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**Changes in the diagnosis of autism:  
How parents and professionals act and react in France**

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**Changes in the Diagnosis of Autism:  
How Parents and Professionals Act and React in France**

**Abstract**

The category of autism has undergone huge changes over the past 20 years. This study was undertaken to analyze the changes and how parents have experienced the diagnostic process in France. Data were obtained from in-depth interviews with parents and psychiatrists, and from 248 questionnaires with open-ended questions filled in by parents. We compared the experiences of parents with adult autistic children to those of parents with young autistic children. Progressively earlier age at diagnosis was evidenced. These changes occurred later than in North America and the UK, due to the reluctance of French professionals to adopt the new classifications of diseases which they viewed as undervaluing both the physician's holistic clinical skills, and psychoanalytical interpretations. Parents' experiences and interviews with psychiatrists were analyzed in order to document changes over time in the diagnostic process following tensions between parents and professionals, and intra-professional debates in psychiatry. Our data support the notion that the diagnosis of autism is historically and nationally contingent. The interactions between changes in the diagnostic process, policy, and parental experiences have led to changes in the way autism is defined, understood, and experienced.

Key words: autism, parents' experiences, diagnosis, child psychiatry, France

Category: Illness narrative

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## **Le diagnostic d'autisme en France: le vécu des familles et le changement des pratiques**

### **Résumé**

Au cours des 20 dernières années, la catégorie “autisme” a subi d’importantes transformations. Cette étude vise à analyser ces changements et le vécu des parents qui ont fait l’expérience du processus diagnostique en France. Les données ont été obtenues à partir d’entretiens approfondis réalisés avec des parents et des psychiatres, et 248 questionnaires remplis par les parents. Nous avons comparé les témoignages de parents d’enfants adultes et de parents de jeunes enfants autistes. L’âge du diagnostic est plus précoce aujourd’hui. Les changements sont apparus plus tardivement qu’en Amérique du Nord ou au Royaume-Uni compte-tenu de la réticence des professionnels français à adopter les nouvelles classifications des maladies qui, selon eux, sous-estiment les compétences cliniques des praticiens et l’apport des interprétations psychanalytiques. L’expérience des parents et les entretiens avec les psychiatres ont permis d’analyser les changements du processus diagnostique, résultats des tensions entre parents et professionnels et des débats au sein de la psychiatrie. Nos données illustrent l’instabilité du diagnostic d’autisme qui change avec le temps et différemment d’un pays à l’autre. Les interactions entre les changements subis par le processus diagnostique, les politiques publiques et l’expérience parentale se concrétisent par des changements dans la manière dont l’autisme est défini, compris et vécu.

Mots clés : autisme, expérience parentale, diagnostic, France

## **Introduction**

For every childhood disorder that receives a medical diagnosis, there is a period of time between the parents' first recognition of an unusual behavior and the diagnosis (Daley 2004; Shaked and Bilu 2006). The analysis of this process can cast light on variations according to era, country, culture, public awareness and training received by professionals. The example of autism is particularly illustrative since the category of autism has undergone huge changes over the past 20 years (Chamak 2008; Eyal 2010; Grinker 2007; Hacking 2002; Nadesan 2005; Silverman 2008, 2012). The aims of the study are: 1) to offer insight into French parents' experiences with the diagnosis of autism and related categories; 2) to document changes over time in policies and the diagnostic process; 3) to compare the situation in France with other countries and analyze why French psychiatrists were reluctant to adopt the broadening of the diagnostic criteria for autism.

The steep rise in the number of recorded cases of autism has raised questions. There was talk of an "autism epidemic" when the state of California reported an increase in the number of recorded cases of autism between 1987 and 1998. Vaccinations, mercury poisoning or other environmental exposures were pointed to as possible causal agents. This idea spread like wildfire and growing numbers of parents chose not to have their children vaccinated, especially in the United Kingdom (Blume 2006; Poltorak et al. 2005). Recently, investigations have evidenced that the doctor who sparked the scare over the safety of the measles, mumps, and rubella vaccine changed and misreported results in his research published in 1998 (Deer 2011). Although the increase in cases of autism is in fact closely linked to the change in the definition of autism, the idea of an epidemic is still widespread. Grinker (2007) evidenced that the high prevalence of autism today is linked to at least four factors: a broadening of the diagnostic criteria, the diagnosis of children at younger ages, the diagnosis of adults not previously diagnosed, and changes in epidemiological methods. The

first epidemiological studies used narrow definitions of autism that excluded milder forms and omitted children diagnosed as ‘mentally retarded’ who may have had autism (Chamak 2008; Grinker 2007; Hacking 2002; Silverman 2008).

During the period from the 1940s through the 1980s, autism remained an uncommon diagnosis (Silverman 2012). In 1987, the American Psychiatric Association’s Diagnostic and Statistical Manual of Mental Disorders (DSM-III-R) changed the category of autism by creating a broader label: Pervasive Developmental Disorder (PDD) including a new label: Pervasive Developmental Disorders - Not Otherwise Specified, defined as atypical autism. Diagnostic criteria were widened to include non-verbal patients as well as persons able to speak but with social interaction problems, communication difficulties and restricted interests. In 1993, the International Classification of Diseases (ICD) adopted the PDD category and added the label Asperger’s syndrome (AS), characterized by the absence of any significant cognitive or language delay (Molloy and Vasil 2002). The broadening of the diagnostic criteria has contributed to a dramatic increase in prevalence: 6-7 per 1,000 for all forms of the autism spectrum disorders (Fombonne 2009) whereas autism prevalence varied from 2 to 5 cases per 10,000 until the late 1990s. The wider diagnostic criteria resulted in many more patients being identified, making autism a public health problem, and fuelling efforts to provide funding for treatments and research.

