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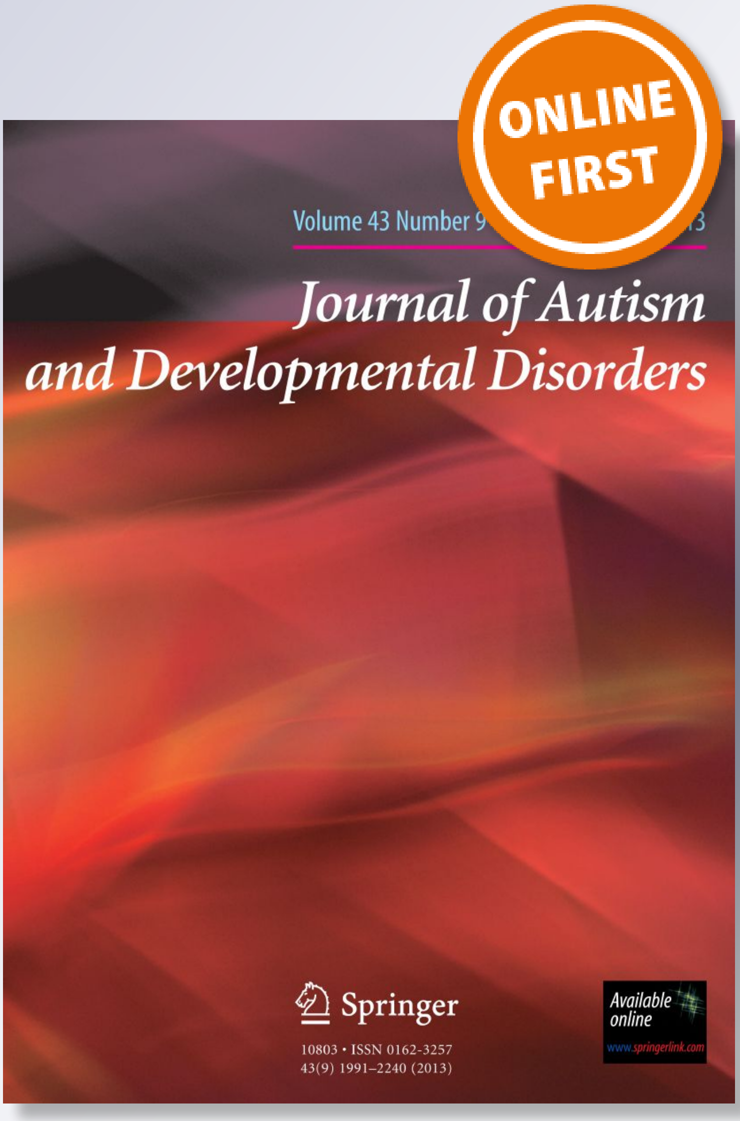

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ORIGINAL PAPER

School Inclusion in Children and Adolescents with Autism Spectrum Disorders in France: Report from the ELENA French Cohort Study

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Abstract

Children and adolescents with ASD are increasingly included in regular school settings, however little is known about how placement decisions are made. In the present study, we examined the types and duration of school attendance among children and adolescents in the ELENA Cohort, a multi-center study of children and adolescents with ASD, ages 2–16 years, in France. Results showed that 88% of subjects were attending school and that children and adolescents with more severe adaptive and cognitive deficits were less likely to attend school. The results provide a topography on school inclusion and ASD in France. Challenging behaviors and sensory processing difficulties were associated with partial-inclusion; and co-occurring anxiety symptoms were associated with inclusion on a full-time basis.

Keywords School inclusion · School duration · ASD · Cohort · France

Inclusion reflects a model in education where children and adolescents with developmental, emotional, as well as physical disabilities are offered the opportunity to spend a significant portion of their time alongside typically developing students in regular school setting with methods of special instruction embedded within the context of general education including appropriate supports and services accommodating individual learning needs. Inclusion as a holistic approach differs from *mainstreaming* in that it goes beyond the focus on remediation of the students' special educational needs, to students' participatory rights in the *least restrictive* educational environment, underscoring the schools' obligation to accommodate their needs, as well as the society's obligation to treat them as equal citizens.

Inclusion has been built on a legacy of segregation and institutionalization of children and adolescents with disabilities (Munir 2009). Therefore, inclusion in its broadest sense is inexorably linked to serving children's rights that is now legislated through a series of acts that have received universal Congressional support in the United States (Munir 2015). The progress in inclusionary education has been a stepwise process with more intensive programs implemented in the United States in the 1990s, first for students with physical disabilities, leading to establishment of full time and partial inclusion programs for students with developmental disabilities, including those with Autism Spectrum Disorder (ASD).

The children and adolescents with ASD in the United States are being increasingly included in regular public schools (Holt 2003; White et al. 2007; Williams et al. 2019). However, the alignment of the ecology of inclusionary classroom placement (Kurth et al. 2016) is dependent on a given student's *individualized educational plan* based on the interplay of multitude of factors that include the characteristics of the student's condition, the extent of assessment, local educational authority resources, family preference, as well

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The mambers of this ELENA STUDY GROUP has been included in 'Acknowledgments' section.

