**Observatoire régional de santé d'Ile-de-France**

# Autism in the United States: early detection and epidemiological surveillance

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Catherine Embersin, research scientist
Isabelle Grémy, Director of the Regional Health Observatory

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*It is not enough to prepare our children for the world*
*We must also prepare the world for our children*

Luis J. Rodriguez
(mentioned by the Autism Society of America's Washington Chapter)

# Introduction

The Regional Health Observatory of the Paris Ile-de-France Region, ORSIF (www.ors-idf.org), is a technical department of the Institute for Urban Planning and Development of the Paris Ile-de-France Region (IAURIF) created in 1974. Its mission is to assist social and health decisions: more precisely, the objectives are to gather and transmit information useful for decisions on the regional health policy. The Regional Health Observatory is funded by the Paris Ile-de-France regional government and by the state Government.

Disability is considered a priority by the Paris Ile-de-France regional government and the state government *Direction régionale des Affaires Sanitaires et Sociales* (Health and Social Regional Affairs Directorate).

A recent study of the Regional Health Observatory of the Paris Ile-de-France Region covering disability and perinatality[1] showed that:

- the prevalence of severe disability was higher among very preterm children (born before 33 gestation weeks) than among children born at full term and the available studies showed that this prevalence was not decreasing amongst children born pre-term;
- some factors contributed to the increase in prevalence of disability:
    - the pre-term and very pre-term national and regional rates were rising,
    - the congenital malformation rate was not declining,
    - the multiple pregnancy rate was increasing,
    - the mother's age at childbirth was rising (which contributed to an increase in the level of chromosomal anomalies and preterm birth).
    - Furthermore, the Paris Ile-de-France region was increasingly characterized by social inequalities: under-privileged women had a higher risk of giving birth to disabled children because of insufficient monitoring during pregnancy and the birth itself;
- other factors helped in the decrease of the prevalence of disability:
    - the improvement of antenatal screening of congenital malformation,
    - the increase of abortion for medical reasons,
    - the improvement in neurological prognosis of very pre-term babies (with some medical techniques such as antenatal corticotherapy and more pre-term children being born in maternity hospitals with appropriate facilities),
    - the decrease of smoking amongst pregnant women.

Finally, the trend of the prevalence of childhood disability depends on the type and character of deficiency and the global trend is, however, at best stable.

[1] Embersin C, Grémy I, Handicap et périnatalité en Ile-de-France, Observatoire régional de santé d'Ile-de-France, décembre 2005, 16 pages.

One limit of this study was the lack of complete and regular data on disability: in the Paris Ile-de-France Region, as in most regions in France, there is no tracking system to measure disability prevalence. In fact, the available data is out-dated (over 10 years old).
Concurrently, there are disparities in the level of detection and early treatment of disabled children in France because there is no standardized process to keep track of children with a high risk of disability. Moreover, there is a deficiency in the number of the Centers whose role is detection, early education and rehabilitation of disabilities (the Early Social-Health Actions Centers, called in France *Centres d'action medico-sociale précoce*).

Exploring how an information system with regard to childhood disability could be set up has become imperative as new French legislation seeks to encourage self-responsibility, integration and rehabilitation and also to fight against discrimination based on disability.

**Objectives of the project**

This project is part of an investigation covering the improvement of information on childhood disability, a project approved by the Scientific Council of the Regional Health Observatory.

The objectives of the project are to:
- identify and analyse the measures set up in the United States covering the registering of information regarding children with a high risk of disability;
- understand how early identification of disabled children is set up in the United States and how the early intervention is organised.

The choice to focus specifically on Autism Spectrum Disorders (ASDs) has been made. Different reasons have led to this choice:
- First, the time to undertake this study, three months, was too short to work on all childhood disabilities, so only one category has been selected. The Autism Spectrum Disorders is however a wide category (this will be shown in the first part of the report).
- Secondly, autism can be a truly severe disability and the need for intervention can be very important.
- Thirdly, there are still debates in France relating to detection of autism and care for people who have autism.
- Fourthly, research on autism seems to be developed in the United States, which may give important information on the epidemiology of autism. Furthermore, in American Universities, Disability Studies and Research Centers on autism and other developmental disabilities exist.
- Fifthly, there is a strong advocacy community on autism in the United States.

**Methodology**

First of all a review of literature has been undertaken. Both national and international literature have been reviewed. We have also decided to select the most recent literature i.e. no more than ten years old-dated, with the exception of certain significant well-documented articles, which should not be ignored, for example the Kanner's article dated 1943. This review covered such subjects as early detection of disability, systems of information, registers that have been set up in the United States or elsewhere in the world.

Secondly, through websites and information given by the Institute for Policy Studies, we have identified those important institutions, organizations, agencies and Research Centers relevant to autism spectrum disorders.

With this information, experts working in systems of autism spectrum disorders surveillance, detection of ASD and early intervention were contacted and certain were interviewed, according to the relevance of their respective research to this project. We furthermore asked each of them to identify any other appropriate contacts covering autism.

Those interviewed were researchers, professors, clinician, program coordinators, etc. Certain were both researchers and clinicians. For a complete list of those interviewed, please refer to annex I.

We interviewed 27 persons in Baltimore and in other places as follows:
- Organizations: Kennedy Krieger Institute affiliated with the Johns Hopkins University (Baltimore), Marcus Institute (Atlanta), Autism Speaks (New York),
- Center for Autism and Developmental Disabilities (Research and) and Epidemiology (CADDE or CADDRE) of the following Universities: Johns Hopkins University (Baltimore), University of Pennsylvania (Philadelphia), University of Medicine and Dentistry of New Jersey (Newark)
- Other Departments of Universities: Center for Mental Health Policy and Services Research in the University of Pennsylvania (Philadelphia), Department of Epidemiology and Biostatistics of the Drexel University School of Public Health (Philadelphia), West Virginia Autism Training Center in the Marshall University (Huntington), Emory Autism Center in the Emory University School of Medicine (Atlanta)
- State agencies: State Department of Education (Maryland), New Jersey Department of Health and Senior Services (Trenton), National Center on Birth Defects and Developmental disabilities in the Centers for Disease Control and Prevention (Atlanta).

Qualitative questionnaires were set up for the interviews undertaken.

**Overview**

First of all, the concept of autism will be explored, and in particular, it will be shown how the classification has changed over time and how autism can be a broad spectrum and represent different realities, according to the severity of the symptoms for example.

Secondly, the issue of early detection will be analysed and will cover in particular screening tests, the practices among the pediatricians and the parents' role. Nowadays, there is research covering biological markers or genetic tests but we won't focus on these aspects but rather consider the developmental and behavioural screening. Additionally, there are important issues regarding intervention. There is no evidence to support what is the most appropriate treatment to give to a child diagnosed with autism, even if publications in the late 80s showed positive outcomes in children receiving intensive behavioral intervention (NEWSCHAFFER *ET AL.*, 2007). However this report does not focus specifically on this issue.

Thirdly, this report explores the epidemiology of autism. Specifically, it describes the characteristics of people with autism, the recent prevalence rate of autism and its evolution. It also describes a monitoring network of autism, the ADDM Network.

An important part of epidemiology is attributable to the influence of environmental factors on autism, for example, these past years, there were debates in the scientific community and in society about the link between MMR (measles, mumps, rubella) vaccine and autism. This report does not, however, treat of the causes of autism.

# I. Autism: towards a classification

According to the Centers for Disease Control and Prevention (CDC)[2], in the United States of America, 17% of children have been reported to have a Developmental Disability such as mental retardation (MR) or cognitive impairment; cerebral palsy (CP); or sensory, behavioral, and learning disorders (RICE *ET AL.*, 2004).

Autism is a complex neurological / behavioral disorder that typically lasts throughout a person's lifetime. Although precise neurobiological mechanisms have not yet been established, it is clear that autism reflects the operation of factors in the developing brain (NATIONAL RESEARCH COUNCIL, 2001).Autism is present from birth or very early in development and affects essential human behaviors such as social interaction, the ability to communicate ideas and feelings, imagination, and the establishment of relationships with others (NATIONAL RESEARCH COUNCIL, 2001).

Most of the causes of autism are unknown. However, psychoanalytical theory, which was blaming parent's attitudes to their children, has been reviewed thanks to scientific research and the community of parents of children with autism (WING & POTTER, 2002). Autism is now known as a neurological disorder. Recent neuroimaging studies have shown that a contributing cause for autism may be abnormal brain development beginning in the infant's first months (STROCK_M, 2007).It is now recognized that the etiology of ASD is strongly influenced by genetic factors (NEWSCHAFFER CJ, 2002). Autism has a heritability of over 90% (BAILEY *ET AL.*, 1995). However, these genetic factors appear to be complex, with estimates of as many as 15 different loci involved (FOLSTEIN & ROSEN-SHEIDLEY, 2001). This genetic component can be seen also through the higher risk of having an ASD for the siblings of affected individuals (RITVO, 1989).

These past years, there were concerns about the link between the use of thimerosal used in the measles-mumps and rubella (MMR) vaccine and autism. The epidemiological studies, however, did not confirm this link (NIEHUS2006).

## 1. The first definition of autism by Kanner and Asperger

The term of *autism* was for the first time used by a Swiss psychiatrist to describe the characteristics of individuals with schizophrenia. However, the two pioneers of autism were Leo Kanner, the first physician in the United States identified as a child psychiatrist, working at the Johns Hopkins Hospital in Baltimore, and a German pediatrician, Hans Asperger, who gave his name to the Asperger syndrome (LYONS & FITZGERALD, 2007).

[2] Centers for Disease Control and Prevention (CDC), www.cdc.gov/ncbddd/child/devtool.htm

Hans Asperger published his thesis on "Autistic in psychopathology in childhood" in 1944, describing four children with *autistic psychopathology.* His work was not discovered in English speaking countries until the 1980's. In his thesis, he noted that the children had good grammar and vocabulary but they used it to talk about a narrow range of special interests and they made inappropriate social approaches (WING & POTTER, 2002).

In 1943 Leo Kanner published a description of 11 cases of *autism* (KANNER L, 1943). In his work he found that the children had some common characteristics to children with schizophrenia, obsessiveness, stereotypy, echolalia. They however also showed different characteristics to schizophrenia: extreme aloneless from the very beginning of their life, "not responding to anything that comes to them from the outside world", lack of affective contact, their activities are governed by the powerful desire of aloneness and sameness and fascination with objects.

Kanner found that for the whole group of children, there were very few really warmhearted fathers and mothers, and that "the question arose as to whether, or to what extent, this fact had contributed to the condition of the children". His belief was that there exists a genetic condition of autism, and that these children lacked an "innate inability to form the usual, biologically provided affective contact with people". He qualified this as "inborn autistic disturbances of affective contact".

The "early infantile autism" described by Kanner is so characterized by severe impairment of social interaction and communication with intensive resistance to change (WING & POTTER, 2002).

## 2. Evolution in the classification

The diagnostic criteria for autism have changed over time and the concept of a spectrum of autistic disorders has been developed.

For the first time in 1980, Autism appeared as a childhood condition in the Diagnostic and Statistical Manual of Mental Disorders, 3rd edition, DSM-III (American Psychiatric Association, APA). It was included in the class of conditions, the *Pervasive Developmental Disorders (PDDs).* Autism was no longer considered as a psychiatric disorder, but rather as a developmental disorder.

The concept of a spectrum was introduced in 1987 in the revision of DSM-III. The two subgroups were then *autistic disorder* and *pervasive developmental disorder not otherwise specified (PDD-NOS).*

The main point in defining a spectrum is that each manifestation of autism can occur in different degrees of severity and in different manifestations (WING & POTTER, 2002).

In 1994, the diagnostic categories of *Asperger syndrome*, *Rett syndrome* and *childhood disintegrative disorder* were introduced in the DSM-IV as subcategories of PDDs.

The tenth edition of the International Statistical Classification of Diseases and Related Health Problems, known as ICD-10 (World Health Organization) has closely similar subgroups. The APA and the WHO have worked together since the 1990s to make concordant classifications in the relevant sections of ICD and DSM.

The DSM-IV was revised in 2000 and this revision concerned the definition of the PDD-NOS for the developmental disabilities, which has become the following: "this category should be used when there is a severe and pervasive impairment in the development of reciprocal social interaction associated with impairment in either verbal and nonverbal communication skills, or with the presence of stereotyped behavior, interests, and activities, but the criteria are not met for a specific Pervasive Developmental Disorder, Schizophrenia, Schizotypal Personality Disorder, or Avoidant Personality Disorder."[3]

## 3. Definition of Autism Spectrum Disorders

### Autism Spectrum Disorders

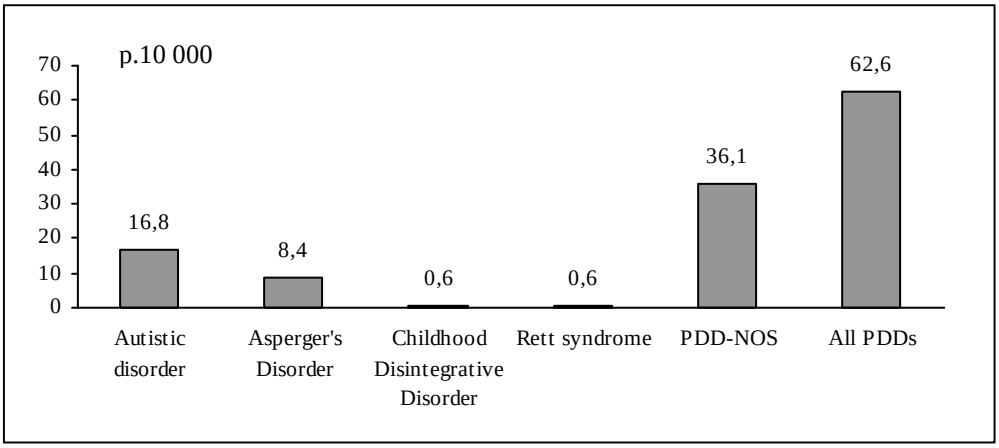
In the DSM-IV-TR, the *Pervasive Developmental Disorders* include *autistic disorder, Asperger's Disorder, Rett's Disorder, Childhood Disintegrative Disorders and the Pervasive Developmental Disorders-Not Otherwise Specified (PDD-NOS).* The most frequent disorders in this spectrum are the autistic disorder, Asperger syndrome and the PDD-NOS, while the Childhood Disintegrative Disorders and Rett's syndrome are very rare conditions.