Eyal et al. (2010) argued that the rise in cases of autism is an indirect product of deinstitutionalization, and that “what happens in the course of therapy loops back to modify how autism is diagnosed, conceptualized and experienced” (Eyal et al. 2010, p. 142). These authors analyzed certain factors that contributed to creating a spiral of looping processes that extended autism into a much larger spectrum. Besides the broadening of the diagnostic criteria, and greater visibility, the development of systems of surveillance in childhood has also increased the frequency with which autism is diagnosed. In the field of care, new patterns

have appeared within a new matrix that has replaced custodial institutions – community treatment, special education, and early intervention programs (Eyal et al. 2010).

Whatever the treatment, the overall outcome for patients with autism has improved if only because the category now includes less severe forms of autism. One of the most significant factors determining outcome appears to be level of intellectual functioning. When children with higher IQ are included in the category, the overall outcome improves but the outcome of those with IQ below 50 does not (Howlin et al. 2004). The statistics contribute to lay and medical belief in the efficacy of early detection and treatment. Proponents of early and intensive interventions and associations of parents are working to change practices and to expand the broadened definition of autism even further (Chamak 2008). The associative movement interacts with the underlying political dynamics and is significantly affected by market forces (Caruso 2010). Regarding changes in professional practices, the broadening of the diagnostic criteria, biological explanations and behavioral methods have not been received in the same way in all countries. In France, psychiatrists refused a classification that they viewed as undervaluing both the physician's holistic and intuitive clinical skills, and psychoanalytical interpretations. Professionals' adherence to standard guidelines varies as a result of numerous factors, including the interpretation of symptoms, the perceived relevance of criteria, the training received, and especially changing historical and cultural environments. For a long time, French psychiatrists were reluctant to give a diagnosis of autism to parents in an effort to avoid negative reactions from parents towards their child (Chamak 2008; Chamak et al. 2011). In France, services are available even without diagnosis, the description of symptoms by professionals being enough to claim help and services. Most French psychiatrists considered autism as a rare and severe disease, and were reluctant to adopt the broader diagnostic criteria. More generally, they rejected the International or American classifications, which had led to a massive reorientation towards biopsychiatry, while French

psychiatrists favored psychodynamic approaches. The French Classification of Mental Disorders in Children and Adolescents categorized autism as a psychosis (this was also the case in other countries such as Argentina, Brazil, and Switzerland). Most child psychiatrists adopted this classification. In the 1990s, families voiced their difficulties in obtaining the diagnosis of autism (*Autisme France* 1994). The parent associations have had a part in fostering the changes in the autism category by promoting the adoption of wider diagnostic criteria, and have influenced public policies (Chamak 2008). In the revised version of the French classification published in 2000, the PDD label was introduced, as well as Asperger's syndrome. In the most recent version in 2010, the ASD (Autism Spectrum Disorders) label was used in line with the international changes.

In this retrospective study in France, data were obtained from interviews with parents and questionnaires filled in by parents for a population of 200 autistic persons from 4 to 45 years of age. The experiences of parents with adult autistic children were compared to those of parents with young autistic children using in-depth interviews and questionnaires including open-ended questions. This approach enabled us to collect both quantitative and qualitative data and thus to compare diagnostic practices and parents' experiences for two periods (1960-1990 and 1990-2005). The quantitative data have been previously published (Chamak et al, 2011). In this study we analyzed the qualitative results obtained from the parents' interviews and the responses to the questionnaire regarding the diagnostic process. Interviews were also conducted with psychiatrists to gain a better understanding of the French system and the changes in professional practices. Parents' experiences and interviews with psychiatrists were analyzed in order to document changes over time in the diagnostic process.

## **Methods**

Parents of adults and young children with autism and related conditions were recruited by contacting parent associations, and also by contacting child psychiatrists and care units



dedicated to autistic persons, so as to diversify parent profiles. A questionnaire and a letter were sent to parents. In total, 248 questionnaires completed by parents were obtained from all over France between 2005 and 2006. Of the 248 questionnaires, 71% were completed by the mothers, 29% by the fathers, and 48 couples completed two questionnaires. Of the 200 autistic persons aged 4 to 45 included in the study, 75% were male. With regard to autistic severity, 60% were described as having severe autism, 19% moderate autism, and 21% had received a diagnosis of high-functioning autism or Asperger's syndrome.

We compared the answers from the parents of 66 adult children (covering the period 1960-1990) and from the parents of 134 young autistic children (1990-2005). A turning point was identified in the 1990s (Chamak 2008). First, the diagnostic criteria were changed at international level and second, parent activism, and especially the action of *Autisme France*, a parent association founded in 1989, led to changes in public policies and professional practices. This is why the periods 1960-1990 and 1990-2005 were chosen to explore the consequences of these changes in France and to analyze the differences compared to other countries. In order to document changes, we explored: 1) the first concerns reported by the parents; 2) the age at diagnosis and the words used; and 3) the level of satisfaction with the diagnostic process.

The questionnaire included both closed and open-ended questions (Chamak et al. 2011). The open-ended questions enabled the families to expand on their views and concerns. The system used for the coding of responses was to allocate each response to one of a set of categories for both qualitative and quantitative processing. Two research team members involved in the study performed the coding independently. Discrepancies between coders were resolved by discussion. This method enabled us to calculate the percentage of parents who were satisfied with the diagnostic process and to identify the reasons for satisfaction or

dissatisfaction. From the 248 responses, 3 were removed because the diagnosis was obtained abroad and 7 because we had not enough data to conclude.

All questionnaire data were captured using Modalisa software ([www.modalisa.com](http://www.modalisa.com)). Among the parents who had given their agreement to answer questions, 20 parents of autistic children and 20 parents of autistic adults were randomly selected for face-to-face in-depth interviews to encourage the participants to go beyond a merely descriptive approach. The “stories” a narrator tells express not only individual experience but also how that experience is shaped, constrained, or marked by society and culture (Kelly 2005).

