THE PREVALENCE ESTIMATES OF AUTISM SPECTRUM DISORDER IN THE SCHOOL POPULATION OF SEVILLE, SPAIN

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Introduction

A primary goal for the planning and development of educational attention measures for people with disabilities is to obtain enough information in order to determine the global volume of the problem that we are dealing with. In this specific case, autism has always been seen as an infrequent clinical phenomenon. As seen in the pioneer research done in this field (Lotter, 1966), the prevalence of autism was studied in a population of 8-10 year-olds and was found to be at 4.5 in 10,000. Other research carried out in Europe and in the USA in later decades offered very similar results ranging in estimated values from 0.7 in 10,000 in the Treffert study (1970) to 5.6 in 10,000 in the study done by Bohman *et al*. (1983). Nevertheless, different studies performed up until the end of the last century show a slow increase in prevalence rates obtained (Bryson and Smith, 1998), ranging from 4.9 in 10,000 (Fombonne and Mazaubrun, 1992) to 9.5 in 10,000 (Gillberg et al., 1991) and have generated a certain controversy on the authenticity of this increase (Bryson, 1996; Fombonne, 1996). A continued increase in this rising tendency has been detected in the studies published starting from the year 2000 in which the proportional rates have reached as high as 30.8 in10,000 (Baird *et al*., 2000).

This steady increase in the estimated autism rate is currently under serious debate. A series of factors that might explain

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this tendency are cited in Wing and Potter (2002) and include: a) changes in the diagnostic criteria, b) the methodological differences of the studies, c) an increase in parental, professional and general population awareness regarding the existence of autism spectrum disorders (ASD), d) a greater recognition regarding the fact that autistic disorders can be associated with severe or profound mental retardation and other physical or developmental disorders, or can be associated with high or normal mental abilities and other psychiatric disorders, e) the development of specialized services, f) possible related causes with the onset age and g) a conceivably real increase in the number of cases.

Clearly, the above mentioned factors have an influence on the results of the studies on prevalence. In the first place, there is a clear relationship among the obtained rates and the diagnostic criteria being used (Lord *et al.*,1994). The studies using the most updated instruments (Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV) and the International Statistical Classification of Diseases and Related Health Problems, 10th revision (ICD-10)) are those that estimate the highest prevalence rates (Wing and Potter, 2002). Secondly, the size and composition of the different samples along with the procedures used in the detection are two methodological decisions that have influenced the sharp increase in the prevalence rates found (Fombonne, 2003). In this sense, taking a closer look at sample size indicates that small sample sizes elevate prevalence rates, while large sample sizes tend to reduce them (Honda *et al.*, 1996). In addition, recent studies (Chakrabarti and Fombonne, 2005) demonstrate that the tendency towards increased to raise the prevalence rates is not actually due to an increase in the incidence of ASD. Therefore, an explanation for this must be found

in the conceptual development of criteria and diagnostics as well as in the improvement of early detection systems.

Thirdly, it is also plausible that variations in the frequency of autism exist with respect to geographic locations and especially in specific ethnic groups. It is interesting to note that studies carried out in Japan show very high prevalence values, for example; 15.5 in10,000 (Matsuishi *et al.*, 1987), to 13.8 in10,000 (Tanoue *et al.*, 1988), 13 in 10,000 (Sugiyama and Abe 1989) and even as high as 21.08 in10,000 (Honda *et al.*, 1996).