In a survey amongst a large sample of the population in England (CHAKRABARTI & FOMBONNE, 2001), the authors found that the overall prevalence for all the PDDs was 62,6 per 10 000, and 36,1 for the PDD-NOS (figure 1). The Autistic Disorder represented less than one third of the overall prevalence of PDDs.

In one of his articles, Newschaffer reminded that the form of autism closest to the one described by Kanner, called *autistic disorder* or *nuclear autism,* was thought to be the most predominant form but represented less than half of the Autism Spectrum Disorders (NEWSCHAFFER CJ, 2003). In his article (CHARMAN, 2002), Charman cited Wing and Potter who estimated that only one third to one half of the children meeting ICD-10 criteria for *childhood autism* would meet Kanner's criteria.

[3] See www.dsmivtr.org/2-3changes.cfm for the revision of the DSM-IV.

**Figure 1: Prevalence of each Pervasive Developmental Disorder in 1998-99**




Data from CHAKRABARTI & FOMBONNE (2001), 15 500 children 2.5-6.5 years screened for developmental problems, Staffordshire, England

According some sources, the term Autism Spectrum Disorders (ASD) is synonymous to Pervasive Developmental Disorders (STROCK M, 2007), while according to other sources, the ASD include the three diagnoses: autistic disorder, Asperger's Disorder and PDD-NOS (NEWSCHAFFER *ET AL.*, 2007).

The term *Autism Spectrum Disorder* (ASD) has been widely adopted in professional literature because it underscores the continuum of symptom severity and is inclusive of children with varying diagnoses along the spectrum. It refers to "a wide continuum of associated cognitive and neurobehavioral disorders, including, but not limited to, three core-defining features: impairments in socialization, impairments in verbal and nonverbal communication and restrictive and repetitive patterns of behaviors" (FILIPEK ET AL, 1999).

### Criteria for Autistic Disorder, Asperger's Disorder and PDD-NOS

*Autistic Disorder* is actually defined by five criteria. Three criteria concern the nature of development abnormalities, one concerns the age at onset of the first symptoms, and the fifth is one of exclusion (figure 2).

*Asperger's Disorder* has similar characteristics than Autistic Disorder in social interaction (at least two in the list (1) in the figure 2) and in patterns of behaviors, interests and activities (at least one in the list (3) in the figure 2). However there is no clinically significant language delay in Asperger's Disorder and there is no significant delay in cognitive development, nor in the development of age-appropriate self-help skills, adaptative behavior (other than in social interaction) and curiosity in the environment during childhood (DSM-IV). This diagnostic category is clearly in evolution and it is unclear whether it will remain a valid syndrome separate from autism (FILIPEK ET AL, 1999).

The term *Pervasive Developmental Disorders Not Otherwise Specified (PDD-NOS)* is used for disorders including the autistic symptomatology (deficits in reciprocal social interactions, verbal or non-verbal communication or stereotyped behavior, interests and activities) but full criteria are not met for an alternative specific diagnosis under the autistic spectrum or PDD umbrella; for example, a child who does not meet the required total of 6 criteria among the 12 criteria (figure 4) or a child aged over 3 who has the onset of symptoms (FILIPEK ET AL, 1999). This category also includes children with atypical or milder symptoms.

**Figure 2: the diagnostic criteria for Autistic Disorder 299.0**

**A. A total of six (or more) items from (1), (2), and (3), with at least two from (1), and one each from (2) and (3):**

*(1) qualitative impairment in social interaction:*

(a) marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction
(b) failure to develop peer relationships appropriate to developmental level
(c) a 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)
(d) lack of social or emotional reciprocity

*(2) qualitative impairment in communication:*

(a) 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)
(b) in individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others
(c) stereotyped and repetitive use of language or idiosyncratic language
(d) lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level

*(3) restricted repetitive and stereotyped patterns of behavior, interests, and activities:*

(a) encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
(b) apparently inflexible adherence to specific, nonfunctional routines or rituals
(c) stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements)
(d) persistent preoccupation with parts of objects

**B. Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years: (1) social interaction, (2) language as used in social communication, or (3) symbolic or imaginative play**.

**C. The disturbance is not better accounted for by Rett's Disorder or Childhood Disintegrative Disorder.**

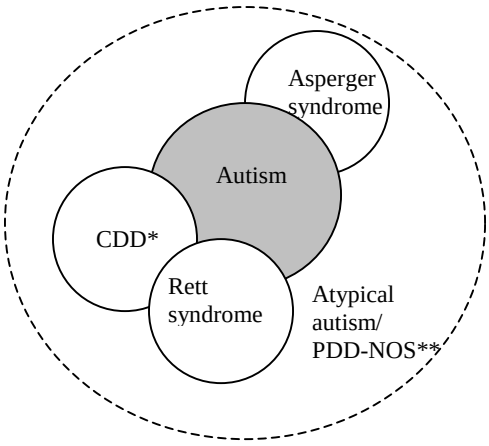
Source: Diagnostic and Statistical Manual of Mental Disorders, 4th edition, Arlington, VA: American Psychiatric Association; 2000.

Figure 3 shows the relationship between Autism Spectrum Disorders. Overlapping circles show that symptoms overlap although the disorders do not. The prototypical

disorder, autism, appears in the center; other disorders extend this phenotype in decreasing severity and in decreasing number of domains affected.

Figure 4 shows that PDD-NOS and Asperger's Syndrome have milder symptoms and those individuals affected by these symptoms are high-functioning. At the opposite end of the scale, Childhood Disintegrative Disorder and The Rett syndrome, both very rare disorders, are more severe and the individuals affected are low-functioning.

**Figure 3 : relationship between Autism Spectrum Disorders (from** LORD C, 2001)




*CDD : Childhood Disintegrative Disorder
**PDD-NOS: Pervasive Developmental Disorders Not Otherwise Specified

**Figure 4: Severity of Autism Spectrum Disorders (**SUSANNAH GRIMM POE, 2007)

| PDD-NOS | **Autism** | Childhood Disintegrative Disorder |
|---|---|---|
| <---------- | | ----------> |
| Asperger syndrome | | Rett syndrome |
| *High-functioning* | | *Low-functioning* |

In this report, autism will be used as a synonym of ASD and classic autism will be called by its scientific name, Autistic Disorder.

# II. Detection and diagnosis of autism

## Background

### Early detection of autism is important

Early detection and early diagnosis of autism are fundamental for different reasons: they can "facilitate earlier educational planning, provisions for family supports and education, management of family stress and anguish and delivery of appropriate medical care and treatment" (FILIPEK PA, 2000). Furthermore, children who receive early intervention services by the age of 3 show significant developmental gains (ROBINS & DUMONT-MATHIEU, 2006). Even if autism, like other neurodevelopmental disabilities, is not "curable", the primary goals of treatment are to minimize the core features and associated deficits, maximize functional independence and quality of life and reduce family distress (MYERS S.M., 2007).

### The diagnosis of autism is still often late

Diagnosis of autism is a more accurate assessment, differentiated from other developmental disabilities.

Despite changes in diagnostic criteria and increased awareness of ASD in the United States, most children with ASD are still identified between 3 and 4 years old, with relatively fewer children identified under 3 years old unless their symptoms are severe (CRAIS *ET AL*, 2006) and even if the ICD-10 and DSM-IV defined as a criteria of autism an onset at 36 months (DE GIACOMO & FOMBONNE, 1998).

According to the Centers for Disease Control (CDC), less than 50% of the children having a developmental or behavior disability (autism, mental retardation, Attention-Deficit / Hyperactivity Disorder, etc) are identified as having a problem before starting school, by which time significant delays have already occurred and opportunities for treatment have been missed.

Thus we will explore the factors that explain why detection and diagnosis of autism is not as early as it could be and what could be done to improve this.

## 1. Diagnosing autism in young children can be challenging

Firstly, detecting autism is difficult because even if there is a strong genetic base for autism, there is no biological or medical test, except for Rett's syndrome, and thus the detection of autism is only behaviorally based.

### There is a range of symptoms

"The manifestations of autism vary considerably across children and within an individual child over time. There is no single behaviour that is always typical of autism and no behaviour that would automatically exclude an individual child from a diagnosis of autism, even though there are strong and consistent commonalities, especially relative to social deficit" (NATIONAL RESEARCH COUNCIL, 2001).

Rebecca Landa, Director of the Center for Autism and Related Disorders at Kennedy Krieger Institute, explains the main reasons: "First we don't want to make mistakes with the parents so we must be sure it is autism when we say that their child has an autism disorder. Secondly, professionals get confused when the children get older and have additional problems, like deficit attention, irritability, and just wonder if it is autism or other problems like ADHD, depression, etc. Also many children don't have the classical signs of autism, like eye contact or flapping the hands, so you can miss them. It's hard to diagnose autism in children with normal IQ and it's hard to diagnose autism in children with mental retardation."

Catherine Trapani at the Marcus Institute explained that "the diagnosis of ASD is a complex process because you don't look at only one thing. You look also at cases from very mild problems to very severe problems. You have to be very careful, very methodical about the diagnosis."

Accordingly, the diagnosis can be complex because of the range of syndrome expression in these conditions along various dimensions such as language abilities and associated mental handicap, and also because of differential diagnosis, particularly in children younger than 3 years old, because of concerns regarding labeling and diagnostic terminology within school systems and also because lack of expertise in assessment and diagnosis among some educational professionals (NATIONAL RESEARCH COUNCIL, 2001).

### The classification is not adapted to young children

The classification used at the present time, the DSM-IV, describes behavior that is not typically seen in very young children, for example, development of peer relationship, stereotyped interests, conversational skills. So there is a great need for additional criteria to help practitioners and parents recognize signs of autism at younger ages (CRAIS *ET AL.*, 2006).

**The diagnosis of autism requires several professionals**

In general, the diagnostic process of autism requires the perspectives of several professionals and not only one person: special educators, general educators, psychologists, speech pathologists, occupational and physical therapists and physicians (NATIONAL RESEARCH COUNCIL, 2001).

Diagnosis of autism can be made by physicians and licensed psychologists, with input from a team of specialists (neurologist, audiologist, gastroenterologist, geneticist, speech therapist, occupational therapist and other professionals). A good evaluation includes history (medical, social, family), structured interviews with caregivers (teachers, therapists), observation, developmental assessment, consideration of comorbidity, treatment plan (SUSANNAH GRIMM POE, 2007).

A Canadian study (SIKLOS & KERNS, 2007) found that the final diagnosis was received from a psychologist (30,9%), from a pediatrician/family doctor (30,9%), a child psychiatrist (13,2%) or a multidisciplinary team (19,1%). 42% of the families had to travel to another city for the diagnosis.

Families saw an average of 4.46 professionals during the diagnostic process and 41% of the families saw 5 or more professionals.

## 2. Identification of children with ASD through the Individuals with Disabilities Education Act (IDEA)

Screening is a procedure for recognizing children at risk for a developmental disorder with use of standardized tools at specific intervals to support and refine the risk.

In the United States, like anywhere, there is no systematic process to detect autism. “ASD identification in both the educational and medical sectors is still largely opportunistic as opposed to systematic” (DOSREIS S, 2007).

For other impairments like hearing impairment, many states in USA have recently passed Early Hearing Detection and Intervention legislation[4], so that systematic screening for hearing impairment among newborns has been set up. Detecting hearing impairments is however biologically possible with efficient tools. But autism can not be detected with biological or by medical test. The detection is behaviorally based.

[4] See www.asha.org/about/legislation-advocacy/state/bill_status.htm#LA

With the Individuals with Disabilities Education Act (IDEA)[5] all states are required to have a "comprehensive Child Find system" to assure that all children who are in need of early intervention or special education services are located, identified, and referred. Public school districts are responsible for identifying all students with disabilities within their district, regardless of whether they are attending public schools, since private institutions may not be funded for providing accommodations under IDEA. IDEA mandates that states refer children, free of charge, for a comprehensive, multi-disciplinary evaluation by a team who, with the family, decides on which services are needed for the child (via the Individualized Family Service Plan).

Children with ASD are eligible for special education services through the IDEA. In 1990, ASD was categorized as a separate condition that qualifies children for special education services, and the US Department of Education, Washington DC, began tracking the number of children with ASD served by each state.