When we began our study in 2005, the agreement of the INSERM ethics committee could not be obtained because of the reorganization of the committee. In 2008, their response was that a retrospective agreement was not possible. However, we were very careful to allow for the ethical problems. Only parents who agreed to fill in the questionnaire did so, and they gave their name only if they wished. In fact, in many instances parents asked us for the questionnaire to complete it when they learned that we were conducting a study on the experiences of parents. They wanted to provide information for a better understanding of their difficulties.

While respecting the issues of anonymity and confidentiality, the interviews raised certain ethical challenges because they involved recollection of distressing events, and the difficulty telling a personal story to a stranger. However, when parents agreed to be interviewed, they often seemed relieved to have a chance to give their version of the story, and sometimes asked for information and support. Throughout the study, and even afterwards, we provided support by making ourselves accessible by email and telephone. The interviews were audio-taped with the parents’ agreement and were then transcribed. Details were collected concerning the history of the child’s development, the parents’ experiences in obtaining the diagnosis of autism for their child, and their feelings. We conducted in-depth interviews with 37 mothers

and 6 fathers. In order to gain a better understanding of the French system and of the changes in professional practices, interviews were also conducted with 18 psychiatrists. Narrative analysis was used for the qualitative data obtained from the in-depth interviews.

### *Limitations*

Some of the data relates to recollections of events that occurred long ago and therefore may have been reshaped. Nevertheless, many parents reported experiences in common with one another and quoted similar phrases from psychiatrists. The interest of this work is to be found in the association of both quantitative and qualitative approaches. Comparing parents' experiences in France in the past and in the present day using the same methodology is a core feature of this study, which provides data for a comparison with other diagnostic systems in other countries.

### **Results**

#### ***The parents are often the first to detect signs of concern***

The first step in the process of seeking a diagnosis is the recognition that some aspect of development is not proceeding as expected. Whatever the period explored, the answers were similar indicating that signs raising concern did not vary. However, parents of young autistic children more readily referred to professional wordings diffused via Internet such as “no babbling” or “no pointing”. Parents reported impairments in social skills, play and communication skills, behavioral disturbances and sensorimotor disorders. They described “social withdrawal”, “isolation”, “the lack of interest in other people”, “avoidance of gaze”, “absence of eye contact”, “a strange, different gaze”, and “sideways glances”. They noticed the lack of reactivity to social stimuli: no reaction when their child was called by his/her name or no answer when solicited. Failure to respond to name, and the lack of eye contact were the earliest and most frequent signs pinpointed by parents:

He did not look at us and when we called him by his name he did not react. We thought he was deaf. [From a mother of an adult born in 1984, interview 03/10/2005.]

A baby who doesn't look at you and doesn't smile, you just can't miss it! So we became concerned very early on. [From a mother of an adult born in 1952, interview 04/03/2006.]

A delay in speech or limited speech was the second significant category of warning signs reported. The parents sometimes described tantrums and socially inappropriate behavior by their children, generating considerable stigmatization for the parents and, in some cases, humiliation, social exclusion and isolation (Gray 1993).

The first professionals from whom parents sought help were pediatricians, psychiatrists and GPs. The parental reports illustrated the tendency of some professionals to minimize problems and/or to enhance the feeling of guilt of the parents:

I told the pediatrician many times that my child had problems. She said to me: "you are too anxious" – It made me feel guilty – "Open up! Have another child!" [From a mother of an adult born in 1988, interview 03/09/2005]

At 15 months my child still wasn't walking. He was hypotonic. The pediatrician told me: "He's just a big lazy baby. Don't worry!" [From a mother of an adult born in 1978, interview 06/02/2006].

Parents' anxiety was sometimes dismissed by professionals as being unfounded, or else behavioral problems were attributed to inadequate parenting, as also illustrated by child psychiatrist interviews and other studies in different countries (Goin-Kochel et al. 2006; Howlin and Asgharian 1999). After the 1990s, this attitude was less frequent but still exists, as confirmed by the interviews: "This child psychiatrist told me firstly, that there was no problem, and secondly that I was too normative, and maybe I was causing my child's problems." [From a mother of a child born in 1996, interview 03/09/2005.]

Generally, it was a child psychiatrist who gave the diagnosis. To the question regarding the effect of having no diagnosis, the responses concerned the difficulty understanding the child's behaviors, the time required to obtain adequate services, the feelings of powerlessness, doubt, uncertainty, and guilt. These responses were obtained from parents with adult children and from parents with young children alike, showing that difficulties obtaining a diagnosis

and services have been encountered until quite recently: “The pediatrician told me: ‘There is no problem for the moment. Let her live in her own way’.” [From a father of a child born in 1996, interview 12/22/2003.]

Parents often perceived the absence of diagnosis as leading to increasing stigmatization. They did not know what to say to the family, friends and other children: “Will he get better? No response. How could we explain things to others, to his brothers, and to the child himself?” [From a mother of an adult born in 1984, interview 05/21/2003.] The narratives of some parents showed a quest for a label, a medical diagnosis to provide objective, medical confirmation of their subjective experience of impairment in their child (Chamak 2008; Farrugia 2009). The diagnosis provides a degree of explanation for a child’s behavior, and helps parents accept that they are not to blame for the condition (Chamak et al. 2011). Many parents are relieved when a professional corroborates what they initially suspected (Midence and O’Neill 1999; Mansell and Morris 2004; Sullivan 1997), and they are often less upset by the term “autism” than by the phrase “mentally retarded”. The relief arises from the feeling that they have obtained an answer to their questions, or a confirmation, and the means to obtain information and services.