The Mercedes Belinchón team (2001) in Spain took a look at the factors predicting prevalence values on previous epidemiological work. Twenty-two variables were analyzed relating to the methodology used in each one of the studies published such as: research collection year, publication year, the continent or country where the study was done, sample size, the sample composition with respect to the number of immigrants, the maximum and minimum ages, the percentage of urban population, the instruments used, and so forth. In conclusion, a regression equation was obtained which identified three variables that were the best predictors of prevalence rates. They were: the maximum age of the participating subjects, the year of the data collection, and the percentage of the population that lived in an urban environment. By using this methodology of analysis, and after applying the regression equation obtained, it was estimated that the average prevalence was 8.34 in10,000 and had a range from 4.96 to 11.7 for each 10,000 babies born. In any case it is clear that, quite different from the initial beliefs, we are not dealing with a minor educational problem with respect to its dimensions. On the contrary, the complexity of determining the exact number of subjects with ASD is evident regardless of the study or the edu-

cational, health or social intervention that we are dealing with. Hence, in order to adequately educate the ASD population, we have the challenge of properly detecting, identifying and diagnosing this group. So, as a preliminary task for analyzing the educational needs of the present autistic group, this study has the following objectives: 1) to determine the volume of students with ASD in the educational system in Seville, Spain; to be exact, determine its prevalence among the schooled population during the compulsory years in all the schools in Seville, and 2) to analyse the prevalence by gender, age, schooling type and diagnostic categories.

Method

Participants

In order to determine the initial data base, all primary schools were contacted in which the presence of ASD students was known. This information was obtained from outside sources such as the Educational Administration and parent/teacher/professional associations. In addition, all high schools were contacted where the presence of ASD, or lack of it, was to be determined. The entire school population in Seville is 127,350. Forty-nine of the fifty-three total high schools in the city of Seville participated while the four remaining declined participation for various reasons. Five of these participating high schools indicated that they had students with ASD diagnosis.

The total number of public and semi-private early childhood and/or elementary schools that participated and which offered information regarding their students with ASD was eighty-one out of a total of eighty-four. In this case the initial search
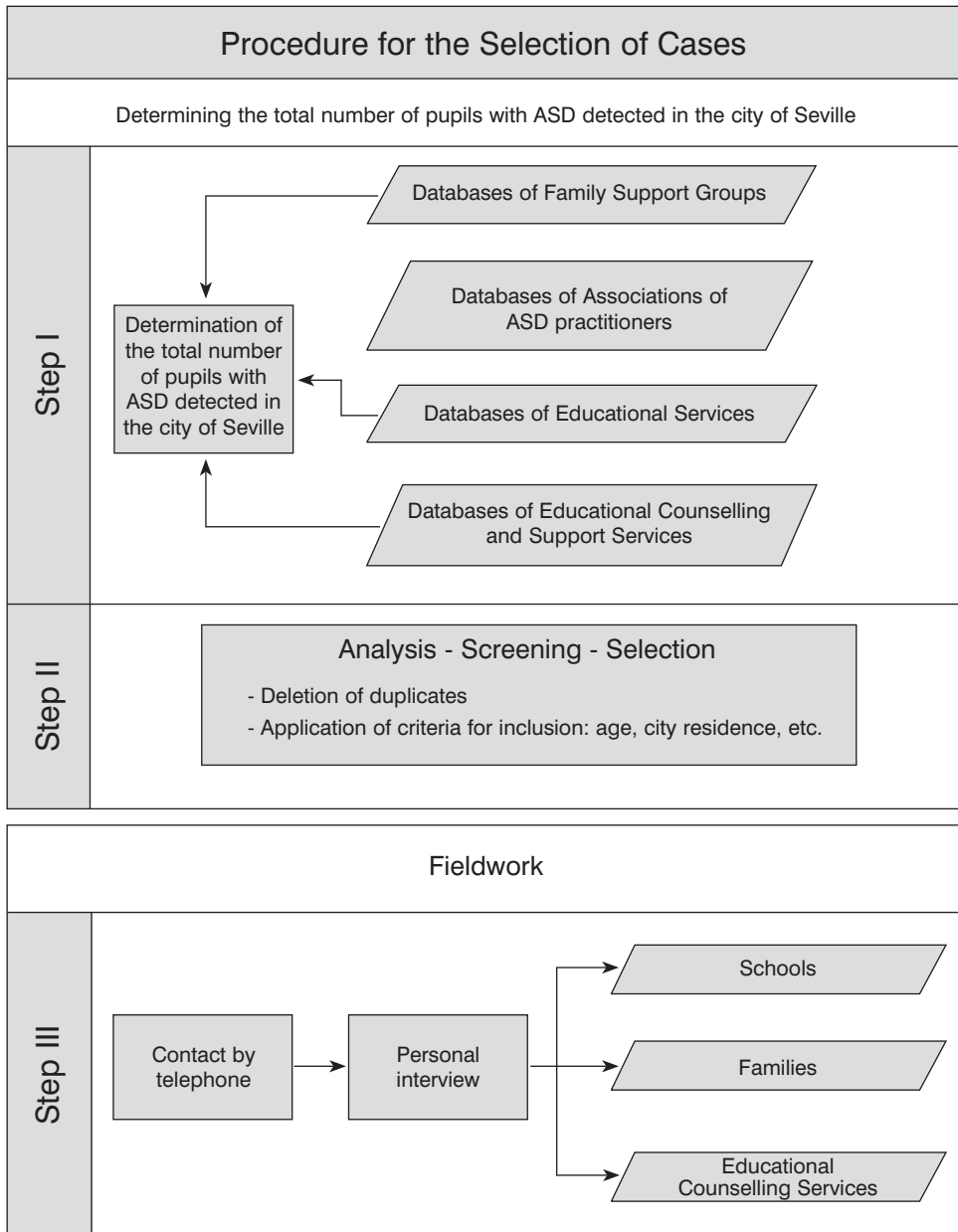
was reduced due to the investigational field characteristics of these educational stages, as can be seen below. In addition, four educational orientation teams participated in the study of the ten total teams that were potentially involved in the study.