These programs are however not designed for population-wide screening and rather, provide a resource for developmental delay evaluation and intervention for children referred to the program (DOSREIS S, 2007).Additionally, for children under 3 years, the program defined by the IDEA (Part C), which has different names according the states, Birth to Three, Infant and Toddlers Program, do not identify children with autism: the children referred to these programs are categorized as having a "diagnosed condition with high probability of developmental delay" (like chromosomal disorders, congenital infection, prematurity, severe congenital malformations, etc), or having a "25% developmental delay" (cognitive, communication, social-emotional, adaptive or motor) or as having an "atypical development" (in the same areas as previous enunciated). In Part B of the IDEA, designed children 3-21 years, children with autism can be identified. However, some surveys found that not all the children with ASD are identified through the IDEA and that the identification can vary among states.

A survey undertaken by the Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP) from the Centers for Disease Control and Prevention (CDC) screened all children receiving special education services in Atlanta and found that 18% of children diagnosed with ASD by the investigators were not identified as such by the special education system (YEARGIN-ALLSOPP *ET AL.*, 2003).

[5] The IDEA was originally enacted by Congress in 1975 to make sure that children with disabilities had the opportunity to receive a free appropriate public education (FAPE), just like other children. The law has been revised many times over the years. The most recent amendments were passed by Congress in December 2004, with final regulations published in August 2006. So, in some senses, the law is very new, even as it has a long, detailed, and powerful history. IDEA guides how states and school districts provide special education and related services to more than six million eligible children with disabilities.

A study based on the education data in the 2000-2001 academic year (MANDELL & PALMER, 2005) and exploring the differences between states in identifying children with ASD showed that there was a link between the identification of students and the money spent on education: the proportion of students diagnosed with ASD was increasing with the per-pupil education spending. Performing a linear regression, in which the prevalence of ASD was the dependant variable (table 1), each additional $1 million in the states' education spending, is associated with a 0.02% increase in prevalence, all other variables held constant.

**Table 1: linear regression predicting the Administrative Prevalence of Autistic Spectrum Disorder (ASD) in 50 states***

| | **Percentage Change in Prevalence (95% Confidence Interval)** |
|---|---|
| **Education system characteristics** | |
| No of students ages 6-21 y in the state, 100s | -0.10 (-95.02 to 171.83) |
| State education spending, $1 million | 0.02 (0.01 to 0.03) |
| No of elementary and secondary school teachers, 100s | 0.02 (-98.20 to 195.63) |
| No of students receiving special education services, 1000s | 0.32 (-99.75 to 172.82) |
| **State resources, No of** | |
| School-based health centers in the state | 0.60 (-0.05 to 1.18) |
| Pediatricians in the state | 0.06 (0.02 to 0.10) |
| **Student characteristics, No of** | |
| Students living in poverty | -0.04 (-84.30 to 193.23) |
| African American students | 0.04 (-63.21 to 638.90) |
| American Indian students | -0.40 (-36.79 to 342.81) |
| Asian students | 0.23 (-86.47 to 994.36) |
| Hispanic students | 60.05 (-74.84 to 816.63) |

*Prevalence was modeled as the natural log of the proportion of children with ASD. Resulting coefficients were then exponentiated. The parameters are presented as the percentage increase in the prevalence of ASD associated with 1 unit increase in each variable, adjusting for the other variables in the model.
Source: MANDELL & PALMER (2005)

The authors' explanations are that the states in which higher spending may attract better-trained staff have a greater awareness of the symptoms of ASD and that these states may also have developed programs in other areas that support children with ASD (like Indiana which has a high prevalence of ASD and has developed a Medicaid program for reimbursing services for individuals with ASD). This model also showed that health resources were associated with better identification of ASD: each additional pediatrician in the state was associated with a 0.06% increase in the prevalence and each school-based health center with a 0.6% increase. This last relation needs however further exploration because the school-based health centers are not dedicated to the detection of ASD.

Results from the data collected through the Autism and Developmental Disabilities monitoring network (ADDM Network), whose methodology will be explained later, showed that in different states in the US in 2002 (table 2):

- the percentage of 8 year-old children with an ASD receiving special education services varied from 61.3% in Maryland to 97.8% in New Jersey,
- the percentage of 8 year-old children with an ASD receiving special education services with autism eligibility was lower and ranged from 27.7% in Colorado to 62.6% in Georgia.

**Table 2: Number and percentage of children aged 8 years with autism spectrum disorders (ASD) receiving a special education services and within eligibility, by site - Autism and Developmental Disabilities Monitoring Network, United States, 2002**

| Site* | Total no with ASDs | Receiving special education services | | Receiving special education services with autism eligibility | |
|---|---|---|---|---|---|
| | | n | % | n | % |
| Arizona | 280 | 271 | 96.8 | 107 | 38.2 |
| Arkansas | 251 | 206 | 82.1 | 120 | 47.8 |
| Colorado | 65 | 59 | 90.8 | 18 | 27.7 |
| Georgia | 337 | 309 | 91.7 | 211 | 62.6 |
| Maryland | 199 | 122 | 61.3 | 90 | 45.2 |
| New Jersey | 316 | 309 | 97.8 | 131 | 41.5 |
| North Carolina | 135 | 121 | 89.6 | 68 | 50.4 |
| South Carolina | 140 | 102 | 72.9 | 48 | 34.3 |
| Utah | 196 | 166 | 84.7 | 82 | 41.8 |
| West Virginia | 153 | 134 | 87.6 | 63 | 41.2 |

(1) With acces to both education and health records

(2) Primary special education eligibility category only

Accordingly, this data showed that at 8 years old, there could be a large number of students with ASD that are not identified at all by the special education system: 38.7% of the children with ASD in Maryland, 27.1% in South Carolina are those states with the highest percentage. In Arizona and New Jersey, most children with ASD were identified and received services: only 3.2% and 2.2% respectively of the children with ASD did not receive education special services. Furthermore, an important number of children were identified as having a disability but not autism, so they were classified in another condition, meaning they received special education services not appropriate for autism: the highest proportions of children receiving special services without autism eligibility can be seen in the states of Colorado (63.1%), Arizona (58.6), New Jersey (56.3) and the lowest percentage in Maryland (16.1%) and Georgia (29.1%).

This data may have two explanations: the children were known as having a disability but didn't receive any service or they were known as having an ASD and received inappropriate services

- the children were even not known by the schools as having a disability. So the question can be asked if they were known outside schools as disabled children. The identification of ASD can take place in the first years of the life and parents and pediatricians are the first persons who may detect this disorder.

## 3. Parents' involvement in the detection of ASD

### The age at first parental concerns is between 1 year and 2 years

Different surveys agree about the age of first parental concerns about the development of their child. BARON-COHEN S (2000) cited Wing to say that parents of children often report that they first suspected that their child was not developing normally around the age of 18 months. In a survey undertaken in the United Kingdom among children with ASD referred between 1993 and 1996 to a specialized clinic for pervasive developmental disorders (DE GIACOMO & FOMBONNE, 1998), the mean age of children was 19,1 months when parents became concerned with their development: 30% of parents had recognized abnormalities in the development by the 1st birthday and 80% by the second birthday. In a study where parents have filled the questionnaires before to know the diagnosis of their child, and comparing children with ASDs and children with developmental delay other than ASDs, the mean age at first concern was 17,8 months for children with autism and 16,6 months for children with Developmental Delay, with no significant difference (COONROD E.E., 2004). In a Canadian study, the first concerns of the parents were on average at 23 months and 88% of the parents had concerns before the child's third birthday (SIKLOS & KERNS, 2007).

### Language delays are the parents' first concerns

DE GIACOMO & FOMBONNE (1998) in their survey among 82 children with ASD found that for 53,7% of the parents, the first concern was the language/speech development, which was in front far the abnormal socio-emotional response (17,1%) and medical problem or delay in milestone (11,0%).

COONROD E.E. (2004) found in their study that 86% of the parents of children with autism were first concerned by delayed language development (73% of the parents of children with developmental delays). In their article related to the screening and diagnosis of autism, Filipek et al. (FILIPEK PA, 2000) reviewed several studies, encompassing 737 children, showing that parental concerns about speech and language development, behavior or other developmental issues had a high sensitivity, from 75% to 83% and a high specificity, from 79% to 81%.

**Parents seem less aware of social-communicative deficits**

In the study of COONROD E.E. (2004) mentioned above, only 23% of the parents of children with autism questioned with open-ended questions reported abnormal social/emotional responses as first concerns, while 86% reported concerns about language, which suggested that the earliest concerns of these parents are not specific to autism. At the child's age of 2 years, only 9% of the parents reported that abnormal social/emotional responses were a current concern. But with a questionnaire of social Behavior checklist, the concerns about social behaviors were more prevalent. Whilst the authors wondered about the generalization of these results, they suggested that "physicians and early childhood professionals should be aware that parents of children with autism may not spontaneously report early concerns in this area". The hypothesis is that parents are less knowledgeable about milestones for social development or simply did not detect them because they put up with their child and used compensatory strategies to engage the child in social interactions (Adrien and Baranek cited by COONROD E.E., 2004). Findings from videotaping studies suggest that social-communicative deficits are present in infants prior to the emergence of parental concerns (Adrien et al. cited by COONROD E.E, 2004).

**Other factors associated with a lower recognition from parents**

In a multiple regression (DE GIACOMO & FOMBONNE, 1998) where the age at first parental concern is the dependant variable, the mean age was significant lower when the child had mental retardation (IQ<70): 15,0 months versus 22,3 months for autistic children without mental retardation. The age at first parental concern was also significantly lower when parents were concerned with speech and language development (14,9 versus 20,5 months) or medical problem (such as seizure) / delay in milestones (12,6 months versus 21,7 months). The area of residence and the social class however were not associated with age at first parental concern.

**The lag between first parental concerns and diagnosis**

Some studies have evaluated the lag between first parental concerns and the first professional advice sought and found that the mean time lag was 5,2 months (DE GIACOMO & FOMBONNE, 1998). They found that the age of the child when professional advice was sought was significantly lower if the child had mental retardation (20,1 versus 27,0 months) and if the child had medical problem/delay in milestone (15,8 versus 27,3 months) and among family factors, if the child had older siblings (21,6 versus 27,3 months). A Canadian study among a small sample of parents of children with ASD (SIKLOS & KERNS, 2007) also found that the time between first parental concerns and first professional advice sought was between 5 and 6 months.

According to Catherine Trapani of the Marcus Institute, the gap between first parents' concerns and the diagnosis of autism is less than it used to be and the diagnosis of autism takes place earlier. However, one of the problems is that pediatricians are not trained in developmental problems.

There is also a lag between the first evaluation and the first diagnosis of the child: the Metropolitan Atlanta developmental Disabilities Surveillance Program (MADDSP) found that the average delay was 13 months, the mean age at first evaluation was 48 months and the mean age at first diagnosis was 61 months (WIGGINS L.D, 2006).

The Canadian survey reported that the lag between the first sought and the diagnosis was 2 years and 8 months (32 months) on average (SIKLOS & KERNS, 2007). This survey reported also that 51% of the parents were not satisfied with the diagnostic process.

**To conclude**, recent research has revealed that parents are usually correct in their concerns about their child's development (COMMITTEE ON CHILDREN WITH DISABILITIES, 2001). Early diagnosis of ASD is dependant on listening to the parents' concerns about their child's development. On the other hand, if parents do not have concerns about their child's development, it does not mean that there are no problems: the absence of such concerns had low specificity in detecting normal development, 47% (FILIPEK PA, 2000).

## 4. Practices among pediatricians

There is little data describing the practices among pediatricians regarding screening for autism. In a survey undertaken in 2002 among pediatricians and family physicians in primary care practice members of the American Medical Association (SICES *ET AL*,. 2003), the methods of screening for developmental delays the most used during routine preventive-care visits with 2-year-old children were a list of developmental milestones (almost 9 pediatricians and family physicians in 10) and prompting for parental concerns (almost 9 pediatricians and family physicians in 10). A validate instrument was used by only half of the pediatricians and by 61% of the family physicians: a validated provider administered screening tool (like the Denver II for example) was used by 30% of the pediatricians and 38% of the family physicians and a validated parent questionnaire (like the Ages and Stages Questionnaires) by 28% of the pediatricians and 34% of the family physicians. When physicians used a specific screening tool,

the Denver-II continued to be the predominant choice. While this screening tool has been the traditional tool used for developmental screening, research found that it was insensitive and lacked specificity (FILIPEK PA, 2000).

One of the barriers to using a developmental tool is the insufficient reimbursement of pediatrician visits: only 11% of the pediatricians and 8% of the physicians agreed that reimbursement for well-care visits is sufficient to cover time spent on developmental screening (SICES *ET AL*,. 2003). Furthermore, physicians who agreed with the statement "I have the clinical expertise to identify most children with developmental delays in my practice without the use of a formal screening instrument" were significantly less likely to use a specific validate screening tool. Although 9 physicians in 10 prompted for parental concerns, only 15% of the pediatricians and 12% of the family physicians agreed with "using parental concern about a child's development as a good substitute for formal developmental screening". This indicated that they may not place enough value on the information obtained from parents to make a referral to appropriate services.

In a survey undertaken in Maryland and Delaware (DOSREIS S, 2007), among the 255 pediatricians who returned the survey and were eligible, 82% routinely screened for developmental delays, not necessarily in a formal way, since a large number indicated that they used informal tests to assessing the child's development. Among these 82%, 50% used the Denver-II and only 8% screened for ASD. The precipitating events for ASD screening were parental concerns (for 90% of the pediatricians), suspicions of ASD during a routine examination (90%) and child failure of a general screen (80%). The main reason why developmental screening is not routinely taken is insufficient time and for ASD, the two main reasons are unfamiliarity with ASD screening tests and referral to a specialist (table 3). In this study, it was also found that referral to a clinician specialist was the most common action taken, whatever the age of the child. However, whenever there was a suspected case of ASD, the "watch-and-wait strategy" was more frequent for the youngest children, and concerned nearly 20% of the patients 2 years and younger.