### ***The change in the mean age at diagnosis and the words used***

Among the 66 adult autistic persons (born before 1990), 32% did not receive an official diagnosis of autism, 12% obtained it when they were adults and only 30% obtained it before the age of 5. Before the 1990s, the mean age at diagnosis was 10 (Chamak et al. 2011). The diagnosis of Asperger’s syndrome was not given before the 1990s because the category did not exist in the French classification.

Of the 134 autistic children in our sample, 64% received the diagnosis of autism or PDD before the age of 5, and 12% did not receive an official diagnosis of autism (Chamak et al. 2011). Compared with the previous period, therefore, the diagnosis of autism was obtained

earlier. The mean age at diagnosis was 5. For the children born from 2000 to 2002, the mean age at diagnosis was 3. These results illustrate the fact that many but not all professionals have adopted new practices since some parents still do not get an early diagnosis for their child.

For the parents of adult children who were not given a diagnosis of autism, the words used by the professionals, according to interviews and the questionnaires filled in by parents, were: child psychosis, progressive disharmony, personality disorder, mental handicap, disabled, serious personality disorder, brain malformation, mental retardation, poor understanding between the mother and the fetus:

As we read books, we suspected that it was autism, but none of the professionals we consulted ever talked about autism, but used phrases like infantile psychosis or progressive disharmony. [From a mother of an adult born in 1984, interview 05/21/2003.]

The child psychiatrist said nothing. He did not talk about autism. He spoke about behavioral dysfunction. For a long time we were not given a diagnosis, and I was extremely upset at not having any diagnosis. Maybe because I am a nurse, I don't know. Anyway, I wanted a diagnosis and I did not succeed in getting it. When Q. was 8 years old, the phrase "autistic syndrome" was used by another child psychiatrist, but it was diluted, maybe to leave a safety margin, by adding: "but that's not it". [From a mother of an adult born in 1984, interview 03/09/2005.]

At 3 he was supposed to be talking and playing with others, but he didn't. He wanted to be alone. I was anxious, but the pediatrician told me: "don't worry". When he was 7 a child psychiatrist used the term "autism". I remember she told me: "here, we take care of children's hearts". I believed she would cure him. [From a mother of an adult born in 1983, interview 03/09/2005.]

Some parents reported sentences that had shocked them: "*If the mother gets better, so will the child*" (1969); "*It would be better to abandon your child*" (1988).

I was pregnant, and I saw a neurologist for my son. She was really nasty and awful. In front of the house doctors, she told me: "Your son is mentally retarded and he will be a burden all your life. To make matters worse, you are pregnant; if I were you I would have an abortion". Even the house doctors didn't like her and they tried to comfort me at the end of the examinations. [From a mother of an adult born in 1984, interview 03/07/2011.]

The phrases used caused parental distress. In this type of situation, the feelings of guilt are enhanced and the doctor's prognosis of permanent disability generates either despair or revolt.

Parents who did not receive a formal diagnosis of autism in France sometimes obtained it abroad (UK, USA, Canada), or informally from professionals in charge of their children.

Some parents of young children did not obtain the diagnosis for their child either. Here again other terms were used instead: child psychosis, disharmonious development, communication problems, disabled, language and communication difficulties, developmental retardation. However, most parents of these children have been able to get help for social and medical services:

When she was one and a half, I noticed that she didn't answer when I called her. I was referred to a ENT specialist, but she was not deaf. When she was 3, she was accepted in a day hospital, but I didn't know exactly what was the matter. I realized that my daughter was autistic when I saw a TV program. [From a mother of a girl born in 2000, interview 10/10/2006.]

Nobody talked about autism but I was satisfied with the day hospital. The psychiatrist explained that E. had difficulties communicating, and language and motor problems, as well as developmental and behavioral disturbances. [From a father of a child born in 1994, interview 09/29/2006.]

The child psychiatrist did not give the diagnosis at once. He talked about disharmonious development. He gave us a letter for the child neurologist. We opened it and we read: "high-functioning autistic syndrome or Asperger". Putting a name on what was the matter with F. was a relief, even though it put us in mourning for our ideal child. [From a mother of a child born in 1996, interview 03/09/2005.]

Compared to the experiences of parents with adult autistic children, particularly shocking wordings were less frequently reported by parents, but some difficulties remained as illustrated by the interviews and responses to the questionnaire.

### ***Dissatisfaction with the diagnostic process and the feeling of guilt***

Ninety-three per cent of the parents of autistic adults were dissatisfied with the diagnostic process because of long delays in obtaining the diagnosis, the words used, and/or a blunt announcement without care or consideration. In contrast, among parents of autistic children, 63% were dissatisfied. The results evidence an improvement alongside continuing delays for some in obtaining a diagnosis of autism, and a lack of services when they had the diagnosis.

For the parents of autistic adults, separation from their child was sometimes recommended: “Mrs. X, your son is unhappy because of you, you should give him up. And you should take care that your second son does not go the same way through contact with him” [From a mother of an adult born in 1986]; “You will have to separate from him or he will be a burden all your life.” [From a mother of an adult born in 1984]. These parents were confronted with oppressive frames of meaning that attributed ‘damaged’ identities to them and their children (Fisher 2008). Medical discourse presented the disability as a permanent and hopeless burden even for children diagnosed with Asperger’s syndrome. One mother, who complained about this deficit model and the judgment of bad parenting from the psychiatrists, explained that she consulted a psychiatrist with her son until he was 9:

Every week we had to go to a psychiatrist who tended to make me feel guilty. He did not say anything. He waited and watched me. Then he asked me how the week had gone. Often I had nothing to say. It lasted for years until we got a psychological report, and another psychiatrist told me it was a very serious problem. He diagnosed Asperger’s syndrome. The first psychiatrist explained that my son would need psychotherapy for years and he probably would not find a job. I didn’t understand because my son was good at school. [From a mother of an adult born in 1979, interview 02/20/2006].