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advocacy. The current national policies in France, including the 4th National Autism Plan, have also emphasized the inclusive model in special education for ASD to the maximum extent possible (National Strategy for Autism and other Developmental Disabilities 2018–2022). It has been shown that students with ASD included in the general education setting obtain significantly higher scores on tests of academic achievement, including measures of abstract and inferential skills (Kurth and Mastergeorge 2010). Inclusion of young children with ASD in the general classroom also promotes social development and communication skills (Dahle 2003). Furthermore, the experience of partial and full school inclusion, if carefully supported, has strong associations with the students' likelihood of demonstrating positive developmental trajectories in ASD symptoms, maladaptive behaviors, and daily living skills (Woodman et al. 2016).

Information about school services for children and adolescents with ASD across all ability levels is of great importance in order to understand the resources that will be necessary as an increasing number of children and adolescents with ASD enter the regular school system (Towle et al. 2018), with a paucity of basic description of these services. In France, there is great variety of the types of classes, weekly duration of instruction, and the categories of assistance the children with ASD will receive. Students with ASD, as well as other neurodevelopmental disorders, can either attend regular school, participate in typical or special education classes, or they may benefit from a special educational service outside school for those who are unable to attend. If the children and adolescents with ASD attend regular schools, they can have full-time or part-time inclusion, akin to that in the United States. Furthermore, they can benefit from a specialized aide who supports them in school-based learning and in guiding their day-to-day schedule and relationship with other students. Nonetheless, in France, as in elsewhere, it is still unclear how educational placements and educational service use decisions are made, and few studies have investigated the links between school attendance and child and adolescent characteristics within the ASD context (White et al. 2007).

Since 2005, the legislation in France has supported the right for every child with ASD to be included in a regular classroom. However, in a survey about special education services conducted by the French Ministry of Health between 2008 and 2010, only 55% of the children and adolescents with ASD were reported to be attending regular schools, including specialized classes in regular schools, most of them on a part-time basis (CNSA 2011; Rattaz et al. 2013a, b). The highest rate of attendance in regular school was among youngest children with ASD, before 6 years of age. These findings underscored the fact that older children and adolescents with ASD in France were more likely to attend specialized services outside regular schools. The trend in the decade since has been an increasing emphasis on inclusion of children and adolescents with ASD in regular schools. This is reflected in the changes in the inclusionary education policies in France with a decreased availability of special education services for ASD outside regular schools. Therefore, increasing numbers of children and adolescents with ASD are currently included in regular schools in contrast to the situation of services for the period 2008–2010, a decade earlier.

Nonetheless, achieving full inclusion has not been without problems in France, as elsewhere, with unremitting difficulties in implementing publicly-funded educational supports and classroom aides, insufficient teacher training, misgivings of some school staff regarding the additional burden of caring for students with ASD, misunderstanding by ordinary parents that the needs of their children will be eclipsed by those with ASD (Harrower and Dunlap 2001; Osborne and Reed 2011). In a paper about school inclusion of students with intellectual disabilities, Smith (2007) noted that access to regular education classrooms was still inconsistently available for such students and that educators remained ambivalent about including them on a full-time basis (Praisner 2003). Rodríguez et al. (2012) investigated special education teachers' attitudes and found that information and social support were among the relatively highest needs expressed by teachers.

Whether children and adolescents with ASD will be included in regular schools continues to depend upon the individual characteristics of their condition, and in particular the severity of their associated cognitive and adaptive impairments (Holt 2003). In a sample of 76 children with ASD, Eaves and Ho (1997) found that age, IQ, and severity of ASD were related to their classroom placement. Older children with ASD were more likely to be in special education classes compared to the young children. White et al. (2007) tried to identify individual characteristics associated with educational placement of high functioning students with ASD. They found that lower cognitive ability and communication skills were associated with placement in special education, whereas social skills were not. Findings such as these therefore highlight the emphasis placed on certain individual characteristics such as cognitive ability with far less emphasis on other areas, such as degree of social deficit in defining educational placement and service provision. Limited adaptive abilities of children and adolescents with ASD have also been shown to have a negative impact on school inclusion (Ferraioli and Harris 2011). Another potential barrier to the inclusion of children and adolescents with ASD in regular classrooms is the comorbid presence of challenging behaviors (McCurdy and Cole 2014). When these behaviors are demonstrated by a student with ASD, the result may be a decision by the school personnel to place the child or adolescent in special education (Arceneaux and

Murdock 1997; Sterling-Turner et al. 2001). Other co-occurring mental conditions in children and adolescent with ASD, besides challenging behaviors, may also impact the decision regarding the extent of school inclusion. Indeed, anxiety (Vasa and Mazurek 2015) or atypical sensory processing (Dellapiazza et al. 2019) commonly co-occur in children and adolescent with ASD. To our knowledge, no prior studies have explored the relationship between co-occurring anxiety, sensory processing difficulties and school inclusion in ASD.

The aim of the current study was to provide a comprehensive overview of school inclusion in children and adolescents with ASD enrolled in the ELENA French Cohort and to gain knowledge as to how better adapt the services and the educational environment for them. First, we determine the percentage of children and adolescents with ASD attending school. Second, we examine the types of school settings the children and adolescents with ASD attended and linkages between them and their psychosocial and clinical characteristics including co-occurring challenging behaviors, anxiety and sensory processing difficulties. Third, we compare characteristics of children and adolescents attending regular and special classrooms and examine the links between their developmental profiles and duration of school attendance in terms of mean weekly half days.