**Table 3: reasons for why Developmental screening is not routinely performed in pediatric primary care**

| | n | % | 95% CI |
|---|---|---|---|
| **General development screening (n=45)** | | | |
| Insufficient time | 33 | 73 | 59-84 |
| Unfamiliar with screeners | 10 | 22 | 12-36 |
| Screeners too expensive | 6 | 13 | 6-26 |
| Other* | 11 | 24 | 14-38 |
| **ASD screening (n=235)** | | | |
| Unfamiliar with screeners | 146 | 62 | 56-68 |
| Refer to a clinical specialist | 110 | 47 | 41-53 |
| Insufficient time to screen | 75 | 32 | 26-38 |
| Screeners too expensive | 8 | 3 | 0.8-5 |
| Screeners are not effective | 2 | 0.9 | 0.3-2 |
| Other** | 30 | 13 | 9-17 |

Source: DOSREIS S, 2007
* include office does not use screens, not applicable to practice, and use general history or clinical screen
**include use of clinical judgment, resource constraints, not necessary; 0.9% (n=2) stated that ASD screening was not applicable to their practice.
CI, confidence interval

## 5. Factors associated with age of diagnosis

A survey undertaken in Pennsylvania from 969 caregivers to children with ASD (39% with autistic disorder, 23% with Asperger's disorder and 38% with PDD-NOS) under 21 years showed that some factors contributed to a later diagnosis of autism: the subcategory of ASD, since children with autistic disorder are diagnosed at a mean age of 3,1 years, those with PDD-NOS at 3,9 years and those with Asperger's syndrome at 7,2 years (MANDELL DS, 2005). According to the results of a linear regression predicting age of diagnosis (MANDELL DS, 2005), children who lived in rural areas were diagnosed on average 0,4 years later than children who lived in urban areas: due to less access to regular and specialty care in rural areas. Children from near-poor families were diagnosed on average 0,9 years later than families whose income is 100% above the federal poverty level. This can be partly explained by the fact that near-poor families are less insured than the other.

Clinically, certain factors contributed to an increase of the age at diagnosis: oversensitivity to pain (0,6 years increase), hearing impairment (0,8 years increase), symptoms and comorbidity that can make the detection of ASD more difficult. Children under the care of 4 or more primary care physicians were on average diagnosed later (0,5 years) than those who had less physicians: this may reflect a discontinuity care because of residential instability, or frustration of the family that their concerns are not acknowledged.

Other factors contributed to a decrease of the average age at diagnosis: severe language deficits (1,2 years decrease), hand flapping (0,4 years decrease), toe walking (0,2 years decrease) and sustained odd play (0,3 years decrease). Signs like hand flapping are most typical symptoms and are an indicator to parents and pediatricians that there may be a disorder. The children referred to a specialist by their pediatrician were, on average, diagnosed earlier (0,3 years).
In the Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP) of the CDC (WIGGINS L.D, 2006), the mean age at first diagnosis was 8 months younger for girls (54 months) than for boys (62 months). Also, the type of ASD was associated with the age of diagnosis: children with ASD, PDD-NOS and general ASD were diagnosed earlier than children with Asperger. Furthermore, the level of impairment was associated with the age of diagnosis: children with severe impairment were diagnosed 17 months before those with mild impairment, independently of whether there was any mental retardation, because when these two variables were simultaneously held constant, there was no association between mental retardation and age of diagnosis, but there was still an association with degree of impairment. There was also a difference according to the source of identification: children diagnosed through non-school sources were diagnosed earlier (56 months on average) than children diagnosed at school (74 months).

**Earlier diagnosis?**

Even if diagnosis is typically not made before the age of 3 years old (FILIPEK ET AL, 1999), research has revealed that diagnosis can be made accurately in children as young as 2 years (COONROD E.E., 2004). Results from videotape studies showed that some signs of ASD could be seen as early as 12 months: deficits in social-communicative and attention behaviors such as pointing to, showing objects, looking at others, smiling socially, using appropriate facial expressions, orienting to visual stimuli, orienting to their name, sustaining attention (Adrien, Baranek, Osterling & Dawnson, Werner cited by COONROD E.E, 2004). In a study from videotaping, Baranek showed that abnormalities as early as at 9 months in orientation to visual stimuli, aversion to touch, and delayed response to name all characterize autism, but not developmental delay nor typical development. Behavior that distinguishes one-year-old children with autism from those with mental retardation includes responsivity to name and looking at others (OSTERLING *ET AL.*, 2002).

In a prospective study comparing three groups, children with ASD, children with language delays and unaffected children, the tests administered at 6 months, 14 months and 24 months showed that there were no differences between the groups at 6 months, but that at 14 months, the ASD group performed less than the unaffected group on all scales except visual reception and that at 24 months, the ASD group performed worse than the unaffected group in all domains and worse than the language delay group in gross motor, fine motor and receptive language

(LANDA R, 2006). This study therefore indicates that the disruption in child development with ASD takes place between 14 and 24 months.

## 6. Recommendations from the American Academy of Pediatrics

Given the apparent increase in prevalence of ASD, a primary care physician is now more likely to encounter a child with ASD. "Diagnosis and management of ASD presents the pediatrician with a challenging task" (COMMITTEE ON CHILDREN WITH DISABILITIES, 2001). In 2001, the American Academy of Pediatrics (AAP) published recommendations for pediatricians stating that physicians should become familiar with at least 1 autism screening tool and perform it on all children. In the event this isn't possible, pediatricians should refer the child to a specialist whenever there was any parental or professional concern.

### The algorithm developed by the American Academy of Pediatrics for surveillance and screening for autism

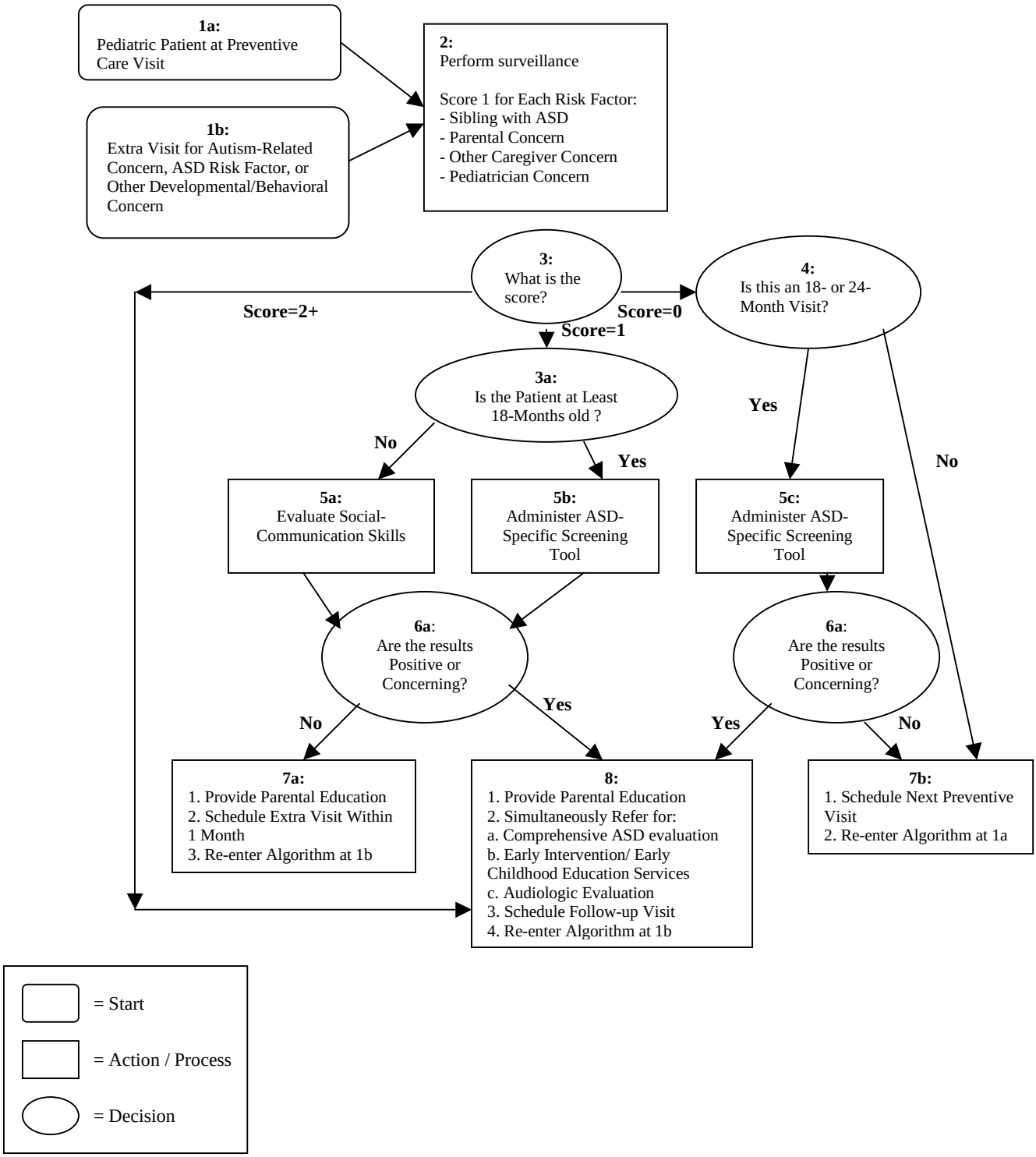
This algorithm (figure 5) has been built to help primary care pediatricians achieve better and earlier identification of children who are at risk of autism (PLAUCHÉ JOHNSON C, 2007). This algorithm was developed in a tool called *Autism ALARM*[6], a flyer distributed to primary care pediatricians highlighting the prevalence of autism, the importance of screening and listening to parents' concerns and the urgency of making simultaneous referrals to specialists in ASDs and early intervention programs to promote improved outcome. *Surveillance* is described as "the ongoing process of identifying children who may be at risk of developmental delays" and the *screening* as the "use of standardized tools at specific intervals to support and refine the risk" (PLAUCHÉ JOHNSON C, 2007). Surveillance, besides asking family history and parents' concerns, should include a checking of certain developmental milestones, including social and emotional milestones in addition to the traditional motor and language. It is therefore important to ask about the verbal and non-verbal communication, reciprocal social interaction (including eye contact, joint attention[7], social referencing, sharing of interests) and representational or pretend play[8] skills.

[6] www.medicalhomeinfo.org/health/Autism%20downloads/AutismAlarm.pdf

[7] Ability to establish a shared focus of attention with another person via pointing, showing or gaze monitoring. It allows children to learn through others and it is seen as the earliest expression of the infant's "mind-reading" capacity, in that the children shows a sensitivity to what another person is interested in or attending to.

[8] It involves the attribution of imaginary features to people, objects or events. Some theorists view it as signaling the emergence of symbolic ability as well as mind-reading.

**Figure 5: Surveillance and screening algorithm for ASD**




Source: PLAUCHE JOHNSON C, 2007

**Red flags for autism**

The American Academy of Neurology and the Child Neurology Society Practice parameter on screening and diagnosis of autism (FILIPEK PA, 2000) suggests that failure to meet the following milestones is associated with a high probability of a developmental disability and are **"red flags" for autism**:

- no babbling by 12 months,
- no gesturing (for example pointing, waving bye-bye) by 12 months,
- no single words by 16 months,
- no 2-word spontaneous (not just echolalic) phrases by 24 months,
- any loss of any language or social skills at any age.

The AAP recommended a routine developmental surveillance at every well-child visit (COMMITTEE ON CHILDREN WITH DISABILITIES, 2001). A screening for autism is recommended by the AAP at the 24-month visit for many reasons (GUPTA *ET AL.*, 2007): because (i) regression in children with autism, which concerns more than 25% of the children, has been reported by the parents to occur at a mean age of 20 months; (ii) the sensitivity of screening tools is not 100%, any missed cases would be then detected; and (iii) this visit is paid by the third-party payers as a scheduled visit.

The use of standardized screening tools is recommended at step 5. Indeed, studies show that when pediatricians only use clinical impressions to assess a child's development, results are less accurate than those with the use of formal screening tools.

## 7. Overview of the screening and diagnostic tools

Many screening tools have been developed for developmental delays, for autism, for Asperger's syndrome but it seems that "appropriately sensitive and specific autism screening tools for infants and toddlers have only recently been developed and (that) this continues to be the current focus of many research centers" (FILIPEK PA, 2000).

The screening tools are used for detecting autism in every child at the well-child visit. The tools developed can rely on professional observations and/or on parents' reports. They are called tools at level I, while the tools at level II are those which assess children already identified at risk.
Screening tools at level I should be fast to administer since they must screen a large population, while the tools at level II can be more time-consuming.

