



HAL
open science

The autism diagnostic experiences of French parents.

Brigitte Chamak, Béatrice Bonniau, Lila Oudaya, Alain Ehrenberg

► **To cite this version:**

Brigitte Chamak, Béatrice Bonniau, Lila Oudaya, Alain Ehrenberg. The autism diagnostic experiences of French parents.. *Autism*, 2011, 15, pp.83-97. 10.1177/1362361309354756 . halshs-00717651

HAL Id: halshs-00717651

<https://shs.hal.science/halshs-00717651>

Submitted on 14 Jan 2022

HAL is a multi-disciplinary open access archive for the deposit and dissemination of scientific research documents, whether they are published or not. The documents may come from teaching and research institutions in France or abroad, or from public or private research centers.

L'archive ouverte pluridisciplinaire **HAL**, est destinée au dépôt et à la diffusion de documents scientifiques de niveau recherche, publiés ou non, émanant des établissements d'enseignement et de recherche français ou étrangers, des laboratoires publics ou privés.

The autism diagnostic experiences of French parents



BRIGITTE CHAMAK Université Paris Descartes and INSERM,
Université Paris Descartes, France

BÉATRICE BONNIAU Université Paris Descartes and
INSERM, Université Paris Descartes, France

LILA OUDAYA Université Paris Descartes, France

ALAIN EHRENBURG Université Paris Descartes and CNRS,
Université Paris Descartes, France

ABSTRACT This survey focused on French parents' views of the diagnostic process relating to their child with autism. Data were collected on the age at diagnosis, the time taken to obtain a diagnosis and the difficulties encountered. Questionnaires filled in by the parents ($n = 248$) and in-depth interviews ($n = 43$) were analyzed in order to obtain quantitative and qualitative results. The ages of the children ranged from 4 to 45. This approach enabled us to compare the practices of professionals now and in the past. The mean age of diagnosis was 10 ± 8 years from 1960 to 1990, 5 ± 3 years from 1990 to 2005 (3 ± 1 from 2003 to 2005). The results showed that the mean delays between first consultation and diagnosis were reduced. Regarding the way the diagnosis was announced, 63% of the parents of children with autism and 93% of the parents of adults with autism were dissatisfied. We discuss the parents' reactions and the changes in the diagnostic process.

KEYWORDS

autism;
diagnosis;
French
diagnostic
system;
parents'
perceptions;
changes in
the diagnostic
process

ADDRESS Correspondence should be addressed to BRIGITTE CHAMAK, CERMES 3 (Centre de Recherche Médecine, Sciences, Santé, Santé mentale et Société) CESAMES – INSERM U 988 - CNRS UMR 8211- EHESS, Université Paris Descartes, 45 rue des Saints-Pères 75270 cedex 06, France. e-mail: brigitte.chamak@parisdescartes.fr

For a long time, French psychiatrists have been reluctant to give a diagnosis of autism (Chamak, 2008, 2009). This position was strengthened by the fact that it was possible to access services even if parents had not received this diagnosis for their child. The French Classification of Mental Troubles in Children and Adolescents (CFTMEA) defined the different forms of autism as early psychoses. In the revised version published in 2000, the expression 'Pervasive Developmental Disorders' (PDD) was introduced as an equivalent to early psychoses. This classification has been adopted by most child

psychiatrists along with a very heterogeneous diagnostic process. Only regional centres specialised in autism and researchers have used the international classification (ICD-10) and standardized instruments.

For more than ten years, the families have expressed their difficulties in obtaining the diagnosis of autism. The recent recommendations of the Haute Autorité de Santé (HAS) published in June 2005 aim to improve the diagnostic process in France. The main points concern the recommendations for an early diagnosis, the use of ICD-10 and standardised assessment instruments (Baghdadli et al., 2006). The current retrospective study was performed to analyse the difficulties encountered by French parents in obtaining a diagnosis, and to compare the practices of the professionals now and in the past. Our study is unique in France since it explores a population from 4 to 45 years of age, and thus enables us to evaluate the improvements as well as ongoing problems.