Methods

The ELENA French Cohort is an open, prospective, multicenter cohort study, including children and adolescents, 2–16 years of age, with ASD. The patients are followed for a period of 6 years (Baghdadli et al. 2019). Clinical, social, environmental, and genetic data, as well as data relating to the parental quality of life are collected. The primary endpoint is the adaptive level in three domains of the Vineland II (Communication, Socialization and Daily living skills). The secondary endpoints include parental quality of life, comorbidities, interventions and severity of ASD. The ELENA study was set-up in order to identify patterns in outcome trajectories for a large sample of children and adolescents with ASD, to examine determinants of these outcome trajectories at the different follow-up stages, and to constitute an open French database on ASD that promotes collaboration in translational studies. Recruitment for the ELENA Cohort started in 2013 and is planned to end in 2019. Participants were recruited in 15 centers specialized in the diagnosis and the follow-up of children with ASD. Inclusion criteria were confirmed diagnosis of ASD according to ICD 10 criteria, age 2 and 16 years, participation in multidisciplinary clinical assessment including ADI-R, ADOS 2, and Vineland II, as well as psychometric tests. Inability to read French (for patients´ parents) was an exclusion criterion. In each center, an investigator conducted patient enrolment during a medical consultation. A written consent was collected for each participant. The protocol was approved by the local ethics committee at each site.

For the current study, we used a subset of cross-sectional data collected during the initial time point of the ELENA Cohort (Baghdadli et al. 2019). For children aged over 2 years and 9 months (youngest age at which children can go to school in France, N = 559), 328 parents answered the questions about schooling ("does your child go to school?") and were included in this study.

Measures

Data were collected by licensed psychologists from the multidisciplinary clinical assessments using standardized tools at baseline. In addition, parents were asked to fill online e-questionnaires investigating current school, placement attributes and services, and child behaviors (ABC, CBCL, SP, see below).

Questionnaire About Current School Placement and Services Received

A structured self-administered questionnaire was filled by parents to inquire about their child and adolescent's current grade and regular school placement, specifying the type of classroom, i.e., in a typical classroom, special classroom, or special classroom in residential setting outside regular school. Information was also obtained on weekly duration of school sessions and whether the child had an aide at school.

Intellectual Functioning

Because of the variable abilities of the participants and differences in IQ test scores across age, the 'Best Estimate' intellectual functioning level was derived for each participant based on an age-appropriate test, from all the assessments available. When standardized test could be administered, Performance IQ (PIQ) was recorded; in other cases, when the participants could not understand test instructions or requirements, Developmental Quotient (DQ) was calculated according to Stern's formula (1912) by dividing developmental age scores (based on revised psycho-educational profile 3 (PEP-3) and developmental scales) with the chronological age *100. The decision was made to divide children and adolescents with ASD into the higher vs. lower functioning group, with a median split at 70.

Vineland Adaptive Behavior Scales, Second Edition (VABS-II) (Sparrow et al. 1984, 2005)

The VABS is a standardized, semi-structured interview administered to parents. Scores derived from this instrument have a mean of 100 and a standard deviation of 15 with a Cronbach α coefficient of .92. Standard scores were obtained for each domain: Communication, Daily Living Skills and Socialization. For the purposes of the current study, the Communication, Daily Living, and Socializations domain standard scores were used.

Aberrant Behavior Checklist (ABC) (Aman et al. 1985)

The ABC is a 58-item rating scale completed by parents, used to measure challenging behaviors across four domains: irritability (ABC1), lethargy/withdrawal (ABC2), stereotypy (ABC3), hyperactivity (ABC4). Items are rated on a 4-point Likert scale (ranging from 0 [not at all a problem] to 3 [the problem is severe in degree]), with higher scores indicating more severe problems. Scores are reduced to a scale of 100 in order to make comparisons. Thresholds have been created to facilitate the description of the four domains.

Child Behavior Checklist (CBCL) (Achenbach and Rescorla 2001, 2000)

The CBCL is a norm-referenced checklist measure completed by parents that assesses a wide range of emotional and behavioral disorders in children and adolescents. Both the preschool version, CBCL/1.5–5 years, and the school age version, CBCL/6–18 years were used. They consist of six different DSM-oriented scales: affective problem, anxiety problem, somatic problem, attention deficit, oppositional problem, conduct problem. Briefly, children in the clinical or borderline clinical range are compared to children in the normal range for each of the seven scales. The internal consistency was ranged from .72 to .91, the interrater reliability from .63 to .88 and the test–retest reliability was respectively .85 for preschool version and .90 for the school-age version.

Sensory Profile (SP) (Dunn 1999)

The SP is a caregiver questionnaire that measures a child's sensory processing abilities. The questionnaire consists of 125 items, rated on a five-point Likert scale, ranging from always (1) to never (5). Dunn and Brown (1997) described the unusual sensory reactions of children by defining hyperreactivity as having a lowered threshold to sensory input (sensory avoiding), or low tolerance to sensory input (sensory sensitivity), and hypo-reactivity as a higher threshold to sensory input (low registration), or seeking out sensory input (sensory seeking). Scores on sensory processing within sensory modalities (such as tactile, visual, auditory) can also be obtained. Although the SP is commonly used with 3–10 year old subjects, it has been used with older participants with ASD (Kern et al. 2007).