**Level I tools**

The **Checklist for Autism in Toddlers (CHAT)**, the first instrument developed for a use in general population, was developed in England for 18-month-old children and has been used to screen more than 16000 toddlers. The CHAT combines 9 questions to parents and 5 to professionals. It was devised to test the prediction that those children not exhibiting joint attention and pretend play by the age of 18 months might be at risk for receiving a later diagnosis of autism (BARON-COHEN S, 2000). It takes 5-10 minutes to administer and is simple to score. Although it has a high specificity, its relatively low sensitivity is a concern (COMMITTEE ON CHILDREN WITH DISABILITIES, 2001). The evaluation of the CHAT found that sensitivity was low, comprised between 18% and 38% (BAIRD *ET AL.*, 2000, BARON-COHEN S, 2000). However, the specificity was between 98% and 100%. The CHAT was used to detect autistic disorder but not the broader spectrum ASD.

A modification of this tool, the **Modified-Checklist for Autism in Toddlers (M-CHAT)** has been developed in the United States with the aim to identify children at risk with any ASD and not only autistic disorder (ROBINS & DUMONT-MATHIEU, 2006). It is a 23 items parent-report for use with children aged 16-30 months, designed to be filled in by the parents in the waiting rooms of the medical consultation. It takes 5-10 minutes to be administered. The M-CHAT has been tested on 1293 children and the sensitivity was found to be 87% and the specificity 99% (DUMONT-MATHIEU T, 2005). The M-CHAT is really interesting because it has metrological qualities, is not expensive and does not need any professional training because it is filled in by the parents only (EXPERTISE COLLECTIVE INSERM, 2002).

Another well-known screening tool is the **Pervasive Developmental Disorders Test-II (PDDST-II)** which consists of 3 stages designed to be used in 3 different clinical settings. It includes 22 questions answered by the parents and is designed for children aged 18-48 months (DUMONT-MATHIEU T, 2005). The sensitivity reported is 92% and the specificity 91% based on a sample of 937 children. The other two stages of the instrument are considered as Level-II screening instruments. Stage 2 consists of 14 items developed for use in developmental clinics, the sensitivity reported is 73% and the specificity 49% (ROBINS & DUMONT-MATHIEU, 2006). Stage 3 consists of 12 items used in autism-specific clinics. Sensitivity and specificity reported are 58% and 60% respectively.

**Level II tools**

The **Screening Tool for Autism in two-year-old (STAT)** has been developed for children between 2 and 3 years old and contains 12 items administered during a session of a game of 20 minutes. The items cover 3 domains, play, joint attention and motor imitation. It is designed to

differentiate autistic disorder from other developmental delays. It is not designed to detect the broader spectrum ASD. Results based on a sample of 52 children indicated a sensibility of 92% and a specificity of 85%.

Other tools are currently used to diagnose autism, such as the **Autism Diagnostic Interview-Revised (ADI-R)** which is a semi-structured, clinical interview for caregivers of children and adults whose mental age is 18 months or above and lasts 2 hours. The diagnostic algorithm generated ADI-R is consistent with DSM-IV and ICD-10. This tool is now used in all the clinical expertise centers. But for children under 3 years, the rate of false positive is 30% and of false negative is 27% (Lord cited by BAGHDADLI A, 2005).

The **Autism Diagnostic Observation Schedule (ADOS)** is the instrument considered to be the current gold standard for diagnosing ASD and, along with information from parents, should be incorporated into a child's evaluation. It is a standardized direct assessment with covers the three important diagnostic areas. It allows to classify the children in autistic disorder, other ASD or unaffected. With the ADI-R, this tool is considered to be one of the best method for diagnostic investigation (EXPERTISE COLLECTIVE INSERM, 2002).

The **Childhood Autism Rating Scale (CARS)** contains 15 items completed by a trained interviewer/observer and is a behavioral rating scale used to evaluate the severity of symptoms of autism. CARS is designed for children aged more than 2 years, has a sensitivity between 92% and 98% and a specificity of 85%.

The **ABC (Autism Behavior Checklist)** is for children aged from 18 months, contains 57 items filled by an interviewer, which takes between 10 and 20 minutes. But the sensitivity is low (between 38% and 58%) and the specificity is between 76% and 97%.

The **Gilliam Autism Rating Scale (GARS)** is designed for children aged from 3 to 22 years and the questionnaire is completed by the parents and takes between 5 and 10 minutes.

The **Social Communication Questionnaire (SCQ)**, formerly the Autism Screening Questionnaire (ASQ), is for children aged 4 years or more and is a questionnaire that must be completed by the parents. It lasts between 5 and 10 minutes. The reported sensibility was between 85% and 96% and the reported specificity between 67% and 80% (PLAUCHÉ JOHNSON C, 2007).

The list above is not exhaustive. There are many other tools for screening and diagnosing autism. It seems, however, that no tool is perfect and that early detection of ASD could be effective if the tools developed for screening for ASD were "sufficiently sensitive, specific, safe, convenient, and acceptable, although not prohibitively expensive" (DOSREIS S, 2007).

# III. Epidemiology of Autism Spectrum Disorders

The first epidemiological study dates back from the mid-sixties in England (LOTTER, 1966) and since, many epidemiological studies have been undertaken in different countries, using different methodologies and criteria of diagnosis. In this chapter, using epidemiological studies, we will examine the prevalence estimates of autism in different parts of the world and in the United States and to consider the evolution of autism over time, which is an important concern in the United States. A large part of the chapter will be dedicated to the Autism and Developmental Disabilities Monitoring (ADDM) network of the Centers for Disease Control and Prevention (CDC). Additionally, the characteristics of the people affected by an ASD will be explored, allowing more accurate identification of those affected by an ASD. Finally, the chapter will round up by considering how this data can be used.

## 1. Characteristics of the population with Autism Spectrum Disorders

One of the main characteristics of autistic disorder is that males are more often affected than girls. In a review of 32 studies published between 1966 and 2001 (FOMBONNE, 2003), the sex ratio (M/F) available was between 1.3 and 16.0 and the mean sex ratio was 4.3. No epidemiological study ever identified more girls than boys with autism. Gender differences were more pronounced when autism was not associated with mental retardation: a median sex ratio of 5.75 in children with autism and without mental retardation (12 studies reviewed by FOMBONNE, 2003) and a median sex ratio of 1.9 in children with autism and moderate to severe mental retardation (11 studies reviewed by FOMBONNE, 2003). Even with the broader criteria of the Autism spectrum, boys are still more affected than girls (table 2), with a ratio varying from 2.7 (BERTRAND *ET AL.*, 2001) to 7.3 (BAIRD *ET AL.*, 2000) and two studies which found a ratio around 4 (3.8 in CHAKRABARTI & FOMBONNE, 2001 and 4.3 in the ADDM network from the CDC, 2007).

One member of a family with ASD increases the risk of other members also having an ASD. Recurrence risk for autism, the frequency of autism in subsequently born siblings, is estimated to be between 4,5% and 10%, over 100 times the risk in the overall population (Cook, Fombonne, Ritvo, Bailey cited by LANDA R, 2006). An association between the prevalence of certain conditions and the socio-cultural environment is often observed, for example, the prevalence rate of obesity is higher in low social classes than in higher ones. For autism, the recent studies didn't find any relation between the social class and the prevalence of autism.

Neither did the studies find any association between race and prevalence of autism. A recent study based on a large sample of population (YEARGIN-ALLSOPP *ET AL.*, 2003) found that the prevalence of autism (autistic disorder, PDD-NOS and Asperger's syndrome) was the same in the different races: 3.4 per 1000 3- to 10-year-old white children, 3.4 among black children and 2.9 among other. In each race, the sex-ratio also showed a predominance of boys: the sex ratio was 3.8 among whites, 4.3 among blacks and 3.5 among the other racial group.

Other conditions commonly concur with autism. Mental retardation (MR),which is defined by an IQ<70, has historically been an associated diagnosis in 70-75% of children with autism in the narrow definition (NEWSCHAFFER *ET AL.*, 2007). In a review of 19 studies (FOMBONNE, 2005), even if there were some differences in the assessment of intellectual function, about 30% of the children with autistic disorder scored in the normal range of intelligence, about 30% scored in the mild-to-moderate mental retardation range, about 40% scored in the serious-to-profound retardation range. In more recent epidemiological surveys, the prevalence rates of mental retardation in autism (the wide spectrum) were between 22% and 56% (table 2). The ADDM network found, in 2002 (CDC, 2007), that the proportion of cognitive impairment (IQ<70) in children with ASDs ranged from 33.1% of the children in Utah to 58.5% in South Carolina, with an average of 44.6%. There are also great differences between the subtypes of ASD: in an English survey (CHAKRABARTI & FOMBONNE, 2001), the mental retardation was 69.2% in children with autistic disorder, 7.5% in children with PDD-NOS and 0% in children with Asperger syndrome and the mean rate for all the ASDs was 24.2%.

Other conditions are often associated with autism: epilepsy, fragile X syndrome, neurofibromatis, Down syndrome, congenital rubella, hearing and visual impairments. Epilepsy seems to be present in 1 child with autistic disorder in 4 (EXPERTISE COLLECTIVE INSERM, 2002), a lower median rate of 16.8% was found in 11 studies reviewed by FOMBONNE (2003). The author found that in children with autistic disorder, the median rate of cerebral palsy was 2.0% (6 studies), of Down syndrome was 1.3% (11 studies), of the genetic disease tuberous sclerosis 1.2% (10 studies) which was 100-fold more than in general population (1 in 10 000 children). Hearing deficits and visual deficits concerned respectively 1.7% (median rate in 7 studies) and 1.3% (median rate in 5 studies) of the children with autism.

## 2. Recent data on the prevalence of Autism Spectrum Disorders

In the United States, the prevalence often cited by organizations and media is 1 in 150 children having autism (the broader spectrum), which means a prevalence of 6.6 per 1000 children. This prevalence comes from a network led by the CDC, the ADDM network, which methodology will be developed below. The prevalence of the all ASDs (or PDDS) in these studies vary from 3.4 per 1000 (table 4) in a survey conducted in 1996 in the Atlanta Metropolitan area to 11.6 per 1000 in a survey conducted in a cohort of 56 946 children born between July, 1990 and December, 1991, in England. The prevalence found in the recent surveys is higher than previously thought and the reasons why will be discussed below. In these seven studies (table 4), with the exception the two studies previously cited, the prevalence rates of ASDs were very comparable and were around 6-7 per 1000 children (from 5.79 to 6.7 per 1000) even though the surveys took place in different areas and the methods were not the same. However, the age groups studied were very close in the different surveys. Furthermore, all these studies shared the methodological feature of multiple ascertainment methods.

In BAIRD *ET AL.* (2000), as a cohort, children were screened at 18 months with the CHAT, rescreened with the Checklist for referral (CR) at 3½ years, rescreened at 5½ years with the Pervasive Developmental Disorders Questionnaire (PDD-Q). Certain children also received a diagnostic assessment, and at 7 years, children not already known to the research team but who were diagnosed with ASD from local professionals were discussed with local teams.

In CHAKRABARTI & FOMBONNE (2001) and the renewed study CHAKRABARTI & FOMBONNE (2005) which used the same methodology, there was initial screening for a target population and referral for children with developmental or behavioral problems. For diagnosing autism, there were three other assessments.

In BERTRAND *ET AL.* (2001), the records came from 4 sources: special education, local clinicians, lists of children from community parent groups, families volunteers (table 4). The autism diagnosis was verified for 71% of children through a full clinical assessment.

In YEARGIN-ALLSOPP *ET AL.* (2003) and CDC (2007), the methodology will be described below, as for the ADDM Network. Data came from both educational and health records.

In BAIRD *ET AL.* (2006), children in the population diagnosed with ASD were screened, as were those children with a statement of special education needs and considered at risk of having an ASD. They were screened with the SCQ (social communication questionnaire). A two-way random sample of children from families who returned the SCQ and who opted for a further assessment received an in-depth clinical assessment.

**Table 4: comparison of different recent studies (table inspired from (CHARMAN, 2002)**

| | Baird & al, 2000 | Chakrabarti & Fombonne, 2001 | Bertrand & al, 2001 | Yeargin-Allsopp et al 2003 | Chakrabarti & Fombonne, 2005 | Baird & al, 2006 | CDC, 2007 |
|---|---|---|---|---|---|---|---|
| Base population size | 16,235 | 15,500 | 8,896 | 289,456 | 10,903 | 56,946 | 407,578 |
| Area | South-East Thames, UK | Staffordshire UK (Midlands) | Brick Township, New Jersey, USA | 5-county Atlanta metropolitan area | Stafford-shire UK (Midlands) | South Thames UK | 14 sites in the United States |
| Age | 7 years | 2.5-6.5 years | 3-10 years | 3-10 years | 4-6 years | 9-10 years | 8 years |
| Proportion of direct assessment | 46% | 95% | 71% | Records screening and review | 100% | 20% | Records screening and review |
| Source | 12-month birth cohort followed during 6 years | children referred at the child development centers | 4 sources(2) | records at multiple medical and educational sources(3) | children referred at the child development centers | Special needs register of the child-health services(5) | Records from health facilities & special education services |
| Diagnostic criteria | ICD-10 | DSM-IV | DSM-IV | DSM-IV | DSM-IV | ICD-10 | DSM-IV |
| Prevalence autistic dis. | 3,08/1000 | 1.68/1000 | 4.05/1000 | | 2.2/1000 | 3.89/1000 | |
| 95% CI | 2.29-4.06 | 1.10-2.46 | 2.80-5.60 | | 1.41-3.27 | 2.99-4.78 | |
| Prevalence other PDDs | 2.71/1000 | 4.58/1000 | 2.7/1000 | | 3.67/1000 | 7.72/1000 | |
| 95% CI | 1.97-3.64 | | 1.70-4.00 | | | 5.21-10.23 | |
| Prevalence all ASDs | 5.79/1000 | 6.26/1000 | 6.7/1000 | 3.4/1000(1) | 5.87/1000 | 11.6/1000 | 6.6/1000(1) |
| 95% CI | | 5.08-7.63 | 5.10-8.70 | 3.2-3.6 | 4.52-7.49 | 9.04-14.18 | 6.3-6.8 |
| Boys:girls all ASDs | 83:11 88%:12% | 77:20 79%:21% | 44:16 73%:27% | 787:197 80%:20% | 55:64 86%:14% | 77%:23% | 81%:19%(6) |
| IQ>70 / <70 all ASDs | 78%:22% | 76%:24% | 51%:49% | 68%:32%(4) | 70%:30% | 44%:56% | 45%:55% |

(1) Autistic disorder + Asperger's disorder + PDD-NOS.
(2) Special education records, records from local clinicians providing diagnosis or treatment for developmental or behavioral disabilities, lists of children from community parent groups, and families who volunteered for participation in the study in response to media attention.
(3) Public schools' special education program or other Department of Education program for children / State Department of Human Resources facilities for children with DDs, pediatric hospitals and associated clinics, comprehensive diagnostic and evaluation centers for individuals with DDs, private physicians and clinicians who provide diagnostic services for children with DDs, particularly autism.
(4) Includes 23% of individuals classified with developmental tests.
(5) Children with a Statement of Special Educational needs,
(6) Average across ten sites with access to both health and education sources.