When her son was 18, another psychiatrist told her: “You are not responsible for the problem. It is a disability, probably of genetic origin. There is no cure”. This example illustrates how the discourse produced by psychiatrists changed over time. Within the context of childhood impairment, parental identity undergoes great upheavals. Childhood impairment challenges the social category and identity of parents in ways that are not far from the subjective experiences of disability (Kelly, 2005). Moreover, some parents considered that if they were not compliant with what the professionals expected of them, their child might be deprived of help and services:

If the parents did not accept the views of the psychiatrists, the children had no services. I experienced this: my daughter was excluded because I did not take the psychiatrist in the institution seriously. Most of the time my wife was told that she was responsible”. Fortunately, I didn’t take it seriously and I managed to comfort her. [From a father of an adult born in 1968, interview 05/31/2006.]



The mothers were often stigmatized by professionals which may be why they were more likely than the fathers to welcome a medical label. Certain mothers explained: “My husband was in denial about our child’s autism”. The label reduced stigmatization and enabled them to find assistance for their child. It is overwhelmingly the mothers who are the primary carers of children, especially when the child is disabled (Landsman 2003; Fisher and Goodley 2007; Read 2000), and the responsibility for the child’s behavior is often attributed to the mothers (Gray 2003).

The comparison between the two periods evidenced changes in professional practices but also changes in parental attitudes. From the 1990s onwards, they increasingly refused to be treated as if they were guilty: “‘Maybe you didn’t cuddle him enough’ the child psychiatrist told me. Fortunately, we belonged to families able to stand up against the feeling of guilt.” [From a mother of a child born in 1988 and a member of a parents’ association, interview 03/11/2005.] More parents became members of parents’ associations. They had access to the Internet and this changed their representations of autism. Thanks to different sources of information, they could explore the content of medical papers, communicate with peers, exchange experiences and form a collective lay expertise. They developed a more critical viewpoint on social care practices and their legitimacy. When parents have access to medical and scientific information, they acquire expertise and ability to modify their relationship with the medical world and hence question the prevailing dissymmetric model.

The parents often pointed out that many of the difficulties are generated by other people’s attitudes. When certain doctors asked them why they wanted to put a label on their children’s difficulties, they answered: “*Other people put a label on them, and often a wrong one*”. The psychoanalytical discourse was rejected and genetic and neurobiological origins were put forward to discredit the judgment of bad parenting. Currently, more and more parents refer to biomedical knowledge and early intervention programs. Farrugia (2009) evidenced that the

parents who are active in support groups are more likely to resist the process of stigmatization by deploying medical constructions of their children's difference.

### ***How have professional practices changed?***

A now retired French child psychiatrist who managed a Parisian child psychiatry unit in the 1970-1980s recalls (interview 20/10/ 2003):

When I was house doctor in the child psychiatric unit (1936-1945), autism was unknown. As I was personally interested in autism, I began to diagnose autistic children in the mid-1940s but when I presented one of them to the head of department he told me: "He is just a mentally retarded child". When I was chief resident I remember that the children were in their beds all day just as for acute diseases. Then teachers and educators were introduced. I disagreed with the ideas regarding the possible links between autism and maternal attitudes, and this was a problem when I was chief resident because all my students were psychoanalysts.

Before the 1990s, psychiatrists defined autism as a severe psychosis characterized by absence of language and social interaction deficits. For a long time, psychoanalysts tried to establish a causal link between family behavior, more particularly the mother's, and the development of autistic disorders. This approach, which prevailed for a long time, led to conflicts between parent associations and professionals (Chamak 2008).

Under pressure from parent associations, political mobilization in France led to the "Veil Decree" of 27 April 1995, which proposed changes to improve the care of autistic individuals, including early diagnosis, wider diagnostic criteria, and educational and behavioral approaches (Chamak 2008). In December 1996, autism was officially recognized as a disability by law (n°96-1076). Changing the status of autism, from a psychiatric disease to a disability, enabled the parents to distance themselves from psychiatry. Since 1999, new regional centers (Centres Ressources Autisme, CRA) have been set up to provide information, diagnosis, and services for parents of autistic children. However, some professionals still resist the new diagnostic practices and behavioral methods.

In 2005, a child psychiatrist from the CRA Ile-de-France explains (interview 12/10/2005):

The situation is slowly evolving. I think there are still no more than 30% of child psychiatrists who, when they diagnose autism, refer to professionals for neurological and cognitive evaluations. When I was in charge of a day hospital it was almost war with my team. It was a Lacanian bastion and it was very difficult. They considered me as a traitor because I dared ask for the evaluations.

The first official initiative from professionals regarding diagnosis took place in 2005, when the French Federation of Psychiatry drew up recommendations published in June 2005 by the 'Haute Autorité de Santé' (HAS). Except for some proponents of the new practices and regional child psychiatry hospital units specialized in autism (such as in Tours, Montpellier, Paris, and Chartres), most professionals were hostile to the changes until recently.

Psychoanalytical references are still evident in the training and interpretations of psychiatrists, who often quote proponents of psychoanalytical interpretations of autistic symptoms, such as D. Meltzer, F. Tustin, D. Winnicott, E. Bick, S. Lebovici, G. Haag, J. Hochmann, and D. Houzel. However, the trends have been different among psychoanalysts, and Lacanian orientations, still widespread, have often been criticized.

Internationally, the changes in practices have followed the same trend: a broadening of the diagnostic criteria and earlier diagnosis. In France these changes took more time and resulted first from pressure from parents' associations and from public policies, not from mobilization among professionals, with the exception of those implicated in the new practices.