Statistical Analyses

A descriptive analysis of data was carried out at regular intervals in order to check the homogeneity of the data collection. Descriptive statistics were computed using means and standard deviations (SD) or median and Inter-Quartile (25th–75th Quartile) for quantitative variables, and proportions for categorical variables at the baseline (W0). Statistical analysis was conducted following three steps. First, the type and duration of school attendance as well as the services received by the children and adolescents are described. Then, the links between school attendance (no school, special or regular classroom) and children's clinical characteristics were studied. Finally, for children included in regular school settings, the links between school duration (hours/week) and children's clinical characteristics were studied. Statistical comparisons were assessed using Chi square tests or independent samples *t* test, Anova, Mann and Whitney or Kruskall-Wallis nonparametric tests, as appropriate. The significance level used was set at 5%. Statistical analyses were performed using SAS version 9.3 (SAS Institute, Cary, North Carolina).

Results

Participants

Among the 328 children who participated in this study, 84.2% were males (5.4–1 male to female ratio). Children's mean age was 6.6 years (SD = 3.3). Mean age of first psychiatric consultation was 3 years (SD = 1.9), mean age of formal ASD diagnosis was 5.3 years (SD = 2.9), and mean age of first intervention was 3.8 years (SD = 2.2). Children's clinical characteristics are described in Table 1.

School Attendance and Services

Among the 328 participants, 88.4% were attending school and 60.7% were benefiting from an individualized aide at school.

The percentage of school attendance was not significantly different according to age: 87.6% for preschool children, ages 2–6; 91.3% for children, ages 7–11; and 80% for adolescents, ages 12–16 (see Table 2).

The mean duration of school attendance was 5.9 half days a week. It was significantly lower for preschool children (mean half-days = 4.8, SD = 2.1), than for

Table 1 ASD children characteristics

	N	%
Sex (% male)	328	84.2
	N	Mean ± SD
Chronological age (years)	328	6.6 ± 3.3
Age first psychiatric advice (years)	225	3.0 ± 1.9
Age first diagnosis (years)	317	5.3 ± 2.9
Age first intervention (years)	306	3.8 ± 2.2
Intellectual functioning	256	74.4 ± 28.5
Vineland Adaptive Behavior Scales (VABS II)		
Communication SS	314	70.5 ± 15.8
Socialization SS	314	68.8 ± 11.5
Daily living skills SS	314	72.9 ± 13.2

SS score standard

children (mean = 7.1, SD = 1.8) and adolescents (mean = 7.4, SD = 2.7).

The type of school attendance was regular classroom (51.9% at preschool, 28.9% at primary school, 9.8% at high school), special classroom (.7% at preschool, 6.3% at primary school, 2.4% at high school), or special classroom in residential placement (3.2% medico-educative institution [IME]).

Forty-three percent of children and adolescents were receiving special education or care services and most children had a therapy with a private professional as follows: 77.1%, speech therapy, 48.5%, physical therapy; 39.3%, psychiatrist; 31.4%, psychologist; 22.9%, educator; and 14.9% occupational therapist.

Table 2 Type of school and services

Interventions	All N = 328		Preschool (P) N = 177		Children (C) N = 126		Adolescents (A) N = 25		p	Post-hoc test
	%	N	%	N	%	N	%	N		
Child attending an school										
Yes	88.4	290	87.6	155	91.3	115	80.0	20	.2	
No	11.6	38	12.4	22	8.7	11	20.0	5		
Among children attending a school	N = 287		N = 152		N = 115		N = 20			
Kindergarten										
Regular	51.9	149	92,1	140	7.8	9				
Special	.7	2	1,3	2						
Elementary school										
Regular	28.9	83	6,6	10	63,5	73				
Special	6.3	18	.	.	15,7	18				
High school or college										
Regular	9.8	28	.	.	11,3	13	75.0	15		
Special	2.4	7	.	.	1,7	2	15.0	5		
	Mean ± SD	N	Mean ± SD	N	Mean ± SD	N	Mean ± SD	N	p	Post-hoc test
School duration (mean weekly half days)	5.9 ± 2.3	266	4.8 ± 2.1	143	7.1 ± 1.8	104	7.4 ± 2.7	19	**< .0001**	P ≠ C,A
	%	N	%	N	%	N	%	N		
Child benefiting from an individualized aid (AVS) at school (N = 305)	61.3	187	66.7	108	59.7	71	33.0	8	**.007**	A ≠ P,C
Child benefiting from a special education or care service (N = 312)	43.0	134	38.5	65	47.9	57	50.0	12	.2	
Therapy with a private professional	%	N	%	N	%	N	%	N		
Speech therapist	77.1	253	87.0	154	72.2	91	32.0	8		
Physical theraapist	48.5	159	52.5	93	46.0	58	32.0	8		
Psychiatrist	39.3	129	43.5	77	34.1	43	36.0	9		
Psychologist	31.4	103	28.8	51	35.7	45	28.0	7		
Educator/nurse	22.9	75	26.0	46	19.8	25	16.0	4		
Occupational therapist	14.9	49	12.4	22	19.0	24	12.0	3		
Other	14.6	48	14.1	25	16.7	21	8.0	2		

Significant associations (p-value < .05) are presented in bold

Links Between School Attendance and Clinical Characteristics

The following analyses were conducted to examine the links between school attendance (no school, regular or special classroom) and child and parental characteristics.