Procedure

The initial data base of students with ASD was obtained from previous data bases provided by associations of families and professionals (Autism Seville and Servicio Educativo y Terapeútico para Niños Autistas or Educational and Therapeutic Service for Autistic Children (SETA)) and by the Educational Administration (the Andalusian Government and Educational Orientation Teams) (SEE FIGURE 1). To begin with, the Autism Association of Seville provided a data base of children and adults with ASD who are affiliated with the association. In this data base a total of 102 people were registered. The people in this data base were of varying ages and many of them beyond compulsory schooling or were not being schooled in the city of Seville.

Other information coming from the aforementioned association was found in hard copy files thanks to documentation filled out by its professionals when a family with an ASD child goes in for the first time to the association or when follow-up visits are carried out. In many cases, files were opened in these initial visits but were not complete because the family members had not been incorporated into the association. Other files dealt with subjects that had gone to the associations for various educational or therapeutic activities or had been included on waiting lists for a possible diagnostic confirmation. They comprised a total of 35 additional subjects which we

FIGURE 1
Procedure used for the selection of cases

Procedure for the Selection of Cases

Determining the total number of pupils with ASD detected in the city of Seville

Step I

Determination of the total number of pupils with ASD detected in the city of Seville

Databases of Family Support Groups

Databases of Associations of ASD practitioners

Databases of Educational Services

Databases of Educational Counselling and Support Services

Step II

Analysis - Screening - Selection

- Deletion of duplicates
- Application of criteria for inclusion: age, city residence, etc.

Fieldwork

Step III

Contact by telephone

Personal interview

Schools

Families

Educational Counselling Services

added to the data base and hence tried to locate.

The data collection of Autism Seville was added to by means of identifying schools and cases through the SETA association which provides educational-therapeutic attention to students attending 3 elementary schools in the city of Seville. SETA provided information for the study on 41 students who attend the 3 mainstream schools, referred to above, as well as its own educational-therapeutic center. After preliminary contact with the association, meetings were established with SETA´s professionals in each one of the schools.