### **The specificity of the French context and the reasons why French psychiatrists were reluctant to adopt the new orientations**

Compared with other countries, psychiatrists are much more numerous in France (WHO 2005). In most countries, deinstitutionalization resulted in drop in the number of psychiatrists, while an increase has been noted in France since the 1970s (Coffin 2009; WHO 2005). How can this phenomenon be explained? From the 1960s, for the purpose of psychiatry France was divided into areas named "sectors" to which were attached services and different interventions in the fields of therapy, education, social interaction, sport and cultural activities, as well as

social services, aiming to address a wide range of situations. The people behind the sector policy had a psychoanalytical background and a collective, public idea of psychiatry. The aims of sectorisation were to maintain the patient in the home or social environment, and to ensure the continuity of care and services provided by teams in the health and social professions. The number of hospital beds fell but not the number of psychiatrists who coordinated the psychiatric teams. Even though the sector policy was very heterogeneous across regions, this pattern of organization aimed to ensure services preventing the separation of children from their parents. In other countries, such as Canada, the children with autistic characteristics were often hospitalized in the same period (1960s-1980s) (unpublished data).

When the DSM changed the diagnostic system, rejecting psychoanalysis, defining diseases by the way of symptoms and widening the diagnostic criteria, the French psychiatrists resisted this orientation. They could not deny their training and references to adopt a system considering people as a list of symptoms. Their numbers and their crucial role in coordinating the system enabled them to resist for a long time, which explains why the broader diagnostic criteria were not adopted until the 2000s. However, more and more psychiatrists changed their mind about the “refrigerator mother” theory.

After the 1990s, some parent associations were convinced that the North American system was better and decided to change professional practices by taking political action (Chamak, 2008). In a context of a decreasing availability of hospital beds and the trend towards liberalisation of the health services, public authorities favoured the involvement of families to foster the creation of new facilities and schools. The parent associations acquired more power. Under pressure from the French parents’ associations, public policy makers proposed changes in line with the demands of parent associations, including early diagnosis, the adoption of the widened diagnostic criteria, and the modification of intervention programmes, adopting a more educational and behavioural approach involving parental collaboration. New

recommendations for professionals were published followed by new classifications and new professional practices. Even though the broadening of the diagnostic criteria in the DSM (for autism, hyperactivity, social phobia, bipolar syndrome, etc) drew criticism, the French psychiatrists were encouraged to adopt it under the pressure from the parent associations, international psychiatry, researchers who needed international standard criteria, new professionals involved in behavioural methods and the bad image of French psychiatry diffused by parents' associations and journalists.

## **Discussion**

### *Changes in the social construction of autism: an international comparison*

Over the past twenty years, there has been a dramatic change in the social construction of autism (Chamak 2008; Eyal et al. 2010; Grinker 2007; Hacking 2002; Nadesan 2005; Silverman 2008, 2012). Its definition, etiological hypotheses, and proposed treatments have changed. Autism has shifted from being a rare disease to a broad syndrome and from a psychiatric disorder to a genetic disease involving an atypical development of the nervous system (Bumiller 2009; Hacking 2002; Nadesan 2005; Silverman 2008). Among parents, biological explanations are preferred because they decrease feelings of guilt (Chamak 2008; Farrugia 2009). In the 1960s psychoanalytic discourse constructed autism as the result of “cold” mothering, and the “refrigerator mother” theory diffused through popular psychology. In the U.S., Bernard Rimland, a psychologist and himself the father of an autistic son, was one of the first to question the psychogenic etiology of autism. In 1964, he put forward an alternative explanation for autism based on neurobiology and deplored the confusion of infantile autism with childhood schizophrenia (Rimland 1964). He was active in studying behavioral treatments for autism and in promoting vitamin therapy. In 1965, he founded the American Society for Autism, a major association of parents which had a part in changing the representations of autism (Caruso 2010).

Currently, the medical and scientific literature represents autism as a biological problem that should be explained by reference to the natural sciences. Nadesan (2005) points to the social conditions enabling the naming of autism as a distinct disorder and its representation:

Although there is a biological aspect to this condition named autism, the social factors involved in its identification, representation, interpretation, remediation, and performance are the most important factors in the determination of what it means to be autistic, for individuals, for families and for society (Nadesan 2005: 2).

In Korea, children with autism are often hidden from neighbors and relatives, largely because of the stigma associated with having a disabled child (Grinker 2007). A recent study conducted in a South Korean community on 55 000 children from 7 to 12 evidenced that two-thirds of ASD cases were in the mainstream school population, undiagnosed, and untreated (Kim et al. 2011). In France, the stigmatization associated with autism for a long time led psychiatrists to avoid giving the diagnosis to the parents. In French child psychiatry the system enabled parents to get help and services even if the diagnosis was not actually given a name.

Over the past two decades, rates of diagnosis of Autism Spectrum Disorders have increased sharply, and the mean age at diagnosis has fallen in most countries around the world, including the UK (Howlin and Moore 1997; Keen and Ward 2004; Latif and Williams 2007), the USA (Goin-Kochel et al. 2006; Mandell et al. 2005), Canada (Siklos and Kerns 2007; Poirier and Goupil 2008), Sweden (Gillberg et al. 1991), Australia (Baker 2002), Finland (Kielinen et al. 2000), Iceland (Magnússen and Sæmundsen 2001), Japan (Honda et al. 1996), India (Daley 2004), and Israel (Senecky et al. 2009). A study conducted in the UK by Latif and Williams (2007) showed that diagnosed cases of ASD more than doubled between 1999 and 2003. The data obtained in Quebec by Poirier and Goupil (2008) indicated that the mean age at diagnosis was 7 for current 7-12 year-olds and 3.5 for children under 7. Most studies have confirmed more frequent detection of high-functioning autistic individuals (Honda 1996; Kielinen et al. 2001; Magnússen and Sæmundsen 2001; Scott et al., 2002).