It is reasonable to say that these prevalence rates above can be considered the closest to the true prevalence of ASDs, mainly autistic disorder, Asperger syndrome and PDD-NOS.

Among the studies which gave information about the subtypes of ASD, there were some differences about the proportion of autistic disorder in the overall spectrum: the autistic disorder represented only 27% of the whole spectrum in CHAKRABARTI & FOMBONNE (2001), 34% in BAIRD *ET AL.* (2006), 37% in CHAKRABARTI & FOMBONNE (2005) and more than half of the spectrum in the two others, 53% in BAIRD *ET AL.* (2000) and 60% in BERTRAND *ET AL.* (2001). These differences can probably be attributed to differences in application of the criteria for classic autism versus atypical forms of autism.

## 3. Is there an epidemic of autism?

A report related to data gathered in California[9] showed that the number of cases of people with autism had increased significantly from the late eighties to the late nineties. The number of cases of Autism increased from 2,778 in 1987 to 10,360 in 1998, so that reports warned about an epidemic of autism.
Nationwide, the number of children receiving special education services for autism increased 500% from the 1991-1992 school year to the 1998-1999 school year[10]. The analysis of available epidemiological data helps to understand if this increase is a true increase in the prevalence or if other factors can be associated with this increase.

### The prevalence rates of autistic disorder vary according the criteria

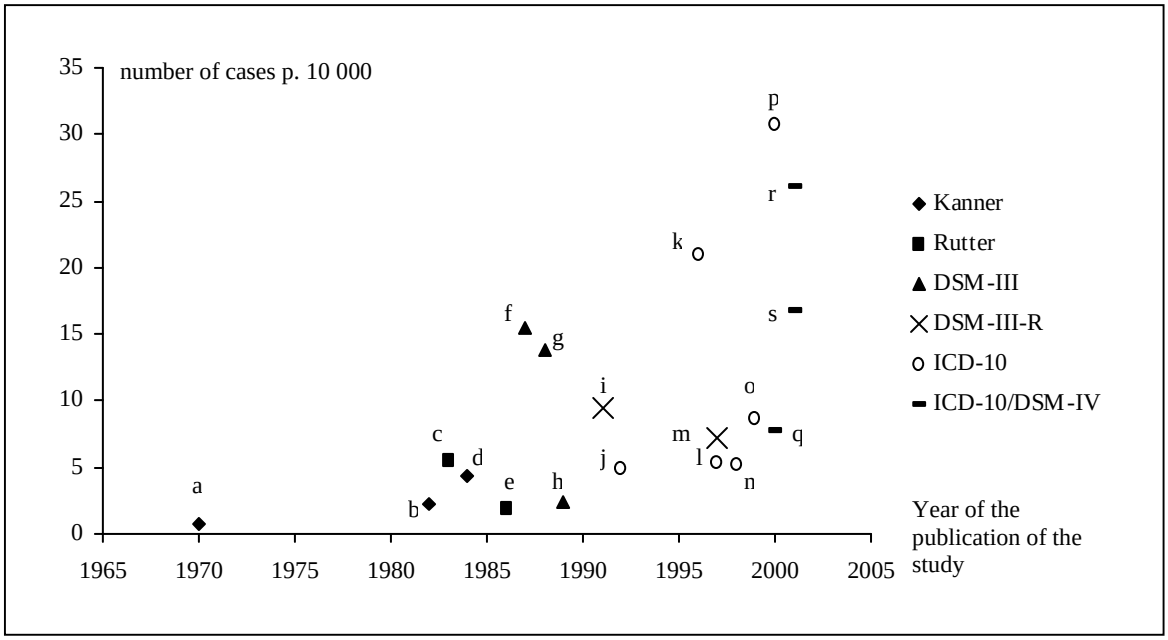
The prevalence of autism can vary strongly with respect to the criteria applied to diagnose autism (Figure 6). Thus, the prevalence rates found with the Kanner criteria were not higher than 4.3 per 10,000 while they are much more higher with the DSM-IV criteria or the ICD-10 criteria, which are those criteria used nowadays. Using the latter, prevalence rates are shown to be between 7.8 and 30.8 per 10,000 in 2000 and 2001.

A Finnish study (KIELINEN *ET AL.*, 2000) applied different criteria of diagnosis (in particular, the Kanner criteria and the DSM-IV criteria) to the same population. This study showed that the incidence rates found with the DSM-IV criteria were systematically higher than those found with the Kanner criteria: at 5-7 years old, the incidence was 14.9 per 10,000 with Kanner

d[9] Department of Developmental Services, Changes in the population of persons with autism and pervasive developmental disorders in California's Developmental Services System: 1987 through 1998, Report to the Legislature, March 1, 1999, available at http://www.dds.ca.gov.
[10] US Department of Education, number of children served under IDEA, 22nd annual report to Congress on the Implementation of the IDEA, Washington, DC, 2000:11-20.

criteria, 22.8 with ICD-10 criteria and 20.7 per 10,000 with ICD-10 and DSM-IV criteria. At 15-18 years, the difference was more significant with a 3-fold variation between the rate with Kanner criteria (2.3 per 10,000) and the rate with ICD-10/DSM-IV criteria (6.1 per 10,000).

**Figure 6: Comparison of autism* rates according different criteria in different surveys overtime**




Sources: a: Treffert & al, 1970 / b: Hoshino & al, 1982 / c: Bohman & al, 1983 / d: McCarthy & al, 1984 / e: Steinhausen & al, 1986 / f: Matshuishi & al, 1987 / g: Tanoue & al, 1988 / h: Ritvo & al, 1989 / i: Gillberg & al, 1991 / j: Fombonne & du Mazaubrun / k: Honda & al, 1996 / l: Fombonne & al, 1997 / m: Webb & al, 1997 / n: Sponheim & Skjeldal, 1998 / o: Taylor & al, 1999 / p: Baird & al, 2000 / q: Powell & al, 2000 / r: Fombonne & al, 2001 / s: Chakrabarti & al, 2001.

* Autism here doesn't include the whole Spectrum Disorders.

**Kanner criteria (1956)**: Lack of affective contact; desire for sameness; fascination with objects; mutism or non-communicative language before 30 months of age.
**Rutter criteria (1978):** Emphasized delayed and unusual social and language development and early onset and unusual behaviors.
**DSM-III (1980):** Differentiated autism from schizophrenia (not a psychiatric disorder, but developmental). Concept of "PDD" introduced: infantile autism; childhood onset PDD; atypical PDD.
**DSM-III -R (1987):** Concept of PDD continued; autism and PDD-NOS defined.
**ICD-10 (1992)**: Greatly expanded PDD concept – autism; atypical autism; Rett syndrome; other childhood disintegrative disorder; overactive disorder associated with MR and stereotyped movements; Asperger's syndrome; other PDDs; PDD, unspecified.
**DSM-IV (1994) and DSM-IV-TR (2000):** Also expanded PDD concept – autistic disorder; Asperger syndrome; Rett syndrome; CDD; PDD-NOS.

## The prevalence rates vary also according the methodology of the survey

Estimates of prevalence are affected by the methodology of the survey (FOMBONNE E, 2005). The methods can be very different in the various surveys: certain use records, for example from education services, certain use direct assessment of the children, certain use multiple sources, etc. In table 5, the studies were undertaken concurrently and the age groups were comparable but the differences in prevalence rates were significant. These differences can be attributed to varying methodologies. Surveys which used only educational services had the lowest prevalence rates of pervasive developmental disorders (from 4.8 to 16.0 per 10 000) while surveys which used direct screening and follow-up identification had higher prevalence rates (57.9 and 62.6 per 10 000). The survey which used multiple sources of ascertainment, even when direct assessment wasn't undertaken, gave a prevalence rate as high as in the surveys with direct screening (67.0 per 10 000).

**Table 5: study design impact on prevalence of Pervasive developmental disorders (PDD)**

| | Location | Population | Age group | Method | PDD rate* |
|---|---|---|---|---|---|
| ***UK Studies*** | | | | | |
| CHAKRABARTI & FOMBONNE, 2001 | Staffordshire | 15,500 | 2.5-6.5 | Intense screening + assessment | 62.6 |
| BAIRD *ET AL.*, 2000 | South East Thames | 16,235 | 7 | Early screening + follow-up identification | 57.9 |
| FOMBONNE E, 2001 | England & Wales | 10,438 | 5-15 | National household survey of psychiatric disorders | 26.1 |
| TAYLOR *ET AL.*, 1999 | North Thames | 490,000 | 0-16 | Administrative records | 10.1 |
| ***US Studies*** | | | | | |
| BERTRAND *ET AL*, 2001 | Brick Township, NJ | 8,896 | 3-10 | Multiple sources of ascertainment | 67.0 |
| STURMEY & JAMES, 2001 | Texas | 3,564,577 | 6-18 | Educational services | 16 |
| California Department of Developmental services, 1999 | California | 3,215,000 | 4-9 | Educational services | 15 |
| HILLMAN *ET AL*, 2000 | Missouri | … | 5-9 | Educational services | 4.8 |

* per 10,000
Source: FOMBONNE E (2005)

**Is the prevalence of autism increasing?**

In his article (FOMBONNE E, 2001), responding to the possible alert of an epidemic of autism made by the California Department of Developmental Services, Fombonne said that we cannot talk about an epidemic of autism and other PDDs for different reasons: in 1987, the change from DSM-III to DSM-III-R has broadened the category of PDDs; in 1994, the categories of Asperger syndrome, Rett syndrome and Childhood Disintegrative Disorder were introduced for the first time in the DSM-IV as subcategories of PDDs and the boundaries of PDD-NOS were broadened; in California and elsewhere, autistic children are now diagnosed at a much earlier age; and lastly, the author found that there were some inaccuracies in the methodology used by the authors.

To measure the evolution of prevalence rates, the comparison can be done between surveys undertaken in the same area. A comparison of two surveys in the same area, Staffordshire in England (table 4), which furthermore used the same methodology, showed that the overall prevalence of all the PDDs were comparable: 6.3 per 1000 for the survey published in 2001 and 5.9 per 1000 in the survey published in 2005.

The apparent increase of the prevalence does not show an epidemic but an increasing number of children accessing services. Also the changes in the IDEA in 1990, when ASDs were recognized as an eligibility condition, may account for some rise in the number of the children earning a diagnosis of autism in US school systems.

According to the CDC (2007), the prevalence of autism is rising for different reasons: there are changes in the availability of services (parents as advocates, development of specialty services, training of professionals), there are changes in diagnostic criteria over time, there is an increased awareness in the community, the recognition of ASDs can occur with severe mental retardation, higher intellectual functioning, other medical and psychiatric disorders. However they also consider if there is a true increase in the incidence or if it is a combination of all these factors cited above.

## 4. The Autism and Developmental Disabilities Monitoring (ADDM) Network

To answer the question of whether there is a possible increase in autism, the ADDM Network is a multiple-source, population-based, active system for monitoring ASDs and other developmental disabilities established by the Centers of Disease Control and prevention (CDC). It was created with the Children's Health Act of 2000. In the Network, ASDs include autistic disorder, Asperger syndrome and PDD-NOS but does not include Rett syndrome and Childhood Disintegrative Disorder.

### Origin of the project

The project began by the MADDSP (Metropolitan Atlanta Developmental Disabilities Surveillance Program), an on-going population-based surveillance system established in 1991 to monitor the rates of mental retardation (MR), cerebral palsy, hearing loss and vision impairment. ASDs were added to the list of surveillance conditions in 1996 because there were concerns at this time about an increasing of autism coming from the general public and the Organizations of autism and pediatricians. Additionally, certain organizations funded the addition of autism in the MADDSP. Before the MADDSP, there was no data available on disability in the United States of America.

