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ORIGINAL ARTICLE

Contributions of the ELENA Cohort to Study Autism Spectrum Disorder in Children and Adolescents from a Biopsychosocial Framework

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Abstract

Autism spectrum disorder (ASD) is a complex neurodevelopmental condition influenced by a myriad of developmental, biological, psychological, and socio-demographic factors. The ELENA cohort seeks to delineate the intricate interplay of these factors, facilitating the identification of risk factors and the development of targeted interventions. This paper emphasizes the clinical profiles of children and outlines key findings from a biopsychosocial perspective. The ELENA cohort, a multicenter initiative across French regional centers, conducted a systematic prospective analysis on children newly diagnosed with DSM-5 ASD between 2012 and 2019. This encompassed direct assessments and parent-reported questionnaires covering a broad spectrum of developmental, biological, psychological and socio-demographic measures. Embedded case–control studies further examined risk and protective factors, alongside specific environmental and psychosocial influences during pregnancy and early childhood. A subset of participants also contributed biospecimens, with data enhancement via linkage to French National Administrative Healthcare Databases. The study unveils baseline clinical characteristics for 876 children, average age 6 (SD ± 3.3) previously unreported in protocol descriptions. It highlights the study's developmental biopsychosocial approach and its novel findings on children's socio-adaptive functioning, ASD severity, comorbidities, quality of life and interventions. Employing developmental biopsychosocial insights offers a promising pathway to integrating health, social care, and experiential insights, ultimately aiming to enhance the future well-being and outcomes for children with ASD. This approach underscores the need of a holistic, interdisciplinary strategy in encouraging and supporting the ASD community.

Keywords Autism spectrum disorder · Developmental course · Cohort · Prognosis · Biopsychosocial

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Introduction

Autism spectrum disorder (ASD) is a highly heterogeneous neurodevelopmental condition typically emerging in early childhood (American Psychiatric Association, 2013; World Health Organization, 1993) with increasing prevalence and global impact (Billstedt et al., 2007; Fein et al., 2013; Gillberg & Billstedt, 2000; Howlin et al., 2004). ASD is generally believed to result from complex interactions between genetic and environmental factors, and includes roles of common genetic variants, rare mutations, prenatal exposures impacting brain development, and maternal health and pregnancy related factors (Chaste & Leboyer, 2012; Modabbernia et al., 2017).

The biopsychosocial framework emphasizes interconnectedness of these factors and highlights the importance of considering these dimensions in understanding not only

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causal mechanisms, but in elucidating the effect of interventions promoting health and well-being.

Children and adolescents with ASD exhibit diverse strengths and challenges, affecting long-term outcomes. Comprehensive regional epidemiologic cohort studies are crucial for improving clinical services and tailored interventions. Limited evidence exists about the optimal efficacy of interventions (Vivanti et al., 2017). ASD significantly impacts families, with elevated stress levels and reduced quality of life (Baghdadli et al., 2014; Ingersoll & Hambrick, 2011; Mugno et al., 2007; Rattaz et al., 2017). ASD services have significant economic and societal implications, with an average annual cost of around $35,000 per family in the United States (Horlin et al., 2014).

Families are concerned about their ASD children's independence and life fulfillment (Baghdadli et al., 2007, 2012; Farley et al., 2009). Previous studies on natural course of ASD and factors influencing outcomes (Baghdadli et al., 2007, 2012; Fountain et al., 2012; Howlin et al., 2004), have been limited by retrospective designs, small sample sizes, and insufficient consideration of genetic-environmental interactions. Prospective data gathering across multiple dimensions at time points is essential to comprehensively investigate the course of ASD and relevant prognostic factors.

The ELENA Autism Cohort Study in France is a multiENtric Longitudinal study of childrEN with ASD (ELENA) that systematically collects prospective data across various dimensions and time intervals. The acronym ELENA, in French, stands for "Etude Longitudinale de l'Enfant et du Nouveau-né avec Autisme." The study aims to scrutinize the course, trajectory patterns and prognostic factors. The inclusion of nested case control studies within the larger cohort design allowed further examination of environmental exposures, drug usage, and variety of developmental and social factors during pregnancy and early infancy. The controls were selected from among the assembled ELENA ASD cohort who have not developed the outcome being examined at the time each case was identified. Biospecimens were collected from a subset of the cohort, and data were linked with the National Administrative Health care Databases (Système national des données de santé—SNDS).

This paper presents baseline clinical characteristics of the ELENA cohort enhancing the original protocol description (Baghdadli et al., 2019). A biopsychosocial perspective is used to showcase key and novel findings, recognizing the interplay of developmental, biological, psychological, and socio-demographic factors in determining ASD outcomes. This approach enables the identification of risk factors and the development of targeted interventions and prevention initiatives moving beyond one-dimensional causality.

Methods

Study Population

The ELENA study followed a standardized protocol across the six regions in France (Baghdadli et al., 2019) between 2012 and 2019. The inclusion criteria were: first diagnosis of ASD following DSM-5 criteria confirmed through multi-disciplinary assessments; age 2–16 years of index children and adolescents; written parental consent; and French language proficiency (Baghdadli et al., 2019). Initially, 1004 children and adolescents were eligible, but 125 were excluded in view of parental refusal (n = 89), and not fully affirming inclusion criteria (n = 39). Consequently, 876 children and adolescents constituted the study baseline cohort (referred to as Wave 0). Figure 1 illustrates ELENA cohort's flow-chart, while Fig. 2 shows the geographical distribution of the six collaborating regions and the recruitment percentage from each region.

Data Collection and Follow-Up

Data Collection

Over six years, the children and adolescent enrolled in the study underwent careful monitoring through regular visits to one of the thirteen designated centers across the six collaborating regions with completion of online questionnaires at specific intervals. Additionally, parents participated in face-to-face interviews with psychologists at each wave and completed self-reported questionnaires for themselves and their child. Clinical data were directly entered online at each site using Ennov Clinical software. Parents used the ELENA database electronic system, facilitated by Epiconcept, to complete self-reported questionnaires online. For participants without internet access or those preferring an alternative method, clinical research assistants conducted telephone questionnaire sessions or filled out hard copies. Data collected via phone or hard copy were subsequently entered into the ELENA database electronic system.