In the UK, a survey indicated that 49% of the parents were not satisfied with the diagnostic process (Howlin and Moore, 1997). Results obtained at the end of the 90's showed that children were diagnosed earlier than in previous decades, but the mean age at diagnosis was around 6 and many parents were still experiencing lengthy delays before they finally received a diagnosis. More recently, a study realized in Doncaster by Keen and Ward (2004) found that the mean age at diagnosis fell from 11.7 years for 1983 births to 3.5 years for 1995 births. The number of recorded diagnoses doubled over a 4-year period. This appeared to be due to a greater recognition of ASD among more able children. The data obtained in the South Wales valleys (Latif and Williams, 2007) evidenced a decrease in the mean age at diagnosis for the autism spectrum disorder (ASD) from 5.9 in the period 1994–1998 to 5.5 in the period 1999–2003. Most of the parents wished for a quicker and easier process as illustrated by a study with fifteen focus groups conducted across a range of locations in England (Osborne and Reed, 2008). However, early diagnosis may be associated with greater levels of potential parenting stress (Osborne et al., 2008b) and presents new challenges to clinical practice, including the accuracy and stability of early diagnosis (Charman and Baird, 2002). In a sample of 126 Scottish parents, 55% indicated that they were satisfied or very satisfied with the diagnostic process (Brogan and Knussen, 2003).

A web-based study conducted in the United States (Goin-Kochel et al., 2006) pointed out that just over 40% of the 494 participants were not satisfied with the diagnostic process, despite the fact that the diagnostic age is decreasing. They found that the average age at diagnosis was 4.5 years but differed according to diagnosis: 7.5 years for Asperger syndrome, 4.2 for pervasive developmental disorder not otherwise specified (PDD-NOS) and 3.4 for autism. A survey in Pennsylvania (Mandell et al., 2005) evidenced

that the average age at diagnosis was 3.1 years for children with autistic disorder, 3.9 years for PDD-NOS, and 7.2 years for Asperger syndrome.

In Canada, Siklos and Kerns (2007) analysed the difficulties of fifty-six parents in obtaining a diagnosis for their child. The parents saw an average of 4.5 professionals, and waited almost 3 years to receive a diagnosis following their first visit to a professional. The data obtained in Quebec by Poirier and Goupil (2008) with the parents of 92 autistic people indicated a general satisfaction regarding the diagnostic process. The mean age at diagnosis was 5.8 and 3.5 for children less than 7 years. However, half the participants thought the information transmitted had to be improved.

In France, we could not find similar studies. Baghdadli et al. (2003) examined the relationship between age of recognition of the first disturbances and severity of autism for 193 children under age 7. However, the difficulties encountered by parents in obtaining a diagnosis for their child have not been explored. A recent survey by a French Regional Centre for disabled children (Naroun and Kroichvili, 2006) was carried out with families in Normandy, showing that almost 4 parents out of 10 considered that the diagnosis of autism was not made explicit. More than one third was dissatisfied with the information and guidance provided. Half the parents considered they were given no choice in the decision making at the various stages of their child's life. All these hurdles caused considerable discontent among the parents and parents' associations (Chamak, 2008). This study was performed to explore the difficulties for parents in obtaining a diagnosis and their reactions when they received it. Parents play a pivotal role in the prospects for the child with ASD. Osborne et al. (2008a) demonstrate a strong relationship between parenting stress and later child progress in children undergoing intervention programs. In the current study, parents' reactions to diagnosis, and their level of satisfaction with the diagnostic process were analysed. Another aim of the retrospective study was to compare the parents' experiences now and in the past in France. Over the last fifteen years, professionals' practices and the diagnostic system have dramatically evolved under pressure from parents' associations and public policy (Chamak, 2008). By using questionnaires, interviews and mail exchanges, we obtained data enabling us to compare parents' experiences from 1960 to 2005.

Method

Recruitment

In order to obtain data from parents of adults and young children with ASD living in France, we contacted parents' associations as well as child psychiatrists and care units dedicated to autistic children nationwide. We invited

them to distribute a letter and a questionnaire to assess the parents' experiences when obtaining the diagnosis of autism for their child. The letter outlined the purpose and nature of the survey and five samples of the questionnaires were sent out either by post with pre-paid, addressed return envelopes for parents or attached files by email. In the letter, we indicated that parents could contact us (first author's email address) to obtain the attached file or to fill it in directly on the Internet (<http://www.cesames.org/spip/IMG/pdf/Qparents8.pdf>). We sent 100 packages by post (in total 500 questionnaires) to the child psychiatrists and care units, and 52 parents' associations were contacted; 42 received packages by post (200 questionnaires) and 10 by email. Local autistic societies and support groups cooperated in the survey by distributing the information letter and the self-report questionnaires to their members or by indicating in their website how to contact us.

The participants were drawn from the population of mothers and fathers of children with ASD, including Asperger syndrome: 248 questionnaires filled in by parents were obtained from all over France between 2005 and 2006 (90 questionnaires were received by email): 51% from support groups, 37% from psychiatrists and care units, and 12% from the Internet. One item in the questionnaire enabled us to know how parents had obtained the questionnaire. The choice to distribute the questionnaire widely (not just in hospital units) made it possible to obtain reports from parents of adults as well as of children. Some parents spontaneously contacted us after seeing the announcement of the survey in a support group's website. The lower response rate was obtained from psychiatrists and care units because the questionnaires had not been systematically distributed to parents. The most represented regions were the densely populated areas: Paris-Ile de France and Rhône-Alpes. No questionnaire was received from those regions with a low population density: Auvergne, Picardie, and Poitou-Charentes.

