higher than 30 years ago and certainly reflect the adoption of a much broader concept of autism, recognition of autism among normally intelligent subjects, changes in diagnostic criteria, and an improved identification of persons with autism attributable to better services, but we ignore the magnitude of the increase of ASD conditions in the EU.

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<sup>16</sup> See <http://pediatrics.aappublications.org/cgi/content/full/107/2/411>.

3. The EU lacks of good data to test hypotheses on secular changes in the incidence of autism. Because of specific methodological limitations, the high prevalence rates reported in recent autism surveys in the EU and in the US cannot be used to derive absolute conclusions on this issue.
4. Nevertheless and according to the existing information, the age specific prevalence rates for 'classical autism' in the EU could be estimated as varying from 3.3 to 16.0 per 10 000. But these rates could increase to a range estimated between 30 and 63 per 10 000 when all forms of autism spectrum disorders are included. Debate remains about the validity and usefulness of a broad definition of autism.
5. These estimations point out the magnitude of the problem, which has been clearly underestimated in the past. An ASD response policy is necessary in the EU. But there is no need to raise false alarms on 'epidemics' to draw the attention to the unmet needs of large numbers of seriously impaired children and adults.
6. The EU definition of rare diseases still always on those diseases lower than 5 per 10 000. ASD could be considered as a rare disease using the most restrictive diagnosis criteria but it seems more appropriated to not refer more to ASD as a rare disease.
7. A more complex monitoring systems than those currently in place are needed to address the issue of changes in the prevalence of ASD. Maintaining DSM-IV case definition and identification constant, focusing on children in the upper range of school age years, controlling for changes in the population (e.g. differential migration) and relying on adequate sample sizes are required for future epidemiologic efforts in this area. The Public Health Program, the RTD Program and in some cases the Statistical Program, should provide the necessary support to all European initiatives in these fields.

### **The costs of ASD**

Also very few studies exist about the cost of ASD. The reference could be one conducted in the UK by Professor Martin Knapp and Krister Jarbrink, of the Centre for the Economics of Mental Health (CEMH), commissioned by the Mental Health Foundation, with funding from The Shirley Foundation, to carry out an exploratory study of the costs of autistic spectrum disorders<sup>17</sup>. The study was based on a review of published international literature, and on analysis of current data which includes people with autism. The study examined both direct costs of resources used (health, social and educational services, residential care, medication, care management, legal services, travel to treatment) and indirect costs of resources lost due to illness (e.g. loss or lack of employment, for the individual with autism and/or their family members). This study is particularly useful in assessing the cost effectiveness of prevention strategies or treatment strategies in future.

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<sup>17</sup> See <http://www.learningdisabilities.org.uk/page.cfm?pagecode=PUUP0117>

**Table 2: Costs of autism in Britain for individuals (lifetime) and society (annual)**

Individual with learning disability (£)	Individual with higher functioning autism (£)	UK total (£ million)	With an assumed prevalence of autism of 5 per 10 000 and with 75% of persons with autism having additional learning disability (million £)
Hospital services	26 600	30 700	11
Medication	3 400	8 300	2
Other health and social services	71 600	31 200	25
Living support	2 134 000	312 500	669
Voluntary support	18 800	---	5
Special education	179 100	108 300	64
Sheltered work	16 200	67 800	12
Day activities	422 400	74 500	134
Lost productivity	---	137 100	14
Family members time	39 600	14 400	13
Family expenses	30 800	---	9
<b>Total</b>	<b>2 940 500</b>	<b>784 800</b>	<b>957</b>