Follow-Up Schedule

The study included four follow-up visits: the first at 18 months after the baseline assessment (Wave 1 or W1), followed by visits at 3, 4.5 and 6 years after the baseline, corresponding to W2, W3 and W4, as illustrated in Fig. 3. Throughout the study, each child underwent clinical evaluations at baseline (W0), W2, and W4, conducted by licensed developmental psychologists using standardized assessment tools.

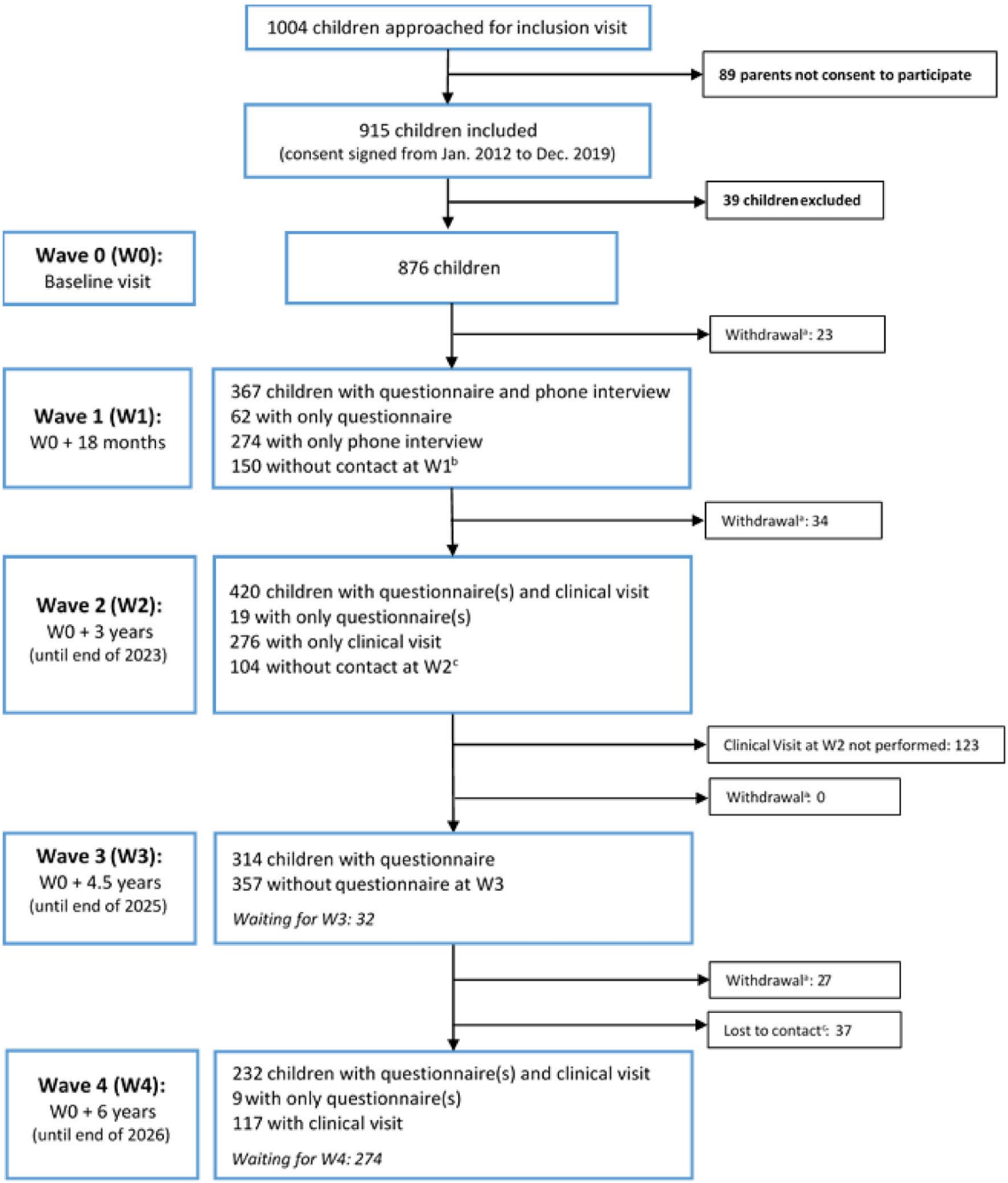

Fig. 1 Flow chart of the ELENA cohort. Figure extracted from the database in January 2023. *W* Wave. [a]Withdrawal: Families who informed by written or oral a request to end their participation. [b]No phone interview and no questionnaire. [c]Clinical visit not performed and no questionnaire

Participation and Attrition

As of January 2024, data collection for W1 and W2 was completed: 641 children's parents (73.2%) participated in phone interviews at W1, and 696 children (79.5%) attended clinical visits at W2, as shown in Fig. 1. Overall, 244 families (27.8%) have either been lost to follow-up or were voluntarily withdrawn from the study. In this situation, families notified the study team through written or oral requests that they wanted to end their participation. However, as no formal withdrawal of informed consent was received, the data collected from these families have been retained in the database and remain available for the analysis. Twenty-eight percent of low socioeconomic status (SES) families were lost to follow up or withdrawn, versus 18% of high and middle SES families. Children