Questionnaire and interviews

The questionnaire was designed to assess the various experiences of parents in obtaining a diagnosis of autism for their child and to get quantitative and qualitative data. It includes both forced choice and open-ended questions. It covers parents' demographic variables, child's age when parents first became concerned, the reasons for the concerns, who was concerned first, child's age when help was sought, the professionals consulted, the different diagnoses obtained, the precise terms used, the parents' reactions to diagnosis, the level of satisfaction with the diagnostic process and the reasons for the satisfaction or dissatisfaction.

The open-ended questions enabled us to get more personal information than we could have with forced-choice questions. The general principle

underlying coding of responses was to transform each answer into a set of categories that enabled both qualitative and quantitative treatment. For example, parents' reactions to diagnosis were coded in five categories: 1) negative effects when the terms 'distress', 'feeling of helplessness', 'despair', 'guilty', 'depression', 'dejection' were used; 2) positive effects ('relief', 'to put a name on the difficulties of my child at last', 'understanding', 'confirmation of what I already knew', 'explanation for the family at last', 'liberating announcement', 'certainty and not questioning', 'I understand at last' . . .); 3) positive/negative effects when parents expressed mixed emotions; 4) perplexity, questioning when the terms used were 'perplexity', 'incredulity', 'indescribable'; 5) no effect when the parents say that they were not affected (because they knew it). Two members involved in the study were in charge of the coding independently in order to compare the results and clear some ambiguities. Regarding the parents' first concerns, the answers were coded in 11 categories of symptoms (Figure 1) for 195 children (5 NR). When both parents filled in a questionnaire, if the father's concerns were different from the mother's, they were added to hers. In some cases we had to interpret some ambiguous assertions since our analysis was based on the spontaneous parents' discourse. We then decided that a single sentence could refer to several categories (i.e., 'do not communicate' could be related to both communication deficit and social skill deficit).

All the questionnaires were captured in the Modalisa software which enables quantitative and qualitative treatments (www.modalisa.com). For 48 families, the questionnaires were filled in by both mothers and fathers (in total 96 questionnaires, since two questionnaires were completed separately as we indicated in the information letter), we used mothers' responses for the data concerning the child (age, first difficulties, age of the diagnosis, et cetera).

We had the possibility to contact most parents since 76% had given their telephone number or email address and their consent to answer questions: 142 families were contacted by phone or email to complete the questionnaires when we found no answer to some questions; 104 answered. Out of the 104 families, we divided the questionnaires into two groups, those filled in by the parents of autistic children and those by the parents of autistic adults, and we randomly selected 20 from each group for face-to-face in-depth interviews (20 from Paris and suburbs, 10 from the Rhône-Alpes and 10 from other regions). The interviews were audiotaped with the parents' agreement and were then transcribed. We asked for details concerning the history of the child's development, the parents' experiences in obtaining the diagnosis of autism for their child, and their feelings. Parents were encouraged to talk freely about their experiences. We conducted in-depth interviews with 37 mothers and 6 fathers using grounded theory

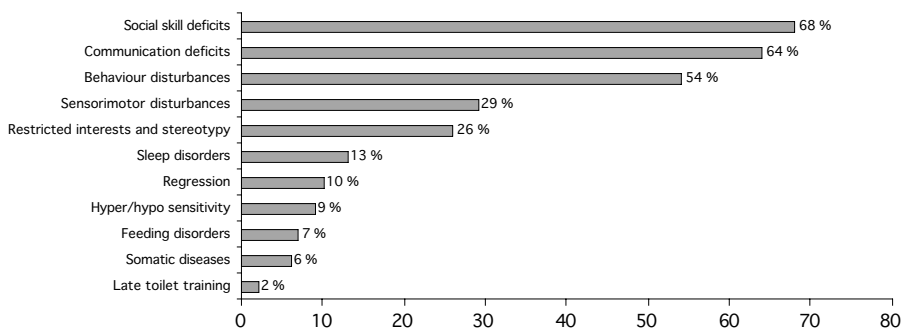


Figure 1 First symptoms alerting parental concern

(Strauss and Corbin, 1990). This approach enabled us to obtain data for questions with no answer in the questionnaires and to better understand the parents' experiences. We wanted to check the relevance and the accuracy of the questionnaires and obtained more information to assess the parents' perceptions and reactions. The interviews will be further analysed for another publication considering the huge amount of data.