### Objectives of the ADDM Network

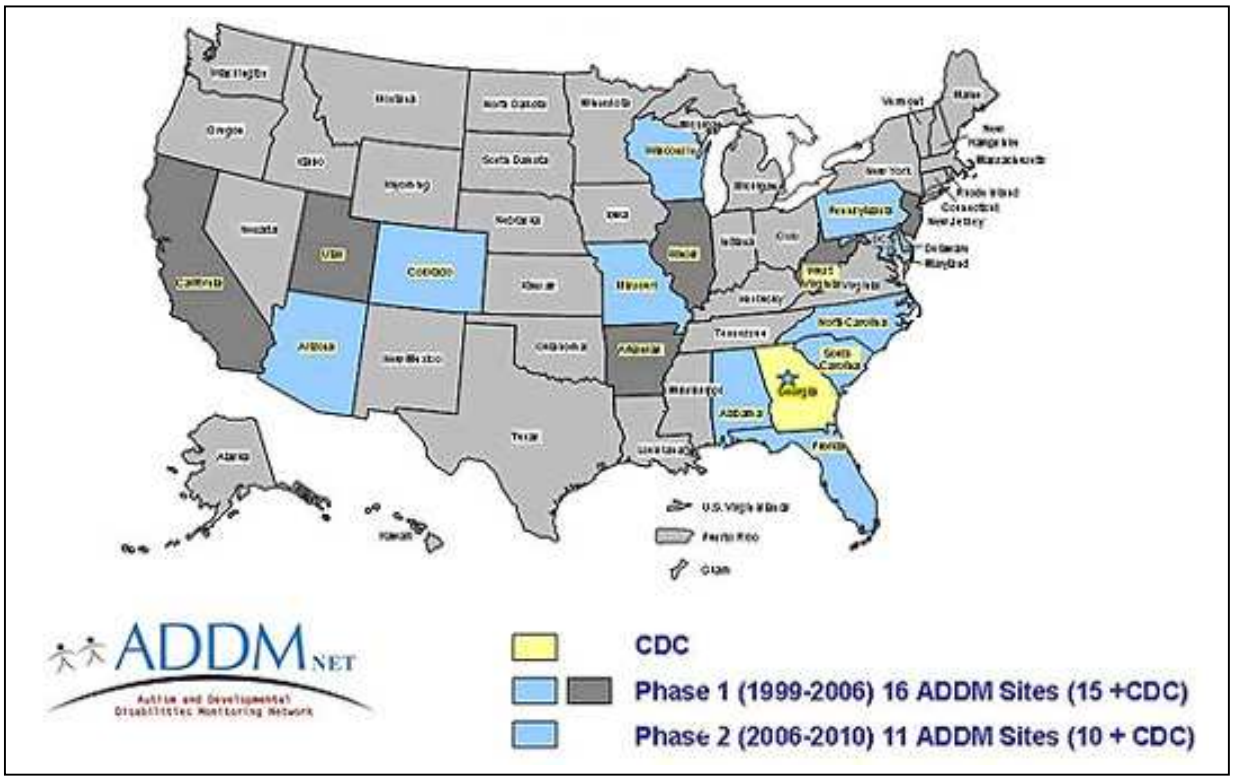
The primary objective of this ongoing surveillance system is to track the prevalence and characteristics of ASD in the United States, and to study whether rates are changing over time. The goal is also to improve the consistency of identification of people with ASDs and to study whether autism is more common in some groups of children than in others. For this, a strong methodology applied in the different sites of the network was set up so that the prevalence estimates are comparable between the different sites and are population-based.

### Method

The surveys concern children aged 8 years. At 8, most children have been appropriately evaluated. For example, Asperger syndrome can not be diagnosed before 7 years, and at 8 years, children have been in school for at least three years. Furthermore, previous surveys undertaken in a population of children aged 3-10 years by the CDC showed that there was a peak in the prevalence of autism at 8 years. To be selected, children should have at least one parent or legal guardian who was residing in the surveillance area during the year of the survey. Children suspected of having an ASD were identified through screening source files, at multiple sources: educational sources (i.e. public schools) and health sources (for example, state health facilities, hospitals, clinics, diagnostic centers and other clinical providers for children with

developmental disabilities, particularly ASDs), for documented or suspected ASD classifications and for descriptions of behaviors associated with ASD diagnostic criteria. The Network uses systematic screening of developmental evaluation records for behaviors associated with autism rather than depending on a medical or educational diagnostic labelling of an ASD. From multiple sources, a composite record was compiled for each child, using the child's name as a variable of recognition. The information on the name was eliminated following review of the records. All abstracted evaluations from the case ascertainment phase were reviewed and scored by an ASD clinician reviewer (i.e. a qualified diagnostician with an advanced degree and/or certification in the assessment and diagnosis of children with developmental disabilities, especially ASDs).

**Figure 7: The ADDM Network in the United States**



**Results**

Data from 2000 and 2002 are now available. For subsequent years, data and surveys are still in process. In 2000, the survey covered approximately 4.5% of the American population aged 8 years from six states (Arizona, Georgia, Maryland, New Jersey, South Carolina, West Virginia) and a total of 1,252 children were identified as having an ASD.

In 2002, the survey covered 10% of the population born in 1994 in USA from 14 states (Alabama, Arizona, Arkansas, Colorado, Georgia, Maryland, Missouri, New Jersey, North Carolina, Pennsylvania, South Carolina, Utah, West Virginia and Wisconsin) and a total of 2,685 children were identified as having an ASD.

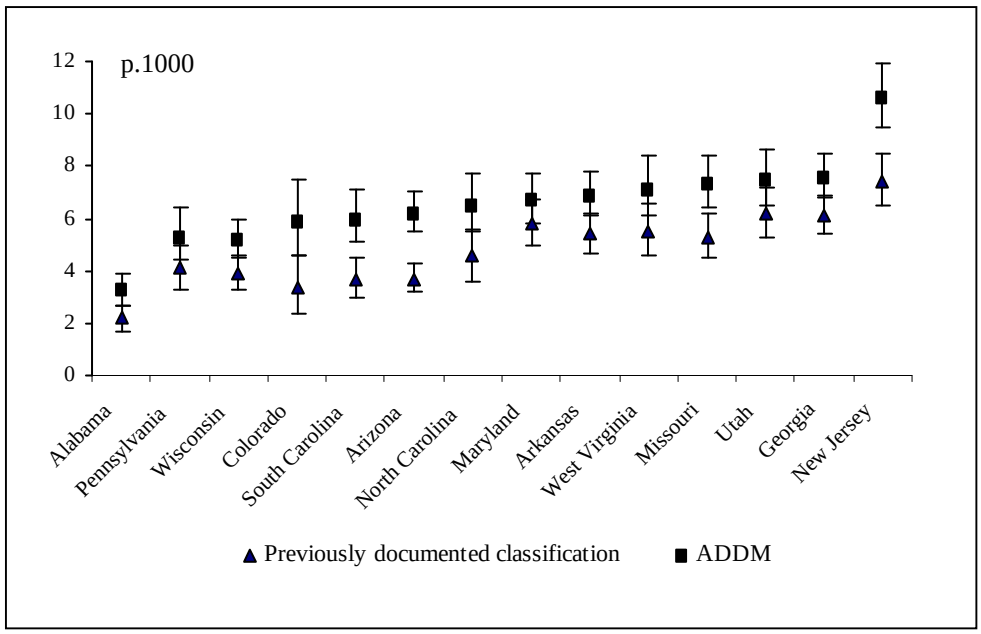
In 2000, the prevalence of ASDs ranged from 4.5 per 1000 (West Virginia) to 9.9 (New Jersey) with the other four sites from 5.5 to 6.5 children with ASD per 1000. The average across all six sites was 6.7 per 1000 children aged 8 years.

In 2002, the prevalence of ASDs ranged from 3.3 per 1000 (Alabama) to 10.6 (New Jersey) but 12 of the 14 sites had a prevalence between 5.2 to 7.6. The average across all 14 sites was 6.6 per 1000 children aged 8 years.

In figure 8, children with a previously documented classification included those who received special education services under an autism special education exceptional category or those diagnosed with ASD documented in their health or education records, or both. In all sites, the prevalence found by the ADDM Network was higher than the prevalence shown by the previous diagnosis of an ASD. The lower prevalence rates found for Alabama, Pennsylvania and Wisconsin could be explained not by a true lower prevalence, but by the fact that these states couldn’t access the educational data.

The highest prevalence rates found for New Jersey may have different explanations. Certain people interviewed pointed out that as New Jersey is well-known as a state providing good services, families with a child diagnosed with autism could have moved to New Jersey specifically to benefit from the better services. However, others have stated that New Jersey has better quality of data than other states. One hypothesis is that the prevalence rates in New Jersey should be the most accurate and that if the other states had the same quality of data than New Jersey, the rates found there would be higher.

**Figure 8: Overall prevalence of ASD among children aged 8 years and prevalence of ASDs among children with a previously documented ASD classification, by source type and order of ASD prevalence - Autism and Developmental Disabilities Monitoring (ADDM) Network, 14 sites, United States 2002**




Source: ADDM network, CDC (2007)
The states Alabama, Pennsylvania, Wisconsin and Missouri didn't have access to educational data

## 5. How can epidemiologic data be used?

Before the ADDM network, data was used from education records to plan services but they were more reactive than proactive i.e. states simply responded to the increase number of children with autism.

"Establishing the current prevalence of ASD is important for clinical and educational planning, and for the families and individuals with ASD themselves" (CHARMAN & BAIRD, 2002).

During interviews, when asking how the surveillance system could help improve knowledge of the needs of the population with ASDs and for planning services, this question was not easily answered. Ellen Giarelli from the Center for Autism and Developmental Disabilities Epidemiology in Pennsylvania, when talking about the site of Pennsylvania in the ADDM Network, said: "There are not enough institutions. Even worse, when the child is out of the school system, there are no facilities to help the child. The problem existed before the health program. There are not enough intervention centers (houses, day programs...) not only for autism but for all severe disabilities. This system (ADDM network) just arguments the needs.

But the data of the system is not precise enough to say what we need in equipment, and we can not translate this".

Susan Evans, from the New Jersey Department of Health and Senior services, talking about the future registry of autism in New Jersey, states: "The idea is for service planning. It will be helpful for us to understand all needs for adults. Even if we cannot say exactly what the children will need when they are adults, we could know as a minimum the number of people that might need services. The registry will provide good data for community services in terms of housing, and the needs for people with autism. We will have to do research based on these people with autism, for example, connected to the unemployment rate, if the causes of unemployment are linked to a developmental disability. If they could have some support to maintain their job, they could keep it."

Catherine Rice and Joan Baio from the MADDSP, CDC "We showed that the prevalence rate was higher than what we thought previously: there are differences between what was planned before and what the ADDM Network found. So we need more services." (figure 8).

Also, "we can give the information back to school systems" which might influence them so they can expand their program. "But it's much more expensive to provide services for children with ASDs than for children with other disabilities. Sometimes, it takes 2 teachers for 1 child with autism." The data can also be used by "advocacy groups, like Autism Speaks, (which) provides a lot of funding for research and pushes for policy. They go to Congress and ask for more services, using the data from ADDM that showed the underestimation of the prevalence rates of ASDs."

The autism registry of West Virginia's Director, Barbara Becker-Cottrill, said that even if the registry is right now not a good source of data scientifically, they go each year to the Federal Government to present the data of the registry, showing that more services are needed for families. In the future, the registry will show the magnitude of the problem and whether the trend is increasing or decreasing.

# Conclusion

### **Autism is now a public health problem** (NEWSCHAFFER CJ, 2003)

Autistic disorder and the other PDDs are not as rare as they were thought to be: the prevalence rates are, like we have seen in more recent studies, around 0.6%, or 1 in 150 children.

Autism has an important public health impact, for example annual costs associated with care for a child with ASD are estimated to be between 85% and 550% higher than annual cost for the care of a typically developing child (Jacobson cited by NEWSCHAFFER *ET AL.*, 2007). Average lifetime public expenditures for a person with ASD are estimated to be approximately $4.7 million (NEWSCHAFFER *ET AL.*, 2007).

Autism is recognized by the government as a serious concern. One of the consequences is that research funding for autism has increased considerably: from 1995 to 2001, it has quintupled, from $11 to $56 millions (NEWSCHAFFER CJ, 2003).

There is also in the United States a very strong advocacy community, like the Autism Society for America (ASA).

### **Early identification is a concern**

The increased interest in behaviorally based educational intervention has resulted in a push for early identification of autism (NEWSCHAFFER *ET AL.*, 2007).

We saw that some factors slowed down the time to diagnosis and that there were differences among the states in the identification of children with autism (MANDELL & PALMER 2005, NEWSCHAFFER *ET AL.* 2007). The two laws, IDEA and Children's Health Act, are beneficial and helpful, as confirmed by all those interviewed. However, these laws are applied differently among the states and "free and appropriate services" does not necessarily mean the best services.

We saw also that there was no systematic identification of autism and that detection depended on parents, pediatricians, caregivers, teachers. It is not rare that detection is very late. "There is evidence that more than half of children with developmental disabilities are not detected before school entry and that physicians under-identify language-related delays and disabilities in children" (SICES *ET AL.*, 2003).

## Early identification can be improved in different ways

The campaign "Learn the signs/Act early"[11], which was mandated by the Children's Health Act[12] of 2000, began four years ago with the goal to educate health care providers, child care providers, community groups and parents about child development, so they could recognize the signs of a developmental delay. It also promoted the use of ASD screening tools by general-practice pediatricians. This campaign is intended to increase the awareness and the knowledge about ASD among general population and professionals.

Some practices among physicians could help earlier identification: systematic use of validated screening tools could significantly improve the detection of these children in primary care" (SICES *ET AL.*, 2003).