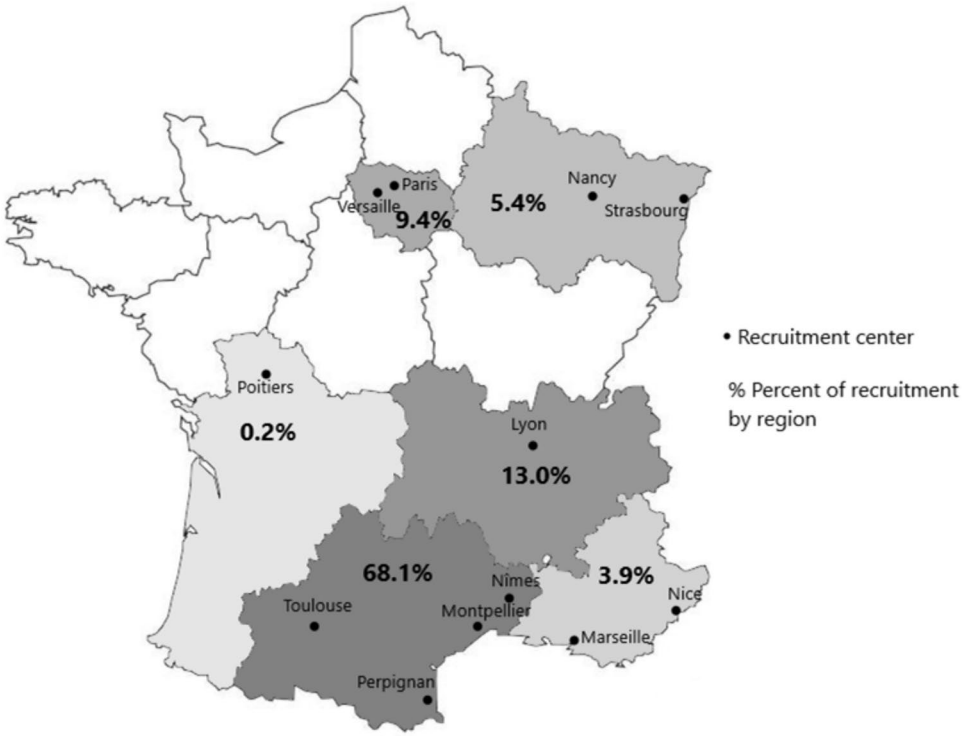

Fig. 2 Localization of the recruitment centers and percent of recruitment by regions

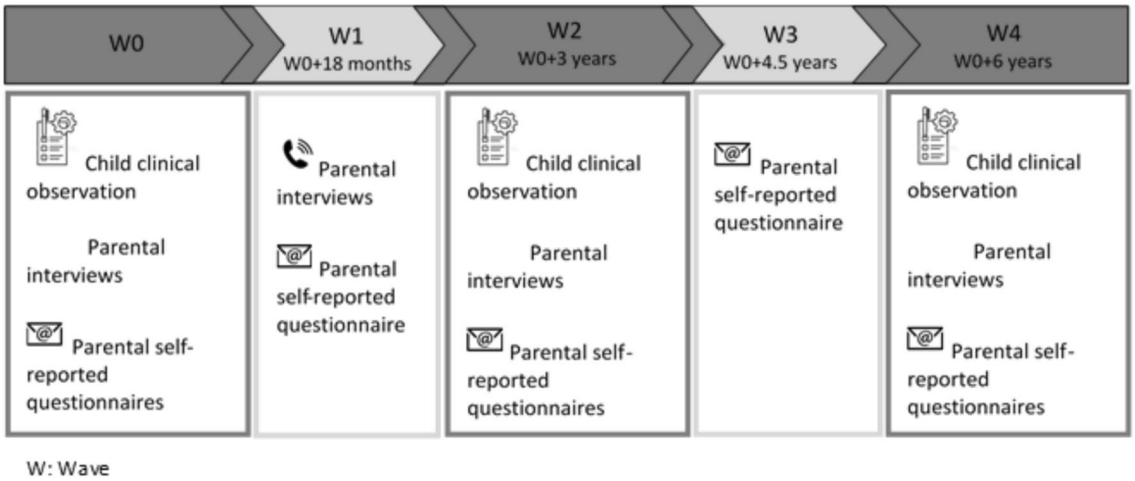

Fig. 3 Follow-up schedule

and adolescents from families not in follow up exhibited lower intellectual quotient (IQ) and reduced adaptive skills (VABS-II scores) ($p < 0.05$). Nonetheless, there were no noticeable disparities in Autism Direct Observational Schedule-2 (ADOS-2) CSS-scores among the index children and adolescent who continued in the study compared to those who were lost to follow up or withdrew (Table 1). Children and adolescents from families not in follow-up had lower socialization scores, regardless their SES. Additionally, those from high SES families exhibited lower IQ and daily living skills scores compared to their peers who continued in the study (Online Resource 1).

Measurements

Study Protocol Measurements

Table 2 presents a comprehensive overview of the data collection at each follow-up stage. To diagnose and evaluate the severity of ASD symptoms, we used two established

Table 1 Comparison of sociodemographic and clinical characteristics at baseline (Wave 0) between participants still being followed and those lost-to follow-up or who withdrew

	Participant still followed (*N* = *632*)	Participants lost to follow-up or withdrew (*N* = *244*)	p value
Children's characteristics			
Chronological age (years)	5.9 (± 3.3)	6.2 (± 3.4)	0.18
Gender			
Boys	528 (83.5%)	196 (80.3%)	0.26
Girls	104 (16.5%)	48 (19.7%)	
Parents' characteristics			
Age at the child's birth (years)	*N* = *513*	*N* = *132*	
Fathers	34.6 (± 6.7)	34.6 (± 7.2)	0.92
	N = *517*	*N* = *136*	
Mothers	31.4 (± 5.4)	31.1 (± 5.5)	0.49
Paternal educational level	*N* = *417*	*N* = *116*	
Middle school	11 (2.6%)	4 (3.4%)	0.68
High school	194 (46.6%)	50 (43.2%)	
Graduated school	212 (50.8%)	62 (53.4%)	
Maternal educational level	*N* = *424*	*N* = *118*	
Middle school	9 (2.1%)	2 (1.7%)	0.61
High school	152 (35.8%)	48 (40.7%)	
Graduated school	263 (62.1%)	68 (57.6%)	
Parental socioeconomic status[b]	*N* = *427*	*N* = *120*	
High	144 (33.7%)	38 (31.7%)	0.01
Middle	123 (28.8%)	20 (16.7%)	
Low	160 (37.5%)	62 (51.7%)	
Children's clinical characteristics			
Best-estimate Intellectual Quotient (IQ)	74.4 (± 26.7)	69.1 (± 25.5)	0.01
Autism Diagnostic Observation Scheduled (ADOS-2)	*N* = *612*	*N* = *232*	
Calibrate severity score (CSS)[c]	7.2 (± 2.0)	7.1 (± 2.1)	0.37
Vineland Adaptive Behavior Scales (VABS-II)	*N* = *632*	*N* = *244*	
Communication standard score	70.9 (± 15.4)[a]	67.6 (± 15.1)[a]	< 0.01
Socialization standard score	70.8 (± 10.8)[a]	67.5 (± 10.2)[a]	< 0.01
Daily living skills standard score	74.3 (± 12.9)	70.8 (± 12.2)	< 0.01