Results

Parents' profiles

The majority of the respondents were mothers. Four mothers had two autistic children and filled in two questionnaires, one for each child. Out of the 248 questionnaires, 175 were filled in by the mothers (71%), and 73 by the fathers (29%), 123 were filled in by the mothers only (50%), 25 by the fathers only (10%), and 48 couples filled in two questionnaires. The parents belonged to all socioeconomic groups (Table 1) but the comparison with the general population indicated that there is an over-representation of higher socioeconomic status.

Autistic person's profiles

Of the 200 autistic persons from age 4 to 45 included in the study (9.5% from 4 to 5, 39% from 6 to 12, 18.5% from 13 to 17, 33%, 75% were male (Table 1). The age of each child at the time of data collection was calculated as the age on 31 December 2006. With regard to the autistic severity, 60% presented severe autism, 19% moderate autism, 21% had received a diagnosis of high-functioning autism or Asperger syndrome (Table 1). More than 68% of the autistic females presented severe autism compared to 51% of the males. The severity of autism was determined according to parents' reports including professionals' terms reported by the

Table 1 Sample characteristics

	n		%	
	<i>Mothers</i>		<i>Fathers</i>	
<i>Parents (4 families have 2 autistic children)</i>	171	70	73	30
<i>Years</i>				
20–30	5	2.9	1	1.4
31–40	73	42.7	21	28.8
41–50	54	31.6	23	31.5
51–60	22	12.9	15	20.5
> 60	17	9.9	13	17.8
<i>Social class</i>				
A: managers, engineers, doctors	38	22	24	33
B: technicians, clerks, service and sales workers	40	23.5	24	33
C: agricultural workers, craft and related trades Workers, low qualified occupations	11	6.5	8	11
D: housewives, old age pensioners, unemployed	81	47.5	13	18
NR	1	0.5	4	5
<i>Children</i>	<i>Female</i>		<i>Male</i>	
	51	25	149	75
<i>Years</i>				
4–5	4	7.8	15	10.1
6–12	14	27.5	64	42.9
13–17	12	23.5	25	16.8
≤ 18	21	41.2	45	30.2
<i>Autistic severity</i>				
Severe autism	35	68.6	76	51
Moderate autism	6	11.8	29	19.5
High functioning autism and Asperger's syndrome	6	11.8	33	22
NR	4	7.8	11	7.4

parents, persisting lack of language in adolescence and adulthood, and the type of services and care units. Epilepsy has been detected for 10% of the patients, genetic diseases for 3% (50% of the children had EEG; 25% genetic tests; 10% MRI).

First difficulties reported by the parents

Impairments in social, play and communication skills (the children tended to less frequently look at others, turn towards the person who called them, combine eye contact with smiling, and vocalize in a communicative manner), behaviour disturbances and sensorimotor peculiarities are among the earliest symptoms to be noted (Figure 1). Failure to respond to name

and quality of eye contact were the signs most frequently pointed out by the parents. In 10% of cases, parents spontaneously noted regression of skills. They reported that their children acquired words, maintained eye contact, and then lost these skills when they were about 2.

Age at first concern

The parents detected the first signs of autism before the age of 2 for 82% of the 196 children (4 out of 200 were not taken into account because they had been adopted). Worries typically began around 18 months of age (Table 2). In our sample, 19 out of the 196 children displayed signs which were a cause of concern for their parents at birth (8 girls, 10 boys).

First consultation and first professionals contacted

The average age of the child when parents first sought help was 26 months (SD 15): 20% before 1 year of age, 40% between 1 and 2 years, 29% between 2 and 3, 9% between 3 and 4, and 2% after 4. The first professionals from whom parents sought help were paediatricians (42.5%), psychiatrists (23%) and GPs (17.5%). Several families saw various combinations of professionals. It is not unusual that when the mothers expressed concerns about their child's development to their paediatricians, they were told not to worry, to wait and see (interviews). Parents' anxiety can sometimes be dismissed by some professionals as being without foundation, or else behavioural problems could be attributed to inadequate parenting. Generally, it is not a paediatrician who gave the diagnosis but a child psychiatrist (83.5%), and the first specialist approached was often reluctant to give a firm diagnosis, especially when the child was still very young.