- The average additional lifetime cost for an individual with autism and additional learning disability is estimated to be £2 940 538.
- For people with high-functioning autism, the additional lifetime cost is estimated to be £784,785.
- The additional lifetime cost for people with Asperger's Syndrome is estimated to be £525 070.
- The costs of residential care/living support and supervised day activities account for the majority of the total costs. For example, a conservative estimate of the average costs of residential care for someone with autistic disorder and additional learning disability is £40 000 per year.
- The annual average cost for attending a special residential school is estimated to be £30 000 compared with £10 000 for a special day school. Assuming that 15% of the children with autism/learning disability who receive special education are in residential schools, the annual average cost for special education for children with autism and additional learning disabilities is £13 000.
- More than 75% of children with Asperger's are able to attend mainstream schools, resulting in an average cost for special education of £1 500. 60% of children with high-functioning autism attend special day schools, which cost £10 000 per year, resulting in annual average costs of £8 550.
- Sheltered employment costs for people with autism are low because few people have had access to these schemes: e.g. £448 per annum for people with autistic disorder aged 20-24 and £2 468 for people with Asperger's, who tend to work more hours per week. The unit

cost of running a supported employment scheme for people with high-functioning autism and Asperger's has been estimated as £388 per month per client (Mawhood & Howlin 1999).

- Other costs include hospital care, medication, lost productivity, family expenses, loss of parental earnings, social services, hospital services and respite care.

The main implications of these figures are that the costs for residential care and day activities are considerable. This implies that potentially great savings could be achieved by interventions which increase the possibility of independent living. For example, an early intervention lasting three years, at an annual cost of £25 000, might prove cost-effective if four out of ten recipients or more were subsequently able to manage in sheltered accommodation and employment rather than in residential care. More research is needed into the cost-effectiveness of early interventions, and their potential impact on education costs. This study has estimated the minimum social costs for autistic disorder, but the economic costs of high-functioning autistic spectrum disorders need further investigation. Further research is also needed into the economic and social costs to families of having a child with autism, and their implications for quality of life.

### **Improving the quality of information about persons affected by ASD**

To improve the quality of information and research on ASD is, all around the EU, the basis for any effective intervention. This is the concern of the main national bodies acting in this field. On the basis of some orientations disseminated by the MRC (Medical Research Council) in the UK<sup>18</sup> we can propose some areas of information improvement:

- **Researching and Refining Case Definition**

Improved definition of the outward characteristics of the ASD subgroups within the spectrum, and avoiding overlaps with other conditions, will underpin research on causes and mechanisms. Accuracy and consistency of case definition and diagnosis is a crucial issue both for services and for research. Further research is needed to develop and evaluate the tools for case definition. There is consensus on the broad criteria used to identify those with autism spectrum disorders. Further work is needed to develop reliable methods to assist researchers in mapping identified impairments onto the currently recognised diagnostic categories.

- **Developing the Epidemiological Framework**

Epidemiology has a central role in addressing questions about prevalence, incidence and their relation to time, place and person within populations. Such a framework is also necessary for research on case definition, co-morbidity, natural history and outcome. There may be potential for some existing epidemiological studies to be combined to test simple hypotheses, for example relating to the prevalence of gastrointestinal symptoms and other conditions among people with ASD. In addition, such large studies can contribute well-characterised cohorts for prospective investigation of longer term outcomes.

- **Enhancing Integrated Research Strategies**

Some EU countries have a long history of internationally cutting edge research on ASD, particularly in developmental psychopathology, behavioural and molecular genetics, neuropathology and assessment. These basic science programmes provide a strong platform on which to build a more integrated approach to defining risk factors and mechanisms, thus laying the basis for new and more effective approaches to diagnosis, treatment and perhaps prevention. An integrated neurosciences approach to working out causal pathways is needed, combining structural, functional, behavioural and genetic approaches.

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<sup>18</sup> MRC Review of autism research : Epidemiology and Causes, Medical Research Council, 2001

- **Developing Hypotheses about Abnormal Physiology**

There are a wide range and variety of observations and theories on the suggested role of vaccines, drugs, toxins, infections and diet as suggested risk factors for autism. Many findings in the area of abnormal physiology are not available in the peer reviewed literature, or are not well described, and these preliminary findings need to be confirmed by independent replication in other centres. Moreover, potentially modifiable risk factors are attractive targets for interventions.