First, the three groups of children differed according to the presence of co-occurring intellectual disability (ID). Among children and adolescents who were not attending school, 80% had an ID, among children who were attending a special class, 50% had an ID, and among those who were attending a regular classroom, 37% had an ID ($p < .0001$, see Table 3). The children attending a special education classroom were older (9 years, SD = 2.8) compared to children attending a regular classroom (6.3 years, SD = 3.1), and those children who were not attending school (6.4 years, SD = 4.1) ($p < .0001$).

The children and adolescents who were not attending school had lower adaptive level compared to the two other groups in terms of communication, and lower adaptive level compared to children in regular classes in terms of socialization and daily living skills (all p values < .0001). No significant differences were found regarding SP in the three groups of children. But there was a significant difference between the three groups regarding the stereotypy domain of the ABC, with more stereotypies among subjects not attending school than among those attending a regular classroom ($p < .0001$). Regarding associated emotional and behavioral disorders measured through the CBCL, we found that children attending a special classroom had more anxiety symptoms than children and adolescents with ASD who were not attending school, or those who were attending a regular classroom ($p < .0001$).

Finally, there was a significant difference in parental educational level between the three groups of children, with a higher educational level in fathers of children attending an ordinary classroom compared to fathers of children who were not attending school ($p = .01$). A similar result was observed for mothers ($p = .002$). Socio-professional status was higher for mothers whose children were attending a regular classroom compared to mothers whose children were not attending school ($p < .0002$), but no significant difference was found for fathers.

Links Between School Duration and Children's Clinical Characteristics

Among children included in the regular classroom settings, the links between their clinical characteristics and the weekly school duration was examined. We compared children and adolescents who were attending school ≤ 4 half days per week (very partial inclusion), with those attending between 4 and 6 half days per week (partial inclusion) as well as those attending ≥ 7 half days per week (full time inclusion) (Table 4).

The duration of school attendance varied according to the children and adolescents' intellectual and adaptive functioning. Most children who were attending school ≥ 7 half days per week had no ID (88.1%), whereas most children who were only very partially attending school, ≤ 4 half days per week, had an ID (70.8%). Among children in partial inclusion (4–6 half days per week) 55.8% had an ID. The same results were found with respect to adaptive functioning, with a significant difference between the three groups of children for communication (mean standard score = 57.8, very partial inclusion, 70.4, partial inclusion, and 80.5, full-time inclusion). The socialization and daily living skills scores were significantly lower in the very partial inclusion (65.8 and 68.3, respectively) compared to the partial and full-time inclusion groups (mean standard scores, 69.4 and 77.8, respectively).

With regards children's SP, we found a significant difference between the full-time inclusion compared to the two other groups. An atypical *sensation seeking* profile was found in less than half the children who had a full-time inclusion (46.9%), whereas it was present in most children in the partial (77.2%) or very partial (81.3%) inclusion groups ($p = .0007$). Similarly, an atypical *sensation avoiding* profile was found in most children who were attending schools partially (82%) or full-time (80%), and it was found in 37.5% of children in very partial inclusion ($p = .02$).

With regards possible linkages between school duration and challenging behaviors or comorbidities, significant relationships were found between school duration and challenging behaviors for the four domains on the ABC. There was more irritability and hyperactivity in the very partial or partial inclusion groups as compared to the full-time inclusion group (all p's < .002). Lethargy was significantly lower in the very partial group as compared to the full-time group ($p = .006$). No difference between the three groups was found regarding stereotypy. Finally, children in the full-time inclusion group had more anxiety than children in the part-time inclusion group on the CBCL, and children in the part-time inclusion group had more anxiety than children in the very part-time inclusion group ($p = .00004$).

Discussion

The results of the ELENA Cohort provide unique knowledge on the profiles of children and adolescents with ASD with respect to their school attendance as well as type and duration of their school inclusion.

First, the study results show that most of the children and adolescents with ASD attended school (88%). This represents a marked increase in school attendance in France since

Table 3 Links between school attendance (no school, special or regular classroom) and children's clinical characteristics