However, epidemiological studies evidence great variability in rates of ASD from one country to another and even within countries. In the USA, the prevalence of all ASDs varied across sites from 42 per 10,000 in Florida to 121 per 10,000 in Missouri (Autism and Developmental Disabilities Monitoring Network 2006). Compared with North America or Europe, low frequency is evidenced in South America. In a pilot study conducted in Brazil the prevalence of PDD was evaluated at 27 per 10,000, with more children diagnosed with PPD-NOS than with autistic disorder (Paula et al. 2011). In Venezuela, a low PDD prevalence of 17 per 10,000 was found, and 11 per 10,000 when autistic disorder alone was considered (Montiel-Nava and Peña 2008). A study carried out in China found a prevalence of 11 per 10,000 (Zhang and Ji 2005). In low-income countries such as Iran the prevalence for typical autism is only 6 per 10,000 with a variation in prevalence between the less-and well-developed provinces (Samadi et al. 2012). The proportion of children assessed as having ASD is twice as high in the better developed provinces. For Samadi et al. (2012), the lower prevalence of autism in Iran is linked to Iranian culture. A diagnosis of disability is likely to be seen as stigmatizing. Parents may under-report the child's difficulties because they are keen for their child to attend mainstream school rather than being referred to a special school. By contrast, in Western countries parents seek diagnosis to obtain services.

There are several hypotheses to explain the variability in rates of ASD between epidemiological studies worldwide. In an attempt to understand the reasons for the variation across countries, Williams et al. (2006) found that diagnostic criteria used, changes in the diagnostic instruments, age of children screened, country of origin and urban/rural location of the sample, all significantly influenced the reported ASD rates. This study confirmed the extent to which the identification of this condition is affected by cultural influences. Different adult tolerance and expectations for children's behaviors, and child-rearing practices could contribute to explain the difference in the prevalence rates of ASD.

### *Differences in France and the role of the parents' associations in the changes*

Before the 1990s, the experiences of parents with autistic children in terms of difficulties in obtaining a diagnosis for their child were similar whatever the country (Gray 1994; Howlin and Moore 1997; Howlin and Asgharian 1999). Parents complained about lengthy delays, and very little help. In this study we have shown that the diagnostic process changed in France but later than in other countries. Whereas the first concerns reported by the parents were similar from the 1960s up to the 2000s, diagnosis was obtained at an earlier age, and the words used by professionals were less hurtful after the 1990s. The number of children receiving no diagnosis decreased, as did the time-lapse between first consultation and diagnosis (Chamak et al. 2011). The level of satisfaction with the diagnostic process increased from 7% to 37% if we compare the periods 1960s-1990s and 1990s-2005. The level of dissatisfaction is nevertheless still high essentially because of the lack of services after obtaining the diagnosis, but also because certain psychiatrists still resist the new diagnostic practices.

Since 1999, new regional centers have been set up in France to improve early diagnosis and services for autistic children and the HAS recommendations in 2005 have changed diagnostic practices. Nevertheless, these changes have been slow, because child psychiatrists put up fierce resistance to the loss of influence of the psychodynamic trend, to 'over-diagnosis', and to the wider stigmatization resulting from the inclusion of a larger population. The practice of categorizing mental illness and emotional problems contrasts with the more holistic approaches advocated by the French psychiatrists, who considered that the American classification constituted an intellectually impoverished statistical approach that did not enable the patients and their symptoms to be understood.

Kirk and Kutchins (1992) and also Horwitz (2002) have pointed out the complete transformation of the system of psychiatric thought when the symptom-based disease entities of the diagnostic system replaced the unconscious mechanisms of the dynamic system. In



contrast to the dynamic model, diagnostic psychiatry defines diseases through the presence of symptoms, regardless of the causes of these symptoms. It regards diseases as natural entities that generate the symptoms a person displays. This orientation was dismissed by most French psychiatrists with psychodynamic training, who justified their system of knowledge by referring to holistic and intuitive clinical skills and a practice of medicine focused on the individual patient.

Parent associations have played a crucial role in the changes. Because the parents were confronted with an oppressive framework of meaning that attributed ‘damaged’ identities to them and their children as can be seen in the parental reports, they set out to change the representations of autism. They fought against the judgment of bad parenting and the definition of autism as a psychiatric disease. The first association of parents involved in the changes was Autisme France, founded in 1989. This association refused the definition of autism as a psychosis, referred to the international classification and promoted behavioral interventions (Chamak 2008). They obtained evolutions in professional practices from the public authorities. This movement expanded in the 2000s with the proliferation of associations calling for changes in professional practices. In 2011, around 200 associations of parents with autistic children and 800 associations managing facilities and services joined forces in a collective motion demanding autism to be labeled as the “Great National Cause for 2012” and they obtained this from the Prime Minister in December 2011. This label gave them the benefit of free messages and campaigns on public TV and radio channels, and enabled them to appeal to public generosity, and to publicize their demands and representations of autism.

The parent associations have contributed to redefining autism as a genetic disease involving an atypical development of the brain (using websites, symposiums). Geneticists and neuroscientists have been invited to their symposiums and the associations have favored the

funding of research in genetics and neurosciences. If autism is hereditary, parents may feel guilty and responsible but only a small number of cases of autism are diagnosed as having a genetic disease, and it is not always hereditary (sporadic mutations). In our sample, 5 cases out of 200 were found to have chromosome abnormalities (probably not transmitted but acquired). In addition, the feeling of guilt is not the same as being accused of bad parenting.

Under pressure from parent associations, early detection has become established and autism has become a public health problem. Parent associations diffused information among parents. The increased level of public awareness and the work of parent organizations have changed the way parents react to diagnoses and altered professional practices. Liu et al. (2010) have shown that the diffusion of information simultaneously contributed to increased prevalence, spatial clustering, and earlier age at diagnosis.