Diagnostic process from 1960 to 1990

Among the 66 autistic persons (18–45) who were born before 1988, 21 did not receive a diagnosis of autism in France (32%), 8 obtained it when they were adults (12%), 29 obtained it before the age of 10 (44%), and

Table 2 Age of first concern

Age of children (y) Mean age: 1.5 (SD 1)	Children	
	n(N = 196)	%
0	19	10
≤ 1	56	28
1–2	87	44
2–3	27	14
3–4	7	4

only 19 before the age of 5 (29%). Even though the parents did not receive a formal diagnosis of autism in France, they sometimes obtained it abroad (in the UK, U.S. or Canada), or informally by professionals in charge of their children, or even implicitly because their children were put in the care of specialised centres for autism (one family read it in the child's health records). The practices were extremely diverse: the mean age at diagnosis was 10 ± 8 years (from 0.5 to 33). The delays between the first consultation and the diagnosis given to the parents varied between 0 and 30 years (Table 3).

When the parents were not given a diagnosis of autism, the terms used by the professionals according to the questionnaires filled in by parents were as follows: child psychosis, personality disorder, mental handicap, disabled, serious personality disorder, brain malformation, mental retardation, bad understanding between the mother and the foetus. The parents quoted in the questionnaires some sentences which shocked them: 'severe psychosis, he's beyond redemption' (1965); 'Your son is imbecile, from Latin 'imbecilus', which means idiot. We will do as a tailor who has to make a suit with a bad material' (1968); 'If the mother gets better, the child will be cured' (1969); 'It's a severe disease: autism. It would be better to abandon your child' (1988).

Ninety three percent of the parents of adults (75/81) were dissatisfied with the diagnostic process because of long delays in obtaining the diagnosis and a blunt announcement without care or consideration sometimes enhancing feelings of guilt. A majority of the parents in our sample faced difficulties in obtaining the diagnosis for their children: no diagnosis, diagnosis changes, diagnosis obtained abroad, a long and exhausting quest. Among those who agreed to be interviewed, some explained that the diagnosis was communicated in a place where they could be overheard despite the fact that they would have preferred the consultation to be held in private. In only a minority of cases, both parents were present at the consultation.

Diagnostic process from 1990 to 2005

For the 134 autistic children (age 4–17) who were born after 1988, 16 did not receive a diagnosis of autism (12%). Instead other terms were used:

Table 3 Mean age at diagnosis and mean delays between the first consultation and the diagnosis

Age groups	n	Age at diagnosis [y] (SD)	Mean delays [y] (SD)	No diagnosis (n)
4–5	19	2.8 (0.75)	1.2 (0.7)	2
6–12	78	4.5 (2)	3 (1.75)	6
13–17	37	6.5 (4)	5.3 (2.5)	8
≥ 18	66	10 (8)	8.7 (10.75)	21

child psychosis, psychotic disharmony, disabled, developmental retardation, communication problem, language and communication difficulties. Among those who obtained the diagnosis of autism or pervasive developmental disorder (PDD), the terms reported in the questionnaires were autism, autistic spectrum, autistic features, autistic behaviours, PDD, atypical autism, Asperger syndrome, autistic withdrawal, and autistic syndrome. Four of them were not given the diagnosis directly but read it in their child's health records or in a letter addressed to another professional.

The mean age for the diagnosis was 5 ± 3 for children and adolescents. The delays between the first consultation and the diagnosis given to the parents varied between 0 and 11 years (for a 14-year-old boy with Asperger syndrome). For the children born from 2000 to 2002 ($n = 30$), the mean age for the diagnosis was 3 ± 1 .

Compared to the questionnaires from parents of adults, the shocking examples quoted by the parents were rare, demonstrating an improvement in practice. The satisfied families mentioned a feeling of being respected, the fact that professionals gave them time, the doctor's open mindedness, directness and sympathetic understanding. Nevertheless, 63% of the parents expressed dissatisfaction (102/162). Even if psychiatrists are less reluctant to use the term 'autism', parents complain about the lack of information and help. More and more parents ask for educational methods and school integration. The age at diagnosis has decreased steadily over the years (Table 3). However, 8% from the 6–12 age group (6/78) and 22% from the 13–17 age group (8/37) have not yet received diagnoses in our sample and doctors often did not check whether parents had understood their initial explanation and whether more time and repetition would have been helpful (some parents believed 'autism' meant 'a problem of hearing'). Mostly, the referral process involved contacts with a large number of professionals. One of the mothers of a 4-year-old boy testified (phone interview):

The first difficulties appeared when my son was 18 months old (tantrums when changes occurred, repetitive games, hyperactivity), I talked to my paediatrician who told me there was nothing to worry about. I made an appointment with a psychologist who asked me whether I was sad, whether I played with him. I consulted a well-known psychoanalyst. He told me that my son was fine and that I was the problem. I did research on the Internet in order to get advice and I came across the description of a young girl with autism who had the same difficulties as my son. I made an appointment at a specialised centre and was given the diagnosis of PDD.