The algorithm developped by the American Academy of Pediatrics (AAP) should be carefully followed by the pediatricians and this could help a decrease in the age of children identified with a developmental delay, including autism.

Another difficulty comes from the system of private health insurance, which doesn't give pediatricians time to make sufficiently long patient visits. So a different healthcare system, for example based on the public system rather than on private one, could allow longer visits and with a better quality visits.

As some results showed, pediatricians are not suffciently familiar to screening tools, implying there should be more training on autism in the medical schools.

## The United States have set up a surveillance system on autism

The Autism and Developmental Disabilities Monitoring (ADDM) network is unique in the world, with a strong methodology. It is population-based, multi-site and multi-source.
This network showed that the use of multiple sources gave a more accurate prevalence of autism (Catherine Rice). Further, this network identifies the evolution of autism and respond to concerns of increases in autism in the United States.

## Improving the quality of this network is a priority

In the ADDM network, some sites don't have access to educational data, so it means that some prevalence rates may have been underestimated. One important development is better access to educational data.

[11] www.cdc.gov/ncbddd/autism/ActEarly/
[12] The Children's Health Act is a Federal law which concerns different topics of childrens' health, of which autism is one of them (Public Law 106-310-oct 17, 2000).

We saw that higher prevalence, such as that observed in New Jersey, were explained by a better quality of data in this state. An important objective of the ADDM network is to improve the quality of data in order to detect more accurate prevalence rates.

## Other initiatives should be encouraged

Some states, responding to state laws, have set up a public health autism registry. The first one was set up in West Virginia, with a state law established in 2002, that mandated anybody who diagnosed a case of autism, Asperger or PDD-NOS had to report it within 30 days to the registry. The registry is housed at and operated by the West Virginia Autism Training Center. There are other autism registries in Utah, Delaware and another is underway in New Jersey. These registries aim to track the cases of autism in their respective states and determine prevalence. Furthermore, a registry determines the incidence, that is to say the number of new cases in the population resident in that state. With this data, it can identify the total number of people affected by autism and its evolution. A registry is also dedicated to research: it provides data to assist research into the causes of autism.

Another interesting initiative is the on-line registry, funded by the organization Autism Speaks[13] and based at the Kennedy Krieger Institute[14] in Baltimore. This registry is dedicated to all families with an autistic child in the United States. It is a volunteer participation, and its main objective is to conduct research on autism and interface families and researchers. The families registered may ask questions on subjects they wish to be explored and the researchers put the results of their researches on-line.

Even if there is a strong awareness of autism in the United States, early detection and epidemiological surveillance could be improved. If there is earlier detection and if data can give more accurate numbers and prevalence of autism, then there should be sufficient services to respond to all such needs and must have a sufficient quality to respond to the autism spectrum disorders.

[13] www.autismspeaks.org/
[14] www.ianproject.org

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# Annex I : List of people interviewed

| Name | Fonction | Organization, Agency | Details |
|---|---|---|---|
| **Aimee Anido** | Study Coordinator | Center for Autism and Developmental Disabilities Research and Epidemiology National Center on Birth Defects | Centers for Disease Control and Prevention, 1600 Clifton road, MS E-86, Atlanta, GA 30333 Phone: 404-498-0058 aanido@cdc.gov |
| **Joan Baio Eds** | Behavioral scientist | National Center on Birth Defects and Developmental disabilities Centers for Disease Control and Prevention | 1600 Clifton road, MS E-86, Atlanta, GA 30333 Phone: 404-498-3873 jbaio@cdc.gov |
| **Barbara Becker-Cottrill, EdD** | Executive Director | West Virginia Autism Training Center Marshall University | 400 Hal Greer Blvd Huntington, WV 25755 Phone: 304-696-2844 beckerco@marshall.edu |
| **Peter James Doehring** | Director | Autism Delaware Program | 144 Brennen Dr., Newark, 19713, DE Phone: 302-454-2202 x411 DOEHRINGP@christina.k12.de.us |
| **Susan Evans EdD** | Autism Project Specialist | Early Intervention system New Jersey Department of Health and Senior services | Capital Center, 50 East State street, PO, Box 364 Trenton NJ, 08625-0364 Phone: 609-777-7734 susan.evans@doh.state.nj.us |
| **Eric Fombonne** | Professeur de Psychiatrie et Epidémiologiste Director of the Child Psychiatry Division Director of the Psychiatry department | MacGill University, Montreal Montreal Children's Hospital | Hôpital de Montréal pour enfants eric.fombonne@mcgill.ca sylvie.lafleur@muhc.mcgill.ca Phone: 514-412-4400 poste 22174 |
| **Ellen Giarelli, EdD, CRNP** | Research associate Professor | Center for Autism and Developmental Disability Research And Epidemiology University of Pennsylvania School of nursing | Claire Fagin Hall, room 437 418 Curie blvd Philadelphia, PA, 19104-6096 Phone: 215-746-0041 giarelli@nursing.upenn.edu |
| **Alycia Halladay PhD** | Associate Director of research for Environmental sciences | Autism Speaks | 2 park avenue, 4th floor New York Phone: 609 638 9917 ahalladay@autismspeaks.org |
| **Maria K Kolotos, MS** | Program Manager | Center for Autism and Developmental Disabilities Epidemiology Bloomberg School of Public Health Johns Hopkins University | 615 North Wolfe street Suite E6037 Baltimore MD 21205 Phone: 410-955-2638 mkolotos@jhsph.edu |

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|---|---|---|---|
| **Rebecca Landa PhD** | Director<br><br>Associate professor | Kennedy Krieger Institute's Center for Autism and Related Disorders<br>REACH research program<br>Department of psychiatry, the Johns Hopkins University School Of medicine | Kennedy Krieger Institute<br>3901 Greenspring avenue,<br>Baltimore, MA, 21211<br>Phone: 443-923-7680<br>landa@kennedykrieger.org |
| **Paul A. Law MD, MPH** | Director | Department of Medical Informatics<br>Department of Pediatrics,<br>The Johns Hopkins University School of Medicine<br>Department of International Health,<br>Health Systems Program,<br>Bloomberg School of Public health | Kennedy Krieger Institute<br>3825 Greenspring avenue<br>Painter Building, 1st floor<br>Baltimore, MA, 21211<br>Phone: 443-923-4140<br>lawp@kennedykrieger.org |
| **Li-Ching Lee PhD, ScM** | | Center for Autism and Developmental Disabilities Epidemiology<br>Bloomberg School of Public Health<br>Department of Epidemiology<br>Johns Hopkins University | 615 North Wolfe street, E6032<br>Baltimore MD 21205<br>Phone: 410-502-0605<br>llee2@jhsph.edu |
| **David S. Mandell , ScD** | Assistant professor of Psychiatry and Pediatrics | University of Pennsylvania School of Medicine<br>Center for Mental Health Policy And Services Research | 3535 Market street, 3rd floor<br>Philadelphia, PA, 19104-3309<br>Phone : 215-662-2504<br>mandelld@mail.edu.upenn.edu |
| **Deborah Metzger** | Branch Chief<br>Part C coordinator | Maryland Infant/Toddler/Preschool Services<br>Division of Special Education<br>Early intervention services<br>State Department of Education | 200 West Baltimore street<br>Baltimore, MD, 21201-2595<br>Phone: 410-767-0261<br>dmetzger@msde.state.md.us |
| **Michael J. Morrier, MA** | Assistant Director | Early Childhood/Research coordinator, Department of Psychiatry and Behavioral Sciences, Division of Child and Adolescent Psychiatry, Emory University School of Medicine | Emory Autism Center<br>1551 Shoup Court<br>Atlanta, GA, 30322<br>Phone: 404-727-8350<br>michael.j.morrier@emory.edu |
| **Craig J. Newschaffer PhD** | Professor of Public Health, Chair | Department of Epidemiology and Biostatistics<br>Drexel University School of Public Health | 245 N. 15th Street<br>Mail stop 660<br>Philadelphia, PA 19102-4110<br>Phone : 215-762-7152<br>cjn32@drexel.edu |
| **Georgina Peacock, MD MPH, FAAP** | Learn the Signs. Act early | National Center on Birth Defects and Developmental disabilities<br>Centers for Disease Control and Prevention | 1600 Clifton road, MS E-86<br>Atlanta, GA, 30333<br>Phone: 404-498-4347<br>gpeacock@cdc.gov |
| **Lusine Poghosyan MPH** | Doctoral student<br>Senior research Coordinator | Center for Autism and Developmental Disabilities Research and Epidemiology<br>University of Pennsylvania School of nursing | Claire Fagin Hall – room 437<br>418 Curie blvd<br>Philadelphia, PA, 19104-6096<br>Phone : 215-746-3041<br>lusine@nursing.upenn.edu |
| **Christine Pruls** | Learn the Signs. Act early | National Center on Birth Defects and Developmental disabilities<br>Centers for Disease Control and Prevention | 1600 Clifton road, MS E-86<br>Atlanta, GA, 30333<br>cpruls@cdc.gov |

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| **Catherine E. Rice, PhD** | Behavioral scientist | National Center on Birth Defects and Developmental disabilities<br>Centers for Disease Control and Prevention | 1600 Clifton road, MS E-86<br>Atlanta, GA, 30333<br>Phone: 404-498-3847<br>crice@cdc.gov |
| **Michael Rosanoff MPH** | Assistant Director Public Health | Autism Speaks | 2 park avenue, 4th floor<br>New York<br>Phone: 609 638 9917<br>mrosanoff@autismspeaks.org |
| **Suzanne Smith** | Grants Manager and Education and Outreach Coordinator | Center for Autism and Developmental Disabilities Research and Epidemiology<br>University of Pennsylvania School of nursing | Claire Fagin Hall, room 437<br>418 Curie blvd<br>Philadelphia, PA, 19104-6096<br>Phone : 215-898-3149<br>suzannms@nursing.upenn.edu |
| **Thomas Stengel** | Technical assistance specialist | Maryland Infants and Toddlers program / Preschool services<br>Division of Special Education / Early intervention services<br>State Department of Education | 200 West Baltimore street<br>Baltimore, MD, 21201-2595<br>Phone: 410-767-1028<br>tsengel2@msde.state.md.us |
| **Catherine Trapani, PhD** | Director of Education | Marcus Institute | 1920 Briarcliff road<br>Atlanta, GA, 30329<br>Phone: 404-419-4459<br>catherine.trapani@marcus.org |
| **Anita Washington** | | National Center on Birth Defects and Developmental disabilities<br>Centers for Disease Control and Prevention | 1600 Clifton road, MS E-86<br>Atlanta, GA, 30333<br>Phone:404-498-3861<br>Czo9@cdc.gov |
| **Julia Whitney** | Learn the signs. Act early | National Center on Birth Defects and Developmental disabilities<br>Centers for Disease Control and Prevention | 1600 Clifton road, MS E-86<br>Atlanta, GA, 30333<br>Phone: 404-498-3864<br>Asn0@cdc.gov |
| **Walter Zahorodny PhD** | Director<br>New Jersey Autism Study | University of Medicine and Dentistry of New Jersey | 30 Bergen street, Building 5<br>Newark, NJ 07103<br>Phone: 973-972-6577<br>zahorodn@umdnj.edu |

# Annex II : Resources

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|---|---|
| ADDM, Autism Developmental disabilities monitoring network | www.cdc.gov/ncbddd/autism/documents/AutismCommunityReport.pdf |
| American Academy of Pediatrics | www.aap.org/healthtopics/autism.cfm |
| Association of University Centers for excellence in developmental disabilities | www.aucd.org/template/index.cfm |
| Autism Epidemiology | www.autismepidemiology.net/ |
| Autism Research Network | www.autismresearchnetwork.org/AN/ |
| Autism Society of America | www.autism-society.org/site/PageServer |
| Autism Speaks, Cure autism now | www.autismspeaks.org |
| CDC, Autism Information Center | www.cdc.gov/ncbddd/autism/ |
| CDC, learn the signs, Act early | www.cdc.gov/ncbddd/autism/actearly/ |
| CDC, Centers for autism and Developmental Disabilities Research and Epidemiology (CADDRE) | www.cdc.gov/ncbddd/autism/caddre.htm |
| Cosac | www.njcosac.org/cosac2/Home%20Page |
| Emory Autism Center | www.psychiatry.emory.edu/PROGRAMS/autism/ |
| European Autism Information System | www.eais.eu/ |
| First signs | www.firstsigns.org/ |
| Help Autism Now Society | www.helpautismnow.com |
| Interactive autism network | www.ianproject.org/ |
| Kennedy Krieger Institute | www.kennedykrieger.org/ |
| Learn the signs/Act early | www.cdc.gov/ncbddd/autism/actearly/ |
| Marcus Institute | www.marcus.org |
| Maryland Infants and Toddlers Program | www.marylandpublicschools.org/MSDE/divisions/earlyinterv/ |
| National Institute of Mental Health | www.nimh.nih.gov/health/topics/autism-spectrum-disorders-pervasive-developmental-disorders/index.shtml |
| National Institute of neurological disorders and stroke | www.ninds.nih.gov/disorders/autism/autism.htm |
| Nectac | www.nectac.org/ |
| Organization for Autism research | www.researchautism.org/ |
| Utah Registry of autism and Developmental disabilities (URADD) | health.utah.gov/autism/ |
| West Virginia Autism Registry | www.marshall.edu/wvasdr/default.asp |