The data base of the Educational Administration was comprised of information on people with ASD classified by school and taken from student census with special education needs for the year 2002/2003. This census was put together by the Educational Orientation Teams from the information that they have available through their diagnostic and follow-up procedures, as well as from the information that they are provided with by the Orientation Department of the high schools and the Orientation Teams of the semi-private and special education schools. This source did not hand out information regarding the identity of the subjects with ASD, but did provide information with respect to their location in different schools. The total number of schools, public and private, that the Educational Administration provided information about was 91, which at first, indicated the presence of 364 students with Generalized Developmental Disorders. The diagnoses identified were: Autism for 67 students, Asperger´s Syndrome for 5 students, Rett´s Disorder for only 1, and the other 291 were identified as having Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS). These students were found in 59 public schools (56 mainstream schools and 3 special education schools). Of the 32 private schools remaining, 26 were from mainstream and 6 from special education schools. The public schools housed 216 boys and girls, whereas the private schools housed 148. The students with ASD in the mainstream schools reached a total of 241 while those in special education schools tallied 123.

Contact was also made with all the high schools in the city of Seville. Information regarding the identification of students with ASD diagnosis was requested. Likewise, the 10 Educational Orientation Teams were asked to participate in the study.

The contact procedure was somewhat different with respect to the nature of the schools. In the high schools, preliminary telephone contact was made with a counselor who was explained the nature and reason for the study. Following this, a personal visit by members of the investigational team was made and information was collected in order to identify the exact number of ASD cases. In total, 49 secondary schools were visited, one of which indicated that they had no cases of ASD whatsoever and preferred not to have the interview. Four other high schools declined any participation in the study and then later on, one school changed its mind after obtaining parental authorization.

The work method in the case of the Educational Orientation Teams was similar; first by telephone contact followed by a professional visit. In these teams the participation rate was less. After telephone contact, information and feedback was received from only 4 Educational Orientation Teams.

Pre-schools, elementary schools and special education schools were located using two different procedures. Schools from the census that indicated having ASD students were contacted by phone. In the cases in which the ASD students were included in the data base of Autism Seville,

an interview with the parents was the first step. Once the parents gave written authorization to talk with the child's teacher, then contact was made with the schools. This was done regardless of the fact that the school was found in the educational administration data base or not. Contact was made with the school administration by telephone in order to inform them of the study's objectives and procedures, as well as to confirm the presence of students with ASD. The schools´ administrative departments then filled out a form identical to that given to the high schools. Of the 84 potential school participants, only 3 did not participate.

These resources (from special educational needs services, schools, and families) provided a total of 501 potential cases of ASD students. It is true that in many cases we were dealing with subjects whose diagnosis was quite doubtful. For example, the diagnostic criteria for the 291 cases labeled as PDD-NOS in the high schools and Special education schools were found to not correspond with other criteria normally used in DSM-IV classification. In light of this, it was necessary to contact all the early childhood, elementary and special education schools where there was a student diagnosed with PDD-NOS. This contact was made in order to confirm that these students were still enrolled in these schools and request their age and gender. To be exact, of the 47 schools that indicated having students of this nature, we were able to contact 44. Therefore, we worked with 73 specific diagnostic cases (Autism, Asperger´s and Rett´s Disorder) and with 14 PDD-NOS cases confirmed by the school. In addition to these cases, 3 more were added that were detected through the subjects' families. Subject duplicates were eliminated either by the schools confirming a lack of autistic diagnosis, by verifying that the subjects were not enrolled

in schools in the city of Seville, or by an unreliable diagnosis.

Thus the final number of potential subjects with ASD was brought down to 200. We reliably confirmed 182 ASD diagnoses. Of the 182 subjects, we were able to contact 165, either by school or family in order to obtain additional information.

Instrumentation

The instrument used for determining the data base of the diagnosed cases was a simple note card in which the subjects´ initials, gender, date of birth, school, grade, homeroom, teacher name and diagnosis were all written down. The initials and date of birth were requested only as a means of avoiding duplication among different data bases. The grade, homeroom and teacher name were necessary for a later interview with the teacher(s). If the professional completing the interview felt that the information was affecting the anonymity of the students in anyway, information that was not absolutely necessary was eliminated.