Although the fathers occasionally accompanied mothers to these appointments, it was usually the mothers who had this responsibility.

Parents' feelings regarding the diagnostic disclosure process

While the parents often felt relieved (43%) when they obtained the diagnosis for their children at the age of 4 or more, the majority of parents (75%) had difficulties accepting it when the child was younger than 4. The relief is associated with the feeling that they have obtained an answer to their questions or a confirmation, and the means to get information and services. The process of receiving an ASD diagnosis leads to mixed emotions. It was considered as positive by 40% of the parents, and 17% expressed mixed emotions. Among those who described negative feelings ('I was in very low spirits', 'It was quite a blow', 'breakdown', 'sadness, anger, feeling of powerlessness', 'dismay', 'difficulties to accept the differences of my child', 'distress', 'it was very hard', 'deep sorrow'), some (4%) read the diagnosis in their child's health records or in letters addressed to other doctors.

Discussion

Parents are usually well aware of problems related to their child's development before the second year of life. Despite this, many families have to wait for years before they obtain a diagnosis. These results were supported by previous accounts in different countries (Frith et al., 1993; Gray, 1994; Smith et al., 1994; De Giacomo and Fombonne, 1998; Howlin and Asgharian, 1999; Goin-Kochel et al., 2006). All indicate that in the case of autism spectrum disorders generally, parents first become aware of their child's difficulties when the child is 18 or 19 months of age. In France, we found that the age of children when the parents first suspected that something was wrong was around 18 months. In a French study with children under 7, Baghdadli et al. (2003) pointed out that, on average, parents recognised disturbances when their child was 17 months old.

In our study, children who were adults at the time of the survey had not, on average, been diagnosed until they were around 10, whereas children who are now below 10 are being diagnosed before their fourth birthday. The last result was obtained in the UK ten years ago by Howlin and Moore (1997), indicating a significant 10-year gap between the UK and France. However, some regional child psychiatry hospital units that specialise in autism, such as in Montpellier, Paris, and Tours, have provided high-quality evaluations and services since the beginning of the 1990s (Adrien et al., 2001; Baghdadli et al., 2006; Barthélémy et al., 1992). Thanks to the actions of parents' associations, there has been a growing awareness of the necessary efforts to be carried out in the field of autism in France. Since 1999, new regional centres have been set up to improve early diagnosis and services for autistic children and the HAS recommendations in 2005 have

changed diagnostic practices. Nevertheless, many parents and parents' associations are dissatisfied (Chamak, 2008). They ask for earlier diagnosis, appropriate educational approaches and integration into mainstream schools. They need to obtain an early diagnosis in order to find other solutions than those proposed by some psychiatrists.

Currently, the diagnosis is obtained earlier than in previous decades but 8% among the 6–12 age group and 22% among the 13–17 age group had not yet received diagnosis in our sample. Some barriers to early and appropriate diagnosis remain. Psychiatrists with a psychoanalytic background were often reluctant to give an autism diagnosis to parents (Chamak, 2008). They considered it could prevent the therapeutic process of their patient and might be too stressful for the parents. Despite increasing pressure to provide early diagnosis, Osborne et al. (2008b) showed that an early diagnosis may be associated with a greater level of potential parenting stress, which can negatively impact the prospective outcomes of the child with autism. Some parents may require a longer period of time to elapse before they receive a diagnosis of ASD for their child. We demonstrated that those who obtained a diagnosis when their child was younger than 4 often had negative feelings. They described reactions of disbelief, shock and anger.

In most cases, the diagnosis provides a degree of explanation for the behaviour of the child, and helps parents accept that they are not to blame for the condition. Many parents are relieved that someone else could corroborate what they initially suspected (Midence and O'Neill, 1999; Mansell and Morris, 2004; Sullivan, 1997). The longer the delay in obtaining the diagnosis of autism the stronger the feeling of relief expressed by the parents. The way the diagnosis is announced to the parents by the professionals is also a crucial point. More consideration and care are necessary and it is essential to be given sufficient time for explanations (Brogan and Knussen, 2003). This is not always the case, as illustrated by the parents' reports of being dissatisfied with the way the diagnosis is initially communicated. Like the parents of children with life threatening or terminal illness (Wooley et al., 1989), some parents are still feeling the impact, remembering every word in detail, the expressions, the manner and the style of delivery. The dissatisfaction is higher for the parents whose children are now adults. Thus, improvement is clear regarding the age at diagnosis as well as the way the diagnosis is announced but there still are problems to be addressed.