Data are given in mean (± SD) or n (%)

[a]1 missing data

[b]Low SES: farm workers, labourers, service workers and unemployed; Medium SES: farmers, supervisors, skilled craftsmen; High SES: business owners, professionals, managers

[c]CSS (calibrate severity score) available for Module 1, 2 and 3

diagnostic tools: Autism Diagnostic Observation Schedule-2 (ADOS-2; Lord et al., 2002, 2012) and Autism Diagnostic Interviewed Revised (ADI-R; Rutter et al., 2003).

Children's examination covered various behavioral and developmental aspects, including: best-estimate intellectual quotient (IQ) using psychometric scales (Baghdadli et al., 2019; Howlin et al., 2014); adaptive skills assessed with Vineland Adaptive Behavior Scales (VABS, VABS-II; Sparrow et al., 1984, 2005); receptive vocabulary using the French adaptation of the Peabody Picture Vocabulary Test-Revised (PPVT-R; Dunn & Dunn, 1981; Dunn et al., 1993); expressive language (item number 30 of ADI-R) and receptive language (Preschool Language Scales 5th edition, PLS-5; Zimmerman et al., 2011); and motor skills examined using the Movement Assessment Battery for children (MABC, MABC-2; Henderson et al., 1992, 2007).

Parents' assessments included: (1) socio-demographic and medical information, interventions and school attendance; (2) parental psychosocial characteristics, encompassing perceptions of their child's Quality of Life (QoL) using the Kidscreen-27 Parental Form (Ravens-Sieberer et al., 2007), their perception of the impact of ASD on their own

Table 2 Study protocol measurements of the ELENA study at baseline and during the follow-up

Measurement	Assessment	W0: Baseline	W1: W0 + 18 months	W2: W0 + 36 months	W3: W0 + 54 months	W4: W0 + 72 months
Direct clinical observation of the child						
ADOS-2 (Lord et al., 2002, 2012)	Assessment of an individual's behavior in the areas of communication, reciprocal social interaction, imagination/creativity, and stereotyped behaviors and restricted interests Provides an ASD diagnosis (W0) and measures the severity of the symptoms (W2 and W4) encompassing the social affect and the restricted and repetitive behaviors	✓		✓		✓
Psychometric tests: Weschler Intelligency scales (WISC-IV (Wechsler, 2003), WISC-V (Wechsler, 2014a), WPPSI-R (Wechsler, 2014b), WAIS-IV (Wechsler, 2008)), KABC (Kaufman & Kaufman, 2004), BECS (Adrien, 2007), Brunet Lézine-R (Brunet et al., 1997), PEP-3 (Schopler et al., 2004), PEP-R (Schopler, 1990), SON-R (Tellegen et al., 2009), RCPM (Raven et al., 1998), WNV (Wechsler & Naglieri, 2006), Echelle de Mullen (Mullen, 1995)	Assessment of the cognitive level (Best estimate IQ)	✓		✓		✓
PPVT-R (Dunn & Dunn, 1981; Dunn et al., 1993)	Assessment of receptive vocabulary	✓		✓		✓
PLS (Zimmerman et al., 2011)[a]	Assessment of receptive speech	✓				
MABC, MABC-2 (Henderson et al., 1992, 2007), DF-MOT (Vaivre-Douret, 1999), NEPSY-I (Korkman, 1998), NEPSY-II (Korkman et al., 2007), Rey-Osterrieth Complex Figure Test (Osterrieth, 1944), BHK (Charles et al., 2003)[a]	Assessment of Motor skills	✓				
Parental interviews						

Table 2 (continued)

Measurement		Assessment	W0: Baseline	W1: W0 + 18 months	W2: W0 + 36 months	W3: W0 + 54 months	W4: W0 + 72 months
	ADI-R (Rutter et al., 2003)	Assessment of skills in communication, social reciprocity and restricted and repetitive behaviors	✓				
		Assessment of expressive language with Item 30					
	VABS II (Sparrow et al., 1984, 2005)	Assessment of child's adaptive skills: communication, daily living skills and socialization	✓	✓	✓		✓
Parents' self-reported questionnaire							
About the child	Medical report	Prenatal and perinatal, medical/health problems, diagnosis, current medication, current nutrition, etc	✓				
	Interventions report	Interventions, scholarship, age at first psychiatric advice, age at first interventions, etc	✓	✓	✓	✓	✓
	SRS-2 school and preschool (Bruni, 2014; Constantino & Gruber, 2012)	Assessment of social impairment and its severity associated with ASD	✓		✓		✓
	Sensory Profile (Dunn, 1999)	Assessment of sensory processing abilities. Results according to four quadrants (low registration, sensory seeking, sensory sensitivity and sensory avoiding), factors and sections	✓		✓		✓
	ABC (Aman et al., 1985)	Assessment of challenging behaviors across four domains: irritability, lethargy/withdrawal, stereotypy, hyperactivity	✓		✓		✓
	CBCL (Achenbach & Rescorla, 2000, 2001)	Assessment of child's specific behaviors, emotions, and emotional problems	✓		✓		✓
	Kidscreen-27 (Ravens-Sieberer et al., 2007)	Assessment of the parental perception of their child's Quality of Life	✓		✓		✓

Table 2 (continued)