Results

Estimation of the Prevalence Rate

From our data we obtained an estimation of a global prevalence rate of 12.97 in 10,000. The breakdown for each according to the diagnostic categories is: 4.79 in 10,000 for Autism, 1.1 in 10,000 for Asperger's, 4.32 in 10,000 for PDD-NOS, and 2.67 in 10,000 for ASD.

The total number of students with a confirmed diagnosis that were identified by the educational system was 165. The distribution of the sample with respect to gender indicated that approximately 83% were boys while 17% were girls.

If we analyze the distribution of the average by age, we can see values which show a range from three to twenty-one. A higher frequency rate occurs at ages four, five, nine and eleven. Passing age eleven and continuing on to age twenty-one, a progressive decrease in frequency is found.

Analysis of the student sample by schooling type related to other variables

If we analyze the student sample, keeping in mind schooling types, we obtain a similar distribution. 52.12% of the sample members were found in special education schools while 47.88% were enrolled in mainstream schools. Hence, a difference of 4.24 percent exists between one type of schooling or another. The distribution analysis with respect to age in each of the groups according to the school type received by each student shows significant differences (t=-4.299, p=0,000). The average age of students in the sample found in special education schools is 11 years (with a standard deviation of 5.06) and 9 years for those students enrolled in mainstream schools (standard deviation of 3.70). Therefore, we can claim that the average age of the student in the sample enrolled in special education schools is significantly higher than the average age of those students found in mainstream schools.

In order to improve the quality of the analysis, the age of the subjects has been separated into four different groups; 3-5 years, 6-11 years, 12-16 years, and 17-21 years. The intersection of these age groups, according to the type of schooling received, can be observed in the following TABLE I.

The statistical comparison indicates that highly significant differences exist ($x2=23.260$, p=0.000). According to the information provided by the residual values, it is apparent that the youngest age range has a relatively homogenous distribution of the students between both types of schooling. Nevertheless, in the other three age categories (6-11, 12-16, 17-21) significant residual values are found. This indicates differences in the type of schooling that boys and girls receive according to the age bracket that they are in.

With respect to age groups, in TABLE I we can appreciate the relationship in which an asymmetric distribution of the percentage of students in each type of schooling is observed. Therefore, there are a greater number of students enrolled in mainstream schools who are between 6-11 years, but this trend is reversed since most of the students are enrolled in special schools for students between 12-16 years of age. This same trend of special school enrolment continues for the 17-21 year-olds. Thus, the distribution among girls and boys in the sample from special education schools is inverse with respect to age. Here, the older a student is, the greater the chances of their enrollment in special education schools.

TABLE I
Contingency table showing age and type of school

			Mainstream Schools	Special Schools	Total
Age Categories	**3 to 5 year olds**	Frequency	20	18	38
		% of age categories	52.6%	47.4%	100%
		% of type of school	25.3%	20.9%	23%
		Adjusted standardised residuals	0.7	-0.7	
	6 to 11 year olds	Frequency	48	27	75
		% of age categories	64%	36%	100%
		% of school type	60.8%	31.4%	45.5%
		Adjusted standardised residuals	3.8	-3.8	
	12 to 16 year olds	Frequency	8	26	34
		% of age categories	23.5%	76.5%	100%
		% of school type	10.1%	30.2%	20.6%
		Adjusted standardised residuals	-3.2	3.2	
	17 to 21 year olds	Frequency	3	15	18
		% of age categories	16.7%	83.3%	100%
		% of school type	3.8%	17.4%	10.9%
		Adjusted standardised residuals	-2.8	2.8	
Total		Frequency	79	86	165
		% of age categories	47.9%	52.1%	100%
		% of type of school	100%	100%	100%

Analysis of the student sample by diagnostic categories with respect to other variables

The sample distribution analysis regarding the type of diagnosis that each child has can be summed up in TABLE II. Approximately one-fifth of the sample (20.6%) has a formal ASD diagnosis. A greater percentage of students appear to be diagnosed with PDD-NOS (33.33%) and Autism (36.97%). Diagnosed cases of Asperger´s (8.48%) are considerably lower, yet far higher than the percentage diagnosed with Rett's Disorder which doesn't even reach 1% of the sample.