Communicating the diagnosis of their child's autism to the parents is a harsh task for professionals faced with the difficulty of delivering the bad news (Wooley et al., 1989; Sharp et al., 1992; Bartolo, 2002). It often puts families under great stress (Osborne and Reed, 2008; Osborne et al., 2008b). The trauma of learning the diagnosis may vary according to the manner of the teller (Wooley et al., 1989; Sloper and Turner, 1993). Many

families thought that the manner in which this was done had affected their ability to cope with their child's autism. Being told the diagnosis directly, with a large amount of information and help, contributes to decrease the high degree of stress that parents experience when facing the disclosure of their child's diagnosis (Hasnat and Graves, 2000; Osborne and Reed, 2008). When the information was repeated, clarified, and explained in straightforward language, and when a list of support services was given, parents felt more able to accept the diagnosis.

As with any survey, the findings need to be treated with caution. First, the rate of returns, although impossible to estimate exactly, is less than 50%. Second, retrospective reports are prone to errors and it was not possible to check the accuracy of the diagnostic labels reported by the parents. Nevertheless, many of the findings are supported by other studies in different countries and the interest of this work is to be found in the association of both quantitative and qualitative approach. Comparing the past and present situations in France with the same methodology lies at the core of this study, which provides data for a comparison with diagnostic systems in other countries.

Acknowledgements

This research was supported by the Fondation de France, the 'Institut National de la Santé et de la Recherche Médicale' (INSERM), Paris Descartes University, and the Centre National de la Recherche Scientifique (CNRS). We wish to thank Pr A. Danion and Dr V. Pascal from Louis Pasteur University (IRIST-Strasbourg) for their participation in the conception and the distribution of the questionnaire, as well as Pr. David Cohen from Pitié-Salpêtrière Hospital. We are particularly grateful to the associations of parents who agreed to distribute the questionnaires and to the parents who took the time to fill in the questionnaires and answer our questions. We are thankful to Béatrice Berna and Martine Chauffeté, English teachers from Paris Descartes University, for their corrections. We would like to express our sincere thanks to the Referees and the Editor for their helpful suggestions that enabled us to improve our manuscript.

References

- Adrien, J.L., Roux, S., Couturier, G., Malvy, J., Guerin, P., Debuly, S., et al. (2001) 'Towards a New Functional Assessment of Autistic Dysfunction in Children with Developmental Disorders: The Behaviour Function Inventory', *Autism* 5(3): 249–64.
- Baghdadli, A., Beuzon, S., Bursztejn, C., Constant, J., Desguerre, I., Roge, B., et al. (2006) 'Clinical Guidelines for the Screening and the Diagnosis of Autism and Pervasive Developmental Disorders', *Archives de Pédiatrie* 13(4): 373–78.
- Baghdadli, A., Picot, M.C., Pascal, C., Pry, R. & Aussilloux, C. (2003) 'Relationship