	0. No school N = 38		1. Special n = 28		2. Regular n = 262		p	Post hoc test
	N	%	N	%	N	%		
Children characteristics								
Best estimate IQ								
1. With Intellectual disability (IQ < 70)	24	80.0	12	50.0	75	37.1	**<.0001**	0 ≠ 1,2
2. Without intellectual disability (IQ >= 70)	6	20.0	12	50.0	127	62.9		
Center (Montpellier/others)	28/10	73.7	15/13	53.6	155/107	59.2	.2	
Sex (boys/girls)	27/11	71.1	23/5	82.1	226/36	86.3	.06	
Chronological age (SD)	38	6.4 (4.1)	28	9.0 (2.8)	262	6.3 (3.1)	**<.0001**	1 ≠ 0,2
	N	Mean(SD)	N	Mean(SD)	N	Mean(SD)	p	Post hoc test
VABS-II								
Communication (standard score)	38	57.0 (11.5)	28	66.9 (9.4)	248	72.9 (15.9)	**<.0001**	0 ≠ 1,2
Socialization (standard score)	38	60.9 (12.6)	28	66.3 (10.7)	248	70.3 (10.9)	**<.0001**	0 ≠ 2
Daily living skills (standard score)	38	63.4 (12.3)	28	68.9 (10.7)	248	74.8 (12.9)	**<.0001**	0 ≠ 2
	N	%	N	%	N	%	p	Post hoc test
Sensory profile (SP)								
Q1: low registration (DICH*)	16/14	53.3	14/8	63.6	115/67	63.2	.6	
Q2: sensation seeking (DICH)	18/5	78.3	9/11	45.0	95/55	63.3	.08	
Q3: sensory sensitivity (DICH)	12/7	63.2	12/5	70.6	86/52	62.3	.8	
Q4: sensation avoiding (DICH)	12/6	66.7	16/4	80.0	104/32	76.5	.6	
	N	Mean(SD)	N	Mean (SD)	N	Mean(SD)	p	Post hoc test
Aberrant behavior checklist (ABC)								
ABC 1: irritability	31	40.4 (20.5)	22	36.0 (26.4)	227	33.5 (19.6)	.3	
ABC 2: lethargy	31	32.1 (20.3)	22	32.0 (20.8)	226	26.8 (17.8)	.2	
ABC 3: stereotypy	30	48.6 (27.6)	22	39.6 (25.6)	227	29.2 (22.4)	**<.0001**	0 ≠ 2
ABC 4: hyperactivity	31	50.6 (20.2)	23	37.0 (27.1)	229	43.2 (23.9)	.07	
	N	%	N	%	N	%	p	Post hoc test
Child Behaviour Checklist (CBCL)								
Internalizing (DICH2)	21/10	67.7	17/5	77.3	169/49	77.5	.5	
Externalizing (DICH2)	17/14	54.8	12/10	54.5	121/97	55.5	.9	
Affective problems (DICH2)	16/15	51.6	14/8	63.6	129/89	59.2	.6	
Anxiety problems (DICH2)	12/19	38.7	17/6	73.9	103/115	47.2	**.02**	1 ≠ 0,2
Attention deficit (DICH2)	11/20	35.5	6/15	28.6	70/148	32.1	.9	
Oppositional problems (DICH2)	5/26	16.1	4/18	18.2	53/165	24.3	.5	
Conduct problems (DICH2)	6/6	50.0	3/19	13.6	31/75	29.2	.09	
Pervasive developmental problems (DICH2)	15/4	78.9	0/0	.	92/21	81.4	.8	
Parental characteristics							p	Post hoc test
Parent's study level	N	%	N	%	N	%		
Fathers								
Elementary	4	10.5	1	4.0	6	2.4	**.01**	0 ≠ 2
Secondary (high school)	23	60.5	13	52.0	114	45.1		
Higher qualifications (college, graduate school)	11	28.9	11	44.0	133	52.6		
Mothers								
Elementary	3	8.3	.		5	1.9	**.002**	0 ≠ 2
Secondary (high school)	20	55.6	15	53.6	86	33.1		
Higher qualifications (college, graduate school)	13	36.1	13	46.4	169	65.0		

Table 3 (continued)

Parental characteristics							p	Post hoc test
Parent's study level	N	%	N	%	N	%		
Socio-professional status								
Fathers								
Agricultural worker	0	0	0	0	4	1.7	.2	
Craftsman, sale worker, or entrepreneur	5	16.7	1	4.2	27	11.3		
Manager, engineer, or doctor	4	13.3	3	15.5	66	27.7		
Intermediate occupation	0	0	1	4.2	15	6.3		
Employee	14	46.7	16	66.6	87	36.6		
Worker	6	20.0	3	12.5	24	10.1		
Retired	0	0	0	0	2	.8		
No professional occupation	1	3.3	0	0	13	5.5		
Mothers								
Agricultural worker	0	0	0	0	1	.4	**.0002**	0≠2
Craftsman, sale worker, or entrepreneur	0	0	2	7.7	9	3.7		
Manager, engineer, or doctor	3	9.7	1	3.8	55	22.8		
Intermediate occupation	1	3.2	3	11.5	21	8.7		
Employee	16	51.6	15	57.7	110	45.6		
Worker	4	12.9	0	0	1	.4		
Retired	0	0	0	0	0	0		
No professional occupation	7	22.6	5	19.2	44	18.3		

Significant associations (p-value < .05) are presented in bold

DICH atypical/typical, *DICH2* pathological/no

a survey conducted a decade earlier, in which it was noted that only 55% of the children and adolescents with ASD were included in school (CNSA 2011). However, 11.6% of subjects in the study did not attend school, the figure in particular increasing to 20% for adolescents, ages 12-16 years. The findings reflect that the schools were not adapted in addressing the inclusion of the more challenging subjects with ASD. For example, we found that children and adolescents with more severe ASD profiles, e.g., those with co-occurring intellectual disability and challenging behaviors (who require additional supports and trained staff) were less likely to be included. Inclusion in regular classrooms without individual aides is a great burden and can be counterproductive without implicit support. Further, teachers often have inadequate behavioral training in managing students with ASD (Praisner 2003; Rattaz et al. 2013a; Smith 2007) and the number of special classes for children and adolescents with ASD are still insufficient, especially for older adolescents.