In FIGURE 2 the current, different and diagnostic categories are shown with respect to gender. According to this, the distribution of the different diagnostic categories, with respect to gender, is quite homogeneous (FIGURE 2). The only clear exception to this is with Rett's Disorder. A statistical analysis of the data present in FIGURE 2 also revealed that no significant relationship was found between gender and

FIGURE 2
Distribution of diagnoses by gender

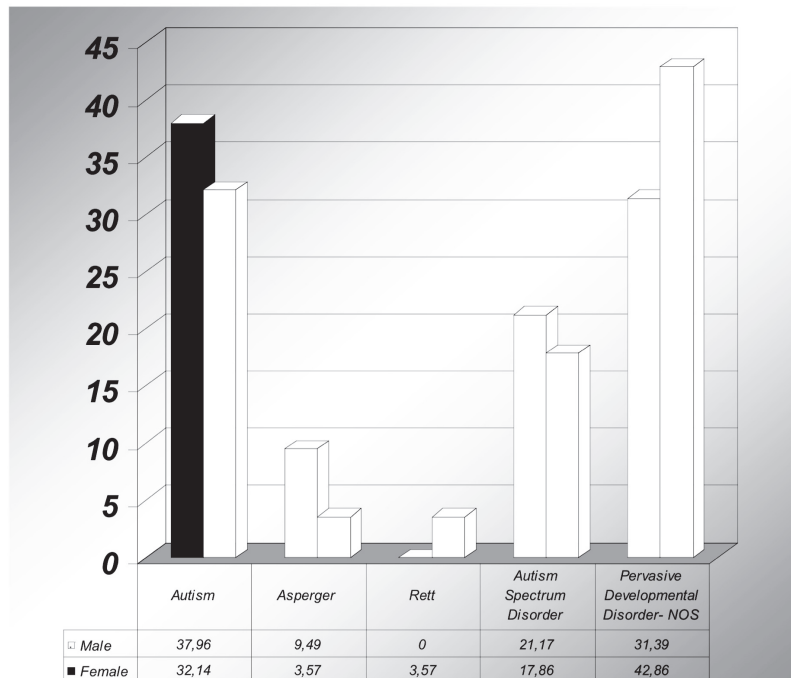|	Autism	Asperger	Rett	Autism Spectrum Disorder	Pervasive Developmental Disorder- NOS
▢ Male	37,96	9,49	0	21,17	31,39
■ Female	32,14	3,57	3,57	17,86	42,86

TABLE II
Contingency table showing type of school and diagnosis

Type of School		Autism	Asperger Syndrome	Rett Syndrome	Autism Spectrum Disorder	PDD-NOS	Total
Mainstream School	**Frequency**	22	13	0	15	29	79
	% of type of school	27.8%	16.5%	0%	19%	36.7%	100%
	% of diagnostic category	36.1%	92.9%	0%	44.1%	52.7%	47.9%
	Standardised adjusted residuals	-2.3	3.5	-1.0	-0.5	0.9	
Special School	**Frequency**	39	1	1	19	26	86
	% of type of school	45.3%	1.2%	1.2%	22.1%	30.2%	100%
	% of diagnostic category	63.9%	7.1%	100%	55.9%	47.3%	52.1%
	Standardised adjusted residuals	2.3	-3.5	1.0	0.5	-0.9	
Total	**Frequency**	61	14	1	34	55	165
	% type of school	37%	8.5%	0.6%	20.6%	33.3%	100%
	% of diagnostic category	100%	100%	100%	100%	100%	100%

Note: PDD-NOS = Pervasive Developmental Disorder - Not Otherwise Specified

the type of current diagnosis (x2=7.106, p= 0.130).