- between Age of Recognition of First Disturbances and Severity in Young Children with Autism', *European Child & Adolescent Psychiatry* 12(3): 122–27.
- Barthélémy, C., Adrien, J.L., Roux, S., Garreau, B., Perrot, A. & Lelord, G. (1992) 'Sensitivity and Specificity of the Behavioral Summarized Evaluation (BSE) for the Assessment of Autistic Behaviors', *Journal of Autism and Developmental Disorders* 22(1): 23–31.
- Bartolo, P.A. (2002) 'Communicating a Diagnosis of Developmental Disability to Parents: Multiprofessional Negotiation Frameworks', *Child: Care, Health and Development* 28(1): 65–71.
- Brogan, C.A. & Knussen, C. (2003) 'The Disclosure of a Diagnosis of an Autistic Spectrum Disorder: Determinants of Satisfaction in a Sample of Scottish Parents', *Autism* 7(1): 31–46.
- Chamak, B. (2008) 'Autism and Social Movements: French Parents' Associations and International Autistic Individuals' Organizations', *Sociology of Health & Illness* 30(1): 76–96.
- Chamak, B. (2009) 'L'autisme dans un service de pédopsychiatrie' [Autism in a child psychiatrist unit], *Ethnologie française* 3: 425–33.
- Charman, T. & Baird, G. (2002) 'Practitioner Review: Diagnosis of Autism Spectrum Disorder in 2- and 3-Year-Old Children', *Journal of Child Psychology and Psychiatry* 43(3): 289–305.
- De Giacomo, A. & Fombonne, E. (1998) 'Parental Recognition of Developmental Abnormalities in Autism', *European Child & Adolescent Psychiatry* 7(3): 131–36.
- Frith, U., Soares, I. & Wing, L. (1993) 'Research into the Earliest Detectable Signs of Autism: What Parents Say', *Communication* 27(3): 17–18.
- Goin-Kochel, R.P., Mackintosh, V.H. & Myers, B. (2006) 'How Many Doctors Does it Take to Make an Autism Spectrum Diagnosis?' *Autism* 10(5): 439–51.
- Gray, D.E. (1994) 'Coping with Autism: Stresses and Strategies', *Sociology of Health and Illness* 16(3): 275–300.
- Hasnat, M.J. & Graves, P. (2000) 'Disclosure of Developmental Disability: A Study of Parent Satisfaction and the Determinants of Satisfaction', *Journal of Paediatrics and Child Health* 36(1): 32–35.
- Howlin, P. & Asgharian, A. (1999) 'The Diagnosis of Autism and Asperger Syndrome: Findings from a Survey of 770 Families', *Developmental Medicine and Child Neurology* 41(12): 834–39.
- Howlin, P. & Moore, A. (1997) 'Diagnosis of Autism', *Autism* 1(2): 135–62.
- Keen, D. & Ward, S. (2004) 'Autistic Spectrum Disorder: A Child Population Profile', *Autism* 8(1): 39–48.
- Latif, A.H.A. & Williams, W.R. (2007) 'Diagnostic Trends in Autistic Spectrum Disorders in the South Wales Valleys', *Autism* 11(6): 479–87.
- Mandell, D.S., Novak, M.M. & Zubritsky, C.D. (2005) 'Factors Associated with Age of Diagnosis among Children with Autism Spectrum Disorders', *Pediatrics* 116(6): 1480–86.
- Mansell, W. & Morris, K. (2004) 'A Survey of Parents' Reactions to the Diagnosis of an Autistic Spectrum Disorder by a Local Service: Access to Information and Use of Services', *Autism* 8(4): 387–407.
- Midence, K. & O'Neill, M. (1999) 'The Experience of Parents in the Diagnosis of Autism: A Pilot Study', *Autism* 3(3): 273–85.
- Naroun, R. & Kroichvili, S. (2006) *Etude Régionale des Besoins et des Attentes: Personnes Atteintes d'Autisme ou de Trouble Envahissant du Développement* [Study of autistic persons' needs in

- Normandy]. Centre Régional d'Etudes et d'Actions pour l'Insertion (CREAI) de Basse Normandie.
- Osborne, L.A., McHugh, L., Saunders, J. & Reed, P. (2008a) 'Parenting Stress Reduces the Effectiveness of Early Teaching Interventions for Autistic Spectrum Disorders', *Journal of Autism & Developmental Disorders* 38(6): 1092–103.
- Osborne, L.A., McHugh, L., Saunders, J. & Reed, P. (2008b) 'A Possible Contraindication for Early Diagnosis of Autistic Spectrum Conditions: Impact on Parenting Stress', *Research in Autism Spectrum Disorders* 2(4): 707–15.
- Osborne, L.A. & Reed, P. (2008) 'Parents' Perceptions of Communication with Professionals During the Diagnosis of Autism', *Autism* 12(3): 309–24.
- Poirier, A. & Goupil, G. (2008) 'Perception des Parents Québécois sur l'Annonce d'un Diagnostic de Trouble Envahissant du Développement' [Perception of parents from Quebec when receiving the diagnosis of pervasive developmental disorders], *Journal on Developmental Disabilities* 14(3): 29–39.
- Sharp, M.C., Strauss, R.P. & Lorch, S.C. (1992) 'Communicating Medical Bad News: Parents Experiences and Preferences', *The Journal of Pediatrics* 121(4): 539–46.
- Siklos, S. & Kerns, K. (2007) 'Assessing the Diagnostic Experiences of a Small Sample of Parents of Children with Autism Spectrum Disorders', *Research in Developmental Disabilities* 28(1): 9–22.
- Sloper, P. & Turner, S. (1993) 'Determinants of Parental Satisfaction with Disclosure of Disability', *Developmental Medicine and Child Neurology* 35(9): 816–25.
- Smith, B., Chung, M.C. & Vostanis, P. (1994) 'The Path to Care in Autism: Is It Better Now?' *Journal of Autism and Developmental Disorders* 24(5): 551–63.
- Strauss, A. & Corbin, J. (1990) *Basics of Quantitative Research: Grounded Theory Procedures and Techniques*. Newbury Park, CA: SAGE.
- Sullivan, R.C. (1997) 'Diagnosis Autism: You Can Handle It!' in D.J. Cohen & F.R. Volkmar (eds) *Handbook of Autism and Pervasive Developmental Disorder*, pp. 1007–20. New York: Wiley.
- Wooley, H., Stein, A., Forrest, G.C. & Baum, J.D. (1989) 'Imparting the Diagnosis of Life Threatening Illness in Children', *British Medical Journal* 298(6688): 1623–26.