Measurement		Assessment	W0: Baseline	W1: W0 + 18 months	W2: W0 + 36 months	W3: W0 + 54 months	W4: W0 + 72 months
About the parents	Medical report	Pregnancy	✓				
	Socio-demographic report	Parental characteristics: age, marital status, education levels, socioeconomic status, siblings, autism training, etc	✓	✓	✓	✓	✓
	HADS (Zigmond & Snaith, 1983)	Assessment of parents' anxiety and depression	✓		✓		✓
	WCC-R (Cousson et al., 1996)	Assessment of the parental coping strategies (problem-focused coping; emotion-focused coping; and seeking social support)	✓		✓		✓
	PSI-4-SF (Abidin, 1995)	Assessment of the parents' stress level associated with their parenting role	✓		✓		✓
	Par-DD-QoL (Baghdadli et al., 2014; Rattaz et al., 2017)	Assessment of the parental perception of the impact of ASD on their QoL (Emotional and Daily Disturbances score)	✓		✓		✓
Biological data							
	Blood[a]	Karyotyping, chromosomal analysis by DNA chip (comparative genomic hybridization, CGH array), exome sequencing and/or targeted sequencing on gene panels or genome	*One time during follow up*				

ABC aberrant behavior checklist, *ADI-R* revised version of the autism diagnostic interview, *ADOS* autism diagnostic observation schedule, *ASD* autism spectrum disorder, *BECS* Batterie d'Évaluation du développement Cognitif et Social, *BHK* Concise Assessment Scale for Children's handwriting, *CBCL* child behavior checklist, *CGH* comparative genomic hybridization, *DF-MOT* motor functional development scale, *HADS* hospital anxiety and depression scale, *KABC* Kaufman assessment battery for children, *NEPSI* neuropsychological performance, *Par-DD-QoL* parental-developmental disorder-quality of life, *PEP-R* psychoeducational profile-revised, *PEP-3* psychoeducational profile-third edition, *PPVT-R* peabody picture vocabulary test-revised, *PSI-4-SF* parenting stress index, fourth edition short form, *QoL* quality of life, *RCPM* Raven's colored progressive matrices, *SON-R* revised Snijders-Oomen nonverbal intelligence test, *SRS-2* social responsiveness scale-2, *VABS-II* vineland adaptive behavior scales, second edition, *W* wave, *WAIS* Wechsler adult intelligence scale, *WISC* Wechsler intelligence scale for children, *WCC* French ways of coping checklist, *WNV* Wechsler nonverbal scale of ability, *WPPSI* Wechsler preschool and primary scale of intelligence

[a]Available only for the Montpellier Center

QoL employing the Parental-Developmental Disorder-Quality of Life (Par-DD-QoL;Baghdadli et al., 2014; Rattaz et al., 2017), and coping strategies using the French Ways of Coping Checklist (WCC-R; Cousson et al., 1996), and assessment of stress levels with the Parenting Stress Index, Fourth Edition Short Form (PSI-4-SF; Abidin, 1995), and anxiety and depression levels using the Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983); and (3) parental report of child's behavior, including social impairment and its severity related to ASD using the Social Responsiveness Scale-2 (SRS-2; Bruni, 2014; Constantino & Gruber, 2012), emotional and behavioral disorders using the Child Behavior Checklist (CBCL; Achenbach & Rescorla, 2000, 2001), challenging behaviors through the Aberrant Behavior Checklist (ABC; Aman et al., 1985), and sensory processing functioning using the Sensory Profile (SP; Dunn, 1999).

More details about the study tools can be found in the study protocol (Baghdadli et al., 2019).

Biological samples: Following the diagnosis of ASD, children were referred to genetic services where blood samples were collected during their follow-up visits for comprehensive genetic analysis, including whole-genome sequencing. The genetic analysis results were compiled to enhance our database.

Measurements: Ancillary Studies

Within the ELENA cohort, several ancillary case control studies were conducted to expand data collection or facilitate biospecimens collection.

A summary of these studies is provided in Table 3.

Parents' assessments encompassed the following dimensions: (1) retrospective assessment of children's exposure to air pollution and agricultural pesticides, detailed in Ongono et al. (2022). Additionally, estimation of contextual socioeconomic parameters based on the geocode of their postal address during fetal life and the first years of their life, including urbanization, deprivation levels, and an index of accessibility to medical resources; (2) retrospective assessment of early feeding patterns, as described in Peries et al. (2023); (3) assessment of neurodevelopmental disorders in siblings of children, as outlined by Baghdadli et al. (2023); and (4) evaluation of the impact of COVID-19 containment measures on children with ASD and their families, as described by Berard et al. (2021, 2022) and Miniarikova et al. (2022).

The national insurance number was collected from participants included under informed consent to facilitate linkage and matching with SNDS data (French National Administrative Health care Databases (Système national des données de santé—SNDS; Scailteux et al., 2019; Tuppin et al., 2017). This linkage provides a comprehensive record of demographic data, medical conditions, prescribed medications, laboratory tests, healthcare visits, and hospital admissions from birth onwards. It enables passive tracking of children who may become lost to follow-up unless their parents explicitly request withdrawal from the study.

Biological samples: An ancillary study (known as LEDA) was extended to children monitored at the Montpellier centre who had received clinical evaluations (including the ADOS) within the last six months of their most recent follow-up appointment. This study involved the collection of stool and blood samples to investigate the gut microbiome, and explore the underlying mechanisms associated with ASD.

Results

The characteristics of the 876 children and their families are detailed in Tables 4 and 5.

Socio-Demographics

At baseline, the mean child age was 6.0 years (±3.3); 62% were under 6 years old (n = 545), 31% were aged 6–12 (n = 268) and 7% were 12 or older (n = 63). The male-to-female ratio was 4.8, consistent across age groups (Table 4). Parental age at the child's birth averaged 31.4 years (±5.4) for mothers and 34.6 years (±6.8) for fathers. Regarding parental education, 51.4% of fathers and 61.1% of mothers completed graduated school. Socioeconomic status was low (40.6% of participants), middle (26.1%), or high (33.3%). Most children (80.1%) lived with both parents. Families had one child (19.0%), two children (40.1%) or three or more (40.9%). In 8.2% of families, another child had an ASD diagnosis (Table 4).