Second, the study results show that the children and adolescents with ASD who did not attend school represent a distinct group including not only subjects with low cognitive and adaptive functioning, but also co-occurring stereotypies as well as lower education level of parents. Although ASD severity and cognitive impairment have been consistently linked with stereotypies (Goldman et al. 2009; Rattaz et al. 2018), its influence on school inclusion is of further interest. We can hypothesize that factors explaining the lack of inclusion in school are, in part, due to individual clinical profiles of the children and adolescents, who might lack prerequisite skills to model the behavior of others, or to follow group instruction without requisite supports. However, the presence of such challenges is not a justification for exclusion but provide responsibility on behalf of school authorities to enable equitable inclusion. As the results regarding the lower educational level of parents suggest, a socio-economical gradient also plays a role in observed disparities related to school inclusion. The finding of higher rate of school inclusion of children and adolescents with ASD with better cognitive and adaptive abilities is consistent with previous studies (Eaves and Ho 1997; White et al. 2007). The children and adolescents who were included in the regular classrooms also had less stereotypies compared to children included in special classes. The presence of stereotypies, which is mostly related to cognitive level (Rattaz et al. 2018), was more common in subjects in special classes, who were more likely to have lower cognitive and adaptive functioning.

Third, among emotional and behavioral comorbidities noted on the CBCL, symptoms of anxiety were more common in children and adolescents in special classes compared to those in regular classes, as well as compared to those not attending school. It is well established that the prevalence

Table 4 Links between school duration and children's clinical characteristics

	a. Half days < 4		b. 4 ≤ Half days < 7		c. Half days ≥ 7		p-value	Post-hoc test
	N	%	N	%	N	%		
Best estimate IQ								
1.With Intellectual disability (IQ < 70)	17	70.8%	43	55.8%	10	11.9	**<.000001**	a,b ≠ c
2. Without intellectual disability (IQ ≥ 70)	7	29.2%	34	44.2%	74	88.1%		
VABS-II	N	Mean ± SD	N	Mean ± SD	N	Mean ± SD		
Communication (standard score)	36	57.8 ± 12.2	96	70.4 ± 14.3	95	80.5 ± 13.5	**.0001**	a ≠ b ≠ c
Socialization (standard score)	36	65.8 ± 9.4	96	69.4 ± 9.8	95	72.5 ± 11.3	**.002**	a ≠ c
Daily living skills (standard score)	36	68.3 ± 12.8	96	73.8 ± 12.7	95	77.8 ± 12.2	**.001**	a ≠ c
Sensory profile (SP)	N	%	N	%	N	%	p-value	Post-hoc test
Q1: Low registration (DICH)	11/9	55.0	47/24	66.2	47/29	61.8	.6	
Q2: Sensation seeking (DICH)	13/3	81.3	44/13	77.2	30/34	46.9	**.0007**	a,b ≠ c
Q3: Sensory sensitivity (DICH)	11/5	68.8	36/16	69.2	30/25	54.5	.3	
Q4: Sensation avoiding (DICH)	3/5	37.5	41/9	82.0	52/13	80.0	**.02**	a ≠ b,c
Aberrant behavior checklist (ABC)	N	Mean ± SD	N	Mean ± SD	N	Mean ± SD	p-value	Post-hoc test
ABC 1 : irritability	28	37.9 ± 20.4	92	38.3 ± 17.8	89	28.4 ± 19.0	**.002**	b ≠ c
ABC 2: lethargy	28	35.0 ± 19.5	92	28.2 ± 15.7	89	24.0 ± 18.7	**.006**	a ≠ c
ABC 3: stereotypy	28	35.0 ± 25.0	92	31.4 ± 21.9	89	26.0 ± 22.2	**.09**	
ABC 4: hyperactivity	29	56.8 ± 21.9	93	49.3 ± 21.8	89	34.6 ± 23.4	**.0001**	a,b ≠ c
CBCL	N	%	N	%	N	%	p-value	Post-hoc test
Internalizing (DICH2)	21/6	77.8	67/21	76.1	71/17	80.7	.7	
externalizing (DICH2)	19/8	70.4	48/40	54.5	49/39	55.7	.3	
Affective problems (DICH2)	15/12	55.6	52/36	59.1	54/34	61.4	.9	
Anxiety problems (DICH2)	5/22	18.5	35/53	39.8	56/32	63.6	**.00004**	a ≠ b≠c
Attention deficit (DICH2)	5/22	18.5	27/61	30.7	35/53	39.8	.1	
Oppositional problems (DICH2)	5/22	18.5	24/64	27.3	22/66	25.0	.7	
Conduct problems (DICH2)	0/2	.0	9/16	36.0	21/49	30.0	.7	
Pervasive developmental problems (DICH2)	24/1	96.0	53/10	84.1	6/12	66.7	**.03**	

Significant associations (p-value < .05) are presented in bold

DICH atypical/typical, *DICH2* pathological/no

of anxiety in children and adolescents with ASD is significantly greater than the prevalence of anxiety in the general population, with as much as 84% of subjects having anxiety symptoms (Vasa and Mazurek 2015). One possible explanation for such a higher rate of anxiety among subjects in special classes may be their older average age (9) compared to children in the other groups (6). A possibility therefore is that anxiety symptoms appear later in development, as reported by (White et al. 2009), with symptoms becoming more prominent during adolescence. Anxiety symptoms were also related to the duration of school inclusion, with more symptoms exhibited by children and adolescents who were attending school on a full time basis. One possible explanation for this is that the duration of school attendance was related to the children and adolescents' cognitive level. Previous studies also report a positive association between cognitive level and anxiety in children and adolescents with ASD (Mayes et al. 2011; Vasa and Mazurek 2015). It is possible that youth with higher cognitive abilities have greater awareness of their social and adaptive impairments, leading to increased anxiety (Vasa and Mazurek 2015). Furthermore, it is conceivable that an entire day of school may represent a considerable challenge for a child and adolescent with ASD, requiring them to maintain attentional abilities, to tolerate other students, and manage their sensory environment, which might lead to an increase in level of anxiety symptoms. This association between duration of school attendance and anxiety therefore is an intuitive result, as difficulties regarding social interaction, rigidity of thinking, and sensory vulnerabilities, coupled with a high level of anxiety, place young people with ASD at particular risk of school refusal (Preece and Howley 2018).