In order to determine if a relationship exists between subject age and the current diagnosis, we have used a unilateral ANOVA analysis. The results indicate that there is no relationship between the variables (F=1.197, p=0.297) and for this reason we can conclude that, in our sample, the type of ASD diagnosis is not influenced by the current age of the subjects. Therefore, we can appreciate that the average age of each one of the diagnostic categories are very similar and all fluctuate in a three-year range, from 9 to 12 years of age.

Nevertheless, a relationship was found between the type of schooling and the diagnosis that the subjects currently have. If we test the data from both variables with a contingency analysis, we obtain results that indicate the existence of a greater number of students diagnosed as autistic who are enrolled in special education schools. Meanwhile, the exact opposite occurs with respect to those students who have been diagnosed with Asperger's Syndrome and are hence enrolled in mainstream schools (TABLE II). In addition, these differences are statistically very significant according to the test values ji-squared (x2=16.390, p=0.003).

As reflected in TABLE II, 63.93% of the sample diagnosed as autistic is found in special education schools, as compared to only 36.07% that are in mainstream schools. In the same manner, there are a greater number of students diagnosed with ASD among the special education student population (55.88%) compared to those ASD students in the mainstream (44.12%). However, the opposite tendency is detected among those with Asperger's Syndrome, where students in the mainstream reach 92.86% while those in special education school remain at a low percentage of 7.14%. On the other hand, the dis- tribution among those students diagnosed with PDD-NOS is quite similar to the ASD distribution, but inverted since 52.73% of these students are in mainstream schools, compared to 47.27% who are not. Lastly, the Rett's Disorder representation in our sample is unique in that all attend special education schools.

Discussion and Conclusion

As mentioned in the introduction of this study, the diagnostic criteria most widely used, and hence the diagnostic categories from which the criteria are derived, are those taken from the international classification systems (DSM-IV and ICD-10). In the Anglo-Saxon world, these criteria are normally applied in a very strict manner (for example Wing and Potter, 2002). In Spain, however, we usually consider some cases that have features similar to ASD as ASD; although these cases cannot be strictly considered ASD according to the criteria established by the classification systems.

Keeping this in mind and relating it to the studies carried out in Spain, the data distribution of the different diagnostic categories found in Seville is quite similar to the data obtained by Belinchón (2001), for example. Similarly, the data presented in recent research done by Fombonne (2003) and Chakrabarti and Fombonne (2005) coincide as well. In TABLE III one can observe how the percentages of the analyzed subjects in each one of the different diagnostic categories are very similar.

The percentages for the different diagnostic labels among our subjects and those found in other countries (Fombonne, 2003; Chakrabarti and Fombonne, 2005) are very similar. The only exception is the fact that we have unified the ASD and PDD-NOS categories for the reasons explained

TABLE III
Comparison of data obtained in Seville and other recent epidemiological studies

	Autism	Asperger Syndrome	Rett Syndrome	ASD	PDD-NOS	ASD+ PDD-NOS
Belinchón (2001)	44%	4%	2%	21%	28.14%	49.14%
Fombonne (2003)	36.36%	9.09%	-	-	-	54.54%
Chakrabarti & Fombonne (2005)*	31.25%	14.62%	-	-	-	51.87%
Seville data	36.97%	8.48%	<1%	33.33%	20.61%	53.94%

Note: ASD = Autism Spectrum Disorder
PDD-NOS = Pervasive Developmental Disorder - Not Otherwise Specified
*Data combining two samples analysed in a cohort study.