Children and Adolescents' Clinical Characteristics

The mean IQ was 72.9 (±26.5), with the presence of an intellectual disability in less than half of the participants (45.7%). Adaptive skills were in the low range for communication (69.9 ± 15.3), socialization (69.9 ± 10.7) and daily living (73.4 ± 12.8). The autism calibrated severity score, evaluated through the ADOS, averaged 7.0 ± 2.0, and in most cases, there was severe social deficit measured by the SRS-2 (86.5%). Expressive language (ADI-R) was present in 36.4% of preschoolers, 82.2% of children, and 87.9% of adolescents. Receptive vocabulary (PPVT) averaged 36.8 months for preschoolers, 90.8 months for children, and 187.3 months for adolescents. A majority of children and adolescents (68.2%) showed impairment in motor development on the MABC-2, affecting both fine and gross motor skills.

Sensory Profile data indicated low registration (65.0%), sensation seeking (69.4%), sensory sensitivity (71.6%)

Table 3 List of ancillary studies embedded in the ELENA Cohort

Name and topic of the ancillary study	Main objective	Study period	n	Additional data the study brought in	Founder	Publications
Environment						
ETAP-ASD: Environmental exposures To Air Pollution and ASD in children	To determine whether exposure to ambient air pollution is associated with the risk of ASD in France	Ongoing	N = 373	Environment questionnaire (residential history from pregnancy to two years after the child's birth; mother's lifestyle during the pregnancy) Estimation of levels of exposure to particulate matter (PM) in the air at the residential address of the children's mothers	National Agency for Food, Environmental, and Occupational Safety (Anses)	Ongono et al. (2022)
ENVIRODISORDERS: Environmental pesticides and genetic predisposition: a path toward ASD	To determine whether there is an association between geographical use of glyphosate and the severity of clinical symptoms in children with ASD	Ongoing	N = 430	Estimation of the number of kg of glyphosate that has been applied within a 1 km radius of homes (during pregnancy and the first two years of life)	Montpellier Université d'Excellence (Muse-Soutien à la recherche 2020)	–
Nutrition						
ELENA-NUTRIL: Pilot study on early breastfeeding in the first year of life and ASD severity in the ELENA cohort	To investigate the association between clinical presentation severity in ASD and (i) the initiation of breastfeeding; (ii) the duration of any and predominant breastfeeding	September–November 2021	N = 243	Early feeding patterns self-questionnaire (initiation and duration of breastfeeding, respective ages at first formula feeding and solid foods)	–	Peries et al. (2023)
COVID-19						
ELENA-COVID: Impact of COVID-19 containment on children and adolescents with ASD included in the ELENA cohort and their parents	To describe the impact of the COVID-19 epidemic on the behavior (sleep, eating, communication skills, and stereotyped and challenging behaviors), living conditions, and care of children with ASD, as well as the psychological state of their parents	April–May 2020	N = 240	COVID-19 questionnaire (family environment, parental professional activity, information on COVID-19 and containment measures, child's health and special education) Standardized tools: HADS (Zigmond & Snaith, 1983)	–	Berard et al. (2021); Miniarikova et al. (2022)

Table 3 (continued)

Name and topic of the ancillary study	Main objective	Study period	n	Additional data the study brought in	Founder	Publications
ELENA-COVID 2: Impact of discrete COVID-19 lockdown period	To describe the course of the child's lifestyle 6 months after the beginning of the COVID-19 epidemic	November–December 2020	N = 249	COVID-19 questionnaire: (i) child characteristics, education and leisure activities, specialized care, sleep, social home environment and relationships; and (ii) child screen time use Standardized tools: HADS (Zigmond & Snaith, 1983); PSS-10 (Cohen, 1988)	–	Berard et al. (2022)
Gut-Brain Axis						
LEDA: Study of the link between intestinal dysbiosis and the integrity of the blood brain barrier in autism	To highlight the link between the gut microbiota and blood–brain barrier integrity in ASD	Recruitment ongoing	Expected N = 60	Standardized tools: Bristol Stool Chart; PedsQL GSS (Varni et al., 2012); SRS-2 (Bruni, 2014; Constantino & Gruber, 2012) Clinical examination Biological analysis: stool (pyrosequençage); blood (Markers of microbial translocation and intestinal permeability; markers of neuroinflammation; immune response; markers of integrity of blood brain barrier; metabolome analysis)	JANSSEN Horizon CHU Montpellier	–
National Health Data System						

Table 3 (continued)

Name and topic of the ancillary study	Main objective	Study period	n	Additional data the study brought in	Founder	Publications
ELENA-SNDS: Care pathway for children with Autism Spectrum Disorder Included in the ELENA Cohort: Matching to the National Health Data System	To identify patterns of care trajectories using data from ELENA cohort matched to data from national health insurance information system (SNDS). Secondary objectives are to examine the links between patterns of care trajectories and clinical characteristics, social environment of children with ASD	Ongoing	N = 691	Care consumption of children between 2007 and 2021	DGOS–PREPS CHU Montpellier	–
Siblings						
FRATSA: Multistage screening process for neurodevelopmental disorders in siblings of children with autism	To examine the feasibility of a selective screening process for NDDs for siblings (aged 2–16 years) of children with ASD prior to referral for diagnosis to general practitioners and intervention	Ongoing	Expected N = 384	Data concerning sibling of children included in ELENA cohort: Standardized tools: SRS-2 (Bruni, 2014; Constantino & Gruber, 2012); IdentiDys scale (Chartier et al., 2020); LDCDQ-FE (Jover et al., 2023; Wilson et al., 2015); DCDQ-FE (Ray-Kaeser et al., 2019) Parent's self-reported questionnaire: Parental concerns questionnaire; medical history; intervention and school data	French Health Ministry (DGOS), Inter-regional grant of GIRCI-SOHO (PHRC-I 2021)	Baghdadli et al. (2023)

Not all ancillary studies capture the complete ELENA cohort

ASD autism spectrum disorder, *DCDQ-FE* developmental coordination disorder questionnaire-French European, *HADS* hospital anxiety and depression scale, *LDCDQ-FE* little developmental coordination disorder questionnaire-French European, *NDD* neurodevelopmental disorder, *PedsQL GSS* gastrointestinal symptom scale, *PSS-10* perceived stress scale-10 items version, *SRS-2* social responsiveness scale-2