As in Landsman's study (2003), we noted that the discourse among parents was of three types: 1°) the discourse of popular culture presenting childhood disability as a tragedy; 2°) the discourse of the medical model defining autism as a pathology; 3°) the "heroic" discourse of progress and integration (predominant in parents from support groups after the 1990s). The discourse of disability rights activism is almost absent in France (Chamak 2010). In the case of autism, the French association of autistic persons aims to help autistic persons and their families whereas the international activist movements define autism as another mode of functioning, and stress the positive and creative features associated with "neurodiversity" (Baker 2011; Chamak 2010; Orsini and Smith 2010; Ortega 2009; Singer 2003). Alternative narratives that recognize diversity are still unusual in France compared to the UK (Fisher and Goodley 2007) because disability studies and the disability movement have not developed (Chamak 2010). This context influences the attitudes of parents. According to the interviews and the responses to the questionnaire, only very few French parents have integrated the social model of disability.

However, in the 2000s, French parents who have children able to speak are not in agreement with the dominant societal and cultural narrative defining autism as a tragedy. Their narratives are organized by notions of identity and reconstruction. They sometimes develop counter-narratives which, at times, go against the medical model and enable parents to enjoy their children as they are (Fisher and Goodley 2007). Although these narratives incorporate a medical diagnosis and explanation regarding their children, this shapes, but does not define, their experience of impairment. They make choices among the different medical discourses. Medical information is mobilized in ways that sustain and support a narrative of social integration and parenting skills (Kelly 2005).

### **Conclusion**

Diagnoses are the product of the instruments available (standardized interviews with parents and psychological tests), of societal values, and of cultural difference at a specific time, and emerge as individuals, professions and society modify the boundaries of what they consider normal or problematic. Aronowitz (2001, p. 803) argues that “although biological and clinical factors have set boundaries for which symptoms might plausibly be linked in a disease concept, social influences have largely determined which symptom clusters have become diseases”. Diagnostic classification meets a range of needs, from health data collection to the determination of treatment protocols, health services, and marketing strategy (Aronowitz 2008; Bowker and Star 1999). The act of diagnosis structures practice, confers social approval on the particular status of illness, and serves bureaucratic approaches (Rosenberg 2002). The organization of disease into discrete categories is consistent with bureaucratic imperatives in a variety of contexts, ranging from life and health insurance to epidemiological, public health and policy debates (Rosenberg 2002).

Over recent years, disease advocacy groups have flourished, all lobbying for social acceptance and support for research (Rosenberg 2002). Brown et al. (2011, p. 940) underlined

that a disconnection between the medical explanatory model and the patient can lead to “a collective work to politicize the illness through social movements.” A disconnection has been evidenced between the experiences of parents with autistic children and the interpretations and practices of child psychiatrists in France, leading to an activist movement that has succeeded in reshaping beliefs and practices in diagnosis, etiology, and treatment for autism.

The data obtained in France enables better understanding of the reasons why the parents sought to speed up changes, and supports the notion that the diagnosis of autism is historically and nationally contingent. Diagnosis has changed over time as a result of the tensions between parents and professionals, and intra-professional debates in psychiatry. The new classifications have widened the diagnostic criteria for autism, and professionals have changed their practices, although with varying degrees of resistance according to the country. The changes have been prompted by lay demand and new cultural attitudes. The case of France illustrates how social forces can change diagnostic classification, representations, and therapies.

The broadening of diagnostic criteria is not specific to autism. A number of researchers have shown how the new classifications of diseases have modified the way we apprehend mental pathologies by focusing on behaviors and widening the diagnostic criteria for bipolar syndrome, autism, hyperactivity, social phobia, etc. (Kirk and Kutchins 1992; Hacking 1999; Ehrenberg and Lovell 2001, Horwitz 2002; Rose 2003; Scott 2006). Like autism, the example of Attention Deficit Hyperactivity Disorder illustrates the intertwined roles of clinicians, experts, parent associations, school, industry and institutions in the rise in prevalence, changes in definition of disorders and professional practices (Singh 2008). According to the era, ideas about what counts as health and disease have evolved to fit changes in value judgments and therapeutic options available. The new international associations of autistic people try to redefine autism as a difference (Baker 2011; Chamak

2008, 2010; Orsini and Smith 2010; Ortega 2009; Silverman 2008; Sinclair 1992). Will they succeed in changing the classification, representations of autism, and services?

The diagnosis of Asperger's syndrome illustrates the looping effects proposed by Ian Hacking (1995) since it can alter understanding and representation of the people diagnosed. Indeed, the proliferation of personal accounts of individuals who have voluntarily adopted the label of Asperger's syndrome challenges the medical model by defining the condition not as a disorder but as a neurological difference. Conversely, stigmatization can be enhanced when children and teenagers who were previously considered eccentric, odd but gifted, are now viewed as suffering from an autistic disorder (Molloy and Vasil 2002). In a draft released February 2010, the American Psychiatric Association's DSM-5 has proposed to eliminate the diagnosis of Asperger's syndrome, and instead to group it together with autism into a single broad category: Autism Spectrum Disorders. Catherine Lord, a DSM-5 working group member, explained that no differences were evidenced between those diagnosed as AS and those with mild forms of autism (Wallis 2009). However, how can the merging with the severe forms be explained? Professionals including Baron-Cohen (2009) and certain associations of individuals with Asperger's syndrome did not agree with this proposal. Fred Volkmar left the DSM-5 working group in 2009, considering that the ASD label do not enable differentiation between AS and severe forms of autism. In a study published in 2012, he and his colleagues showed that the new DSM-5 criteria will exclude people with cognitive abilities in need of services, who will be no longer able to obtain them (McPartland et al. 2012). Parents generally seek diagnosis because they hope that the identification and classification of a set of symptoms will be followed by treatment, interventions, or social support that will ultimately lead to improving the situation of the children and their families. In France, diagnostic practices have evolved and more children are being identified as autistic,

but the services and interventions for these children and their families have not increased in proportion to the increase in diagnoses (authors, unpublished data).

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