Fourth, the study findings also point to a link between duration of school attendance and the cognitive and adaptive functioning of the children and adolescents with ASD. Among children and adolescents with ASD who were in partial inclusion (4–6 half days per week), almost half had no intellectual disability (44.2%), with standard scores on VABS-II ranging from 72.5 (socialization), 77.8 (daily living skills), and communication (80.5), in borderline adaptation range. It is therefore interesting as to why these children and adolescents with ASD were not as likely to be in full time classes. There was definite agreement between increasing number of half-days per week in school inclusion and increasing level of Best Estimate IQ and VABS-II scores. Another important consideration was the restrictive role of comorbid challenging behaviors on school inclusion. A significant relationship was noted between duration of school attendance and challenging behaviors. The domains more significantly impacted for subjects in partial inclusion compared to those in full-time inclusion were irritability, lethargy and hyperactivity. Irritability and hyperactivity are challenging behaviors that are not part of the ASD core symptoms; their co-occurrence also reflect greater degree of communicative difficulties and frustration tolerance. Furthermore, it is well known that irritability and hyperactivity are a significant concern for teachers who may worry about the potential impact of these behaviors on their other students (Ferraioli and Harris 2011). Such behaviors may reduce the effectiveness of the instructional environment for teachers, and result in decreased opportunities for learning, not only for index student with ASD, but for an entire class (McCurdy and Cole 2014), reflecting the need for additional supports, e.g., individual aides, pull-out support staff, that may not otherwise be available to them. The partial inclusion may also reflect time taken away from school for interventions and therapies outside the school setting, as many children in the sample benefited from interventions such as speech, occupational and physical therapies.

Fifth, an important potential factor limiting full time school inclusion relates to sensory processing difficulties, particularly prominent in children who were partially included. Results showed that a *sensation seeking* profile was present in most children who were partially, or very partially, included in the regular classroom. The sensory processing difficulties such as hyper- or hypo-reactivity to sensory input or unusual interests in sensory aspects of the environment are currently conceptualized as part of the ASD diagnostic criteria and have been found to have a significant impact on daily functioning of children and adolescents with ASD (Bogdashina 2006; Dellapiazza et al. 2019; Leekam et al. 2007). In a study about the impact of sensory processing on school inclusion in adolescents with ASD, most of the participants considered their sensory experiences to affect their ability to learn, describing concentration difficulties, anxiety and discomfort (Howe and Stagg 2016). It is possible therefore that sensory processing difficulties can be a limiting factor for full time inclusion. On the other hand, we found *sensation avoiding* profile in many children and adolescents with ASD in full time inclusion. Sensation avoidance can be considered as an adaptive strategy for youth with ASD (Ashburner et al. 2013) and might thus be directly related to the possibility to benefit from full time inclusion.

Limitations

The study findings need to be considered in the light of number of important limitations. The ELENA Cohort is not a representative sample of the French general population but embodies systematic data collection at the collaborating national sites. The initial data utilized in this report is cross-sectional. Nonetheless, the overall objective of the ELENA Cohort is to contribute to novel findings with regards to clinical characteristics of the children with ASD and their developmental trajectories. The strengths of the study are a large sample of children and adolescents with ASD across different departments in France with a well-established diagnosis and an exhaustive and standardized collection of clinical and psychosocial data allowing assessment of school inclusion during this period.

Conclusion and Future Directions

A number of findings from the initial phase of the data from the ELENA Cohort study reveal that children and adolescents with ASD who participated in inclusionary school services in France had better cognitive and adaptive characteristics than those in out of school and specialized settings. To our knowledge, the atypical *sensation seeking* profile of children and adolescents with ASD who were partially, or very partially included, compared to *sensation avoiding* profiles of children and adolescents with ASD in full inclusion has not been previously reported. The association between duration of school attendance and anxiety among children and adolescents with ASD in the full inclusionary classes is also an important result that suggests the need for additional supports for students, in particular, with higher functioning profile of ASD in schools. Such supports are likely to help students with ASD to better adapt to their inclusionary school environment. Among the factors that might be helpful for successful school inclusion, we can further cite the importance of the appropriate learning environment, a focus on the individual characteristics of the children and adolescents, and the consistency of staffing and an effective communication and collaboration with the families (Preece and Howley 2018).

Many questions remain open regarding the type and degree of inclusion, what kind of training and which supports, for what types of students (Ferraioli and Harris 2011).

Research should continue to explore and develop a deeper understanding of practical ways to create opportunities for children and adolescents to attend school and benefit from learning and social inputs. Further studies are also needed to probe the role of the school professionals and the type of supports that promote inclusion.

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Compliance with Ethical Standards

Conflict of interest The authors declare that they have no conflict of interest.

Ethical Approval This study was approved by the Medical ethical committee and the National Commission for Computing and Liberties (CNIL: DR-2015-393).

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