Table 4 Sociodemographic characteristics at baseline (Wave 0)

	All *(N = 876)*	Preschoolers [2–6 years[*(N = 545)*	Children [6–12 years[*(N = 268)*	Adolescents ≥ 12 years *(N = 63)*
Children's characteristics				
Chronological age (years)	6.0 (± 3.3)	3.8 (± 1.1)	8.5 (± 1.7)	14.0 (± 1.4)
Gender				
Boys	724 (82.7%)	453 (83.1%)	217 (81.0%)	54 (85.7%)
Girls	152 (17.3%)	92 (16.9%)	51 (19.0%)	9 (14.3%)
Sex-ratio (B/G)	4.8	4.9	4.3	6.0
Parents' characteristics				
Age at the child's birth (years)	*N = 645*	*N = 392*	*N = 209*	*N = 44*
Fathers	34.6 (± 6.8)	34.8 (± 6.7)	34.5 (± 7.2)	32.6 (± 5.7)
	N = 653	*N = 395*	*N = 212*	*N = 46*
Mothers	31.4 (± 5.4)	31.3 (± 5.3)	31.8 (± 5.7)	30.2 (± 4.7)
Paternal educational level	*N = 533*	*N = 310*	*N = 183*	*N = 40*
Middle school	15 (2.8%)	10 (3.2%)	4 (2.2%)	1 (2.5%)
High school	244 (45.8%)	140 (45.2%)	84 (45.9%)	20 (50.0%)
Graduated school	274 (51.4%)	160 (51.6%)	95 (51.9%)	19 (47.5%)
Maternal educational level	*N = 542*	*N = 312*	*N = 188*	*N = 42*
Middle school	11 (2.0%)	7 (2.2%)	2 (1.1%)	2 (4.8%)
High school	200 (36.9%)	118 (37.8%)	65 (34.6%)	17 (40.5%)
Graduated school	331 (61.1%)	187 (59.9%)	121 (64.4%)	23 (54.8%)
Parental socioeconomic status[c]	*N = 547*	*N = 317*	*N = 188*	*N = 42*
Low	222 (40.6%)	132 (41.6%)	77 (41.0%)	13 (31.0%)
Middle	143 (26.1%)	83 (26.2%)	46 (24.5%)	14 (33.3%)
High	182 (33.3%)	102 (32.2%)	65 (34.5%)	15 (35.7%)
Families' characteristics				
Participant's place of living	*N = 558*	*N = 326*	*N = 190*	*N = 42*
With both parents	447 (80.1%)	272 (83.4%)	142 (74.7%)	33 (78.6%)
With new step family	22 (3.9%)	7 (2.2%)	11 (5.9%)	4 (9.5%)
With one parent	85 (15.2%)	45 (13.8%)	36 (18.9%)	4 (9.5%)
Other	4 (0.8%)	2 (0.6%)	1 (0.5%)	1 (2.4%)
Siblings (full and half)	*N = 795*	*N = 498*	*N = 241*	*N = 56*
1	151 (19.0%)	113 (22.7%)	34 (14.1%)	4 (7.2%)
2	319 (40.1%)	202 (40.6%)	91 (37.8%)	26 (46.4%)
> = 3	325 (40.9%)	183 (36.7%)	116 (48.1%)	26 (46.4%)
Other child with ASD in the family	*N = 428*	*N = 233*	*N = 155*	*N = 40*
Yes	35 (8.2%)	23 (9.9%)	8 (5.2%)	4 (10.0%)
No	393 (91.8%)	210 (90.1%)	147 (94.8%)	36 (90.0%)

Data are given in mean (± SD) or n (%)

[a]1 missing data

[b]CSS (calibrate severity score) available for Module 1, 2 and 3

[c]Low SES: farm workers, labourers, service workers and unemployed; Medium SES: farmers, supervisors, skilled craftsmen; High SES: business owners, professionals, managers

and sensation avoiding (76.4%). Challenging behaviors (ABC) revealed moderate levels of irritability (mean score = 33.9 ± 20.9), lethargy (27.3 ± 18.6) and stereotypy (32.0 ± 23.9), and high levels of hyperactivity (44.0 ± 23.5). Comorbid disorders were frequent, with internalizing problems in 74.4% and externalizing problems in 53.2% of the participants (see details in Table 5).

Table 5 Children's and adolescent's clinical characteristics at baseline (W0)