- **Strengthening Research Capacity**

Researchers and service providers need to consider how best to achieve strategic, integrated research alliances both to sustain excellence and to develop new areas of enquiry; and to ensure the availability of sufficient and appropriately skilled manpower at the research-service interface. There may be a need for specific measures to promote multidisciplinary collaboration around shared strategic goals. Such collaboration offers established centres of excellence the kind of new scientific opportunities that are essential if they are to sustain their competitiveness internationally. Similarly, there is a need to strengthen the scientific expertise in relation to the epidemiological study of neuro-developmental disorders more generally.

- **Link with services**

The links between research and services need to be strong in order to recruit and gain access to participants and so that children identified through research can be given appropriate ongoing care and support. Consequently, much research needs to work through service providers (schools, clinics, parent organisations) thinking beyond ASD. Other disabilities, such as learning and language difficulties, and sensory and motor impairments, are of practical importance to the same teachers, parents and service providers who also work with people with autism spectrum disorders.

- **Partnership and exchange of experiences**

The effectiveness of interventions, the extent of service needs, and the organisation and delivery of services across health, social services and education are significant themes needing to be shared between partners. Specifically, aspects of patient and carer experience can help scientists better frame their research questions and to work towards outcomes that are more relevant to the intended beneficiaries.

## **The rights of persons suffering from ASD**

A general framework for the rights for people with autism was presented at the 4th Autism-Europe Congress (Den Haag, May 10th, 1992) and adopted as a Written Declaration by the European Parliament (May 9th, 1996)<sup>19</sup> stating that people with autism should share the same rights and privileges enjoyed by all of the European population where such are appropriate and in the best interests of the person with autism. These rights should be enhanced, protected, and enforced by appropriate legislation in each state. The United Nations declaration on the Rights of Mentally Retarded Persons (1971) and the Rights of Handicapped Persons (1975) and other relevant declarations on Human rights should be considered and in particular, for people with autism the following should be included. This EP Declaration, fully supported by the European Commission, includes:

1. THE RIGHT of people with autism to live independent and full lives to the limit of their potential;
2. THE RIGHT of people with autism to an accessible, unbiased and accurate clinical diagnosis and assessment;
3. THE RIGHT of people with autism to accessible and appropriate education:

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<sup>19</sup> See <http://www.autismeurope.arc.be/english/charter.htm>

4. THE RIGHT of people with autism (and their representatives) to be involved in all decisions affecting their future; the wishes of the individual must be, as far as possible, ascertained and respected;
5. THE RIGHT of people with autism to accessible and suitable housing;
6. THE RIGHT of people with autism to the equipment, assistance and support services necessary to live a fully productive life with dignity and independence.
7. THE RIGHT of people with autism to an income or wage sufficient to provide adequate food, clothing, accommodation and the other necessities of life;
8. THE RIGHT of people with autism to participate, as far as possible, in the development and management of services provided for their wellbeing;
9. THE RIGHT of people with autism to appropriate counselling and care for their physical, mental and spiritual health; this includes the provision of appropriate treatment and medication administered in the best interest of the individual with all protective measures taken;
10. THE RIGHT of people with autism to meaningful employment and vocational training without discrimination or stereotype; training and employment should have regard to the ability and choice of the individual;
11. THE RIGHT of people with autism to accessible transport and freedom of movement;
12. THE RIGHT of people with autism to participate in and benefit from culture, entertainment, recreation and sport;
13. THE RIGHT of people with autism of equal access to and use of all facilities, services and activities in the community.
14. THE RIGHT of people with autism to sexual and other relationships, including marriage, without exploitation or coercion;
15. THE RIGHT of people with autism (and their representatives) to legal representation and assistance and to the full protection of all legal rights;
16. THE RIGHT of people with autism to freedom from fear or threat of unwarranted incarceration in psychiatric hospitals or any other restrictive institution;
17. THE RIGHT of people with autism to freedom from abusive physical treatment or neglect;
18. THE RIGHT of people with autism to freedom from pharmacological abuse or misuse;
19. THE RIGHT of access of people with autism (and their representatives) to all information contained in their personal, medical, psychological, psychiatric and educational records.

The European Commission will fully support any effort and project in order to enlarge and develop all the rights included in the EP Declaration.

Luxembourg, February 2005.

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