above. Our data closely reflects results obtained in other studies carried out in Spain, as in Belinchón (2001) where subtle discrepancies are found in the less specific diagnostic groups of ASD and PDD-NOS and where more obvious discrepancies are seen in the Autism and Asperger's group. A 7.03 percent lower estimation of cases of Autism was found in our study, with a concomitant 4.48 percent higher estimation of Asperger's syndrome. Referring back to Belinchón (2001), a hypothesis that might explain this discrepancy is the possibility of jumping back and forth between diagnoses regarding high functional autistic cases and Asperger's cases. This is due to the inherent difficulty of differential diagnoses and the short diagnostic history of the latter diagnostic category. These issues are extremely relevant and the latest research points out that these factors (i.e. the theoretical evolution of the conception of the Autism Spectrum and changes in the applicable diagnostic criteria as well as to the improvement in the detection system and services) can explain the increase in the prevalence estimation observed in recent years and not an actual increase in the incidence of ASD (Chakrabarti and Fombonne, 2005).

If this hypothesis is correct, it is no wonder that most of the discrepancies are in the Asperger's group, as this is due to the fact that detection systems and cultural variables can have an influence on a positive diagnosis. So, when treating subjects with a high functioning level it is quite possible to send them on to another clinical unit or even pass them on in the school system without being detected.

In terms of frequency, the obtained results clearly contrast with the estimations provided by the educational administration of the Seville delegation. The numbers coincide substantially with respect to the Autism and Asperger's diagnostic categories, but differ greatly with respect to the less clear diagnostic types. Our study has detected 61 Autism cases and 14 Asperger´s cases, while the educational administration informed us of 51 Autism cases and 11 Asperger's cases. Nevertheless, considerable differences exist among the cases detected in our study regarding Pervasive Developmental Disorder- Not Otherwise Specified (55 cases) and those cases offered by the data from the educational administration (180 cases). The discrepancy of this information demonstrates how difficult it can be to make an exact diagnosis of ASD and it is, quite possibly, the lack of time which explains why professionals tend to make more general diagnostic labels and less specific ones within Autism Spectrum

Disorder. This under-diagnosis carries considerable consequences for the educational intervention of this group of people, as it influences in undervaluing the seriousness of the problem and for that reason the material, personnel resources and teacher instruction necessary are not provided.

With respect to the prevalence estimates very clearly pointed out in the introduction of this paper, it seems that dispersion of the numbers is the norm with clearly higher tendencies in the most recent years. Our results show global prevalence rates very similar to those obtained from other recent research such as Magnusson and Saemundsen (2001) (13.2 in 10,000) or Kielinen *et al.* (2000) (12.2 in 10,000). In any case, the prevalence numbers found in our study are congruent with the current thesis referring to ASD as much more frequent disorder than traditionally believed in recent decades (Volkmar *et al.*, 2004).

With respect to the gender distribution of ASD subjects in our data, we find that there is a ratio of 4.89 boys for every 1 girl. This ratio is within the range limit estimated by specialized international literature (see Fombonne, 2003, for example) and by the reference studies carried out in Spain (for example, Belinchón, 2001, which offers an estimation of 3.93).

Lastly, with respect to the educational attention that ASD students receive, it is interesting to contrast how a relationship exists between age and schooling type. In this manner, the older the student is, the greater his or her chances are of being enrolled in a school with special education services. It seems that as ASD students grow the mainstream schooling systems have more difficulty meeting the needs of these students and tend to transfer them to special education schools.

Summary

A preliminary task for the design and development of interventions for different groups of people with disabilities is to determine the prevalence rate of the target population to which the interventions are directed. In the case of Autism Spectrum Disorder (ASD), the determination of such a percentage remains a controversial matter; and when combined with educating these people, makes detection, identification and diagnosis of the disorder an important challenge. In this research a study of the prevalence of ASD is presented for the compulsory, school-age population of children in the city of Seville, Spain. The results were analyzed as a function of age and gender of the subjects, the schooling type, and the different diagnostic categories that are considered within Autism Spectrum Disorder. These results demonstrate prevalence rates similar to those results recently obtained in other studies carried out both in and outside of Spain.

Acknowledgements

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