	All	Preschoolers [2–6 years[	Children [6–12 years[	Adolescents ≥ 12 years
	N = 876	*N = 545*	*N = 268*	*N = 63*
Best-estimate Intellectual Quotient (IQ)	72.9 (± 26.5)	65.3 (± 22.5)	84.7 (± 28.0)	88.3 (± 26.8)
With intellectual disability (IQ < 70)	400 (45.7%)	318 (58.3%)	67 (25.0%)	15 (23.8%)
Without intellectual disability (IQ > = 70)	476 (54.3%)	227 (41.7%)	201 (75.0%)	48 (76.2%)
Autism Diagnostic Observation Scheduled (ADOS-2)	*N = 776*	*N = 464*	*N = 260*	*N = 52*
Calibrate severity score (CSS)[¤]	7.0 (± 2.0)	7.2 (± 1.8)	6.7 (± 2.1)	7.4 (± 2.3)
Adaptive Skills	*N = 876*	*N = 545*	*N = 268*	*N = 63*
Vineland Adaptive Behavior Scales (VABS-II)				
Communication standard score	69.9 (± 15.3)[a]	67.05 (± 14.8)	75.5 (± 15.5)	71.5 (± 12.6)[a]
Socialization standard score	69.9 (± 10.7)[a]	70.54 (± 9.9)	70.2 (± 11.9)	63.2 (± 10.0)[a]
Daily living skills standard score	73.4 (± 12.8)	73.25 (± 12.9)	74.8 (± 12.6)	68.1 (± 11.9)
	N = 600	*N = 540*	*N = 60*	
Motor skills Standard score (only < 7years)	76.7 (± 12.3)	77.08 (± 12.0)	73.1 (± 14.4)	-
Social responsiveness	*N = 378*	*N = 219*	*N = 122*	*N = 37*
Social Responsiveness Scale (SRS-2)[µ]				
Social awareness t-score	77.6 (± 14.5)[q]	77.4 (± 14.5)[l]	76.9 (± 13.6)[d]	81.1 (± 16.4)[b]
Social cognition t-score	89.4 (± 16.6)[£]	90.0 (± 18.3)[¥]	88.7 (± 14.8)[g]	89.1 (± 13.6)[e]
Social communication t-score	88.9 (± 17.9)[¥]	90.7 (± 20.7)[x]	86.7 (± 13.9)[k]	86.5 (± 11.6)[c]
Social motivation t-score	77.9 (± 15.8)[v]	77.9 (± 16.6)[r]	76.7 (± 14.6)[h]	81.1 (± 14.3)[a]
Restricted interests and repetitive behavior t-score	99.7 (± 22.5)[t]	99.6 (± 24.3)[m]	100.7 (± 20.6)[f]	97.1 (± 16.3)[c]
Overall total score t-score	94.3 (± 18.6)[g]	96.0 (± 20.8)[f]	91.8 (± 15.4)[a]	92.4 (± 12.5)
Overall total score t-score in classes				
< 60 No social deficit	17 (4.6%)[$]	13 (6.1%)[f]	4 (3.3%)[a]	–
[60–66[Mild social deficit	7 (1.9%)	4 (1.9%)	3 (2.5%)	–
[66–76[Moderate social deficit	26 (7.0%)	16 (7.5%)	8 (6.6%)	2 (5.4%)
> = 76 Severe social deficit	321 (86.5%)	180 (84.5%)	106 (87.6%)	35 (94.6%)
Expressive language				
ADI item 19	*N = 692*	*N = 387*	*N = 247*	*N = 58*
Functional	395 (57.1%)	141 (36.4%)	203 (82.2%)	51 (87.9%)
Few words	108 (15.6%)	86 (22.2%)	20 (8.1%)	2 (3.4%)
Less than five words	189 (27.3%)	160 (41.3%)	24 (9.7%)	5 (8.6%)
Receptive language				
Preschool language scale (PLS-5)	*N = 49*	*N = 49*		
Total Language (Developmental age—months)	15.1 (± 7.9)[b]	15.1 (± 7.9)[b]	–	–
Expressive language (Developmental age—months)	15.5 (± 7.6)	15.5 (± 7.6)	–	–
Receptive vocabulary (Developmental age—months)	15.9 (± 7.9)	15.9 (± 7.9)	–	–
Peabody Picture Vocabulary Test (PPVT)	*N = 210*	*N = 64*	*N = 116*	*N = 30*
Lexical comprehension (Developmental age—months)	88.1 (± 72.9)	36.8 (± 14.5)	90.8 (± 54.3)	187.3 (± 100.7)
Motricity				
Movement assessment battery for children (MABC, MABC-2)	*N = 233*	*N = 63*	*N = 133*	*N = 37*
Global score[ββ]				
Pathological	159 (68.2%)	39 (61.9%)	91 (68.4%)	29 (78.4%)
Non pathological	74 (31.8%)	24 (38.1%)	42 (31.6%)	8 (21.6%)
Motor domain impacted				
Gross motor	34 (15.1%)[h]	6 (9.8%)[b]	25 (19.5%)[e]	3 (8.3%)[a]
Fine motor	25 (11.1%)	9 (14.8%)	11 (8.6%)	5 (13.9%)
Mixed motor	123 (54.7%)	29 (47.5%)	69 (53.9%)	25 (69.4%)

Table 5 (continued)

	All *N = 876*	Preschoolers [2–6 years[*N = 545*	Children [6–12 years[*N = 268*	Adolescents ≥ 12 years *N = 63*
Without pathologia	43 (19.1%)	17 (27.9%)	23 (18.0%)	3 (8.3%)
Sensory processing	*N = 456*	*N = 278*	*N = 148*	*N = 30*
Short-form sensory profile				
Total score	135.6 (± 22.1)	138.7 (± 21.1)	131.6 (± 22.6)	127.2 (± 23.7)
Long-form sensory profile				
Q1: Low registration				
Atypical	286 (65.0%)[p]	155 (57.8%)[j]	102 (71.8%)[f]	29 (96.7%)
Typical	154 (34.0%)	113 (42.2%)	40 (28.2%)	1 (3.3%)
Q2: Sensation Seeking				
Atypical	290 (69.4%)[y]	177 (70.8%)[v]	96 (69.1%)[i]	17 (58.6%)[a]
Typical	128 (30.6%)	73 (29.2%)	43 (30.9%)	12 (41.4%)
Q3: Sensory sensitivity				
Atypical	302 (71.6%)[w]	178 (69.5%)[t]	103 (73.6%)[h]	21 (80.8%)[d]
Typical	120 (28.4%)	78 (30.5%)	37 (26.4%)	5 (19.2%)
Q4: Sensation avoiding				
Atypical	291 (76.4%)[¤]	149 (67.4%)[$]	117 (87.3%)[n]	25 (96.2%)[d]
Typical	90 (23.6%)	72 (32.6%)	17 (12.7%)	1 (3.8%)
Aberrant disorders				
Aberrant Behavior Checklist (ABC)**	*N = 499*	*N = 298*	N = 160	N = 41
ABC 1: Irritability	33.9 (± 20.9)[c]	35.4 (± 19.9)[b]	31.2 (± 20.6)[a]	33.7 (± 28.3)
ABC 2: Lethargy/withdrawal	27.3 (± 18.6)[d]	26.7 (± 17.7)[c]	25.8 (± 17.9)[a]	36.8 (± 23.9)
ABC 3: Stereotypy	32.0 (± 23.9)[d]	31.5 (± 23.7)[c]	33.5 (± 24.3)[a]	29.7 (± 23.3)
ABC 4: Hyperactivity	44.0 (± 23.5)[a]	46.3 (± 23.4)[a]	41.8 (± 22.1)	36.4 (± 27.3)
Psychiatric disorders				
Child behavior checklist (CBCL)[β]				
Internalizing problems[α]	*N = 479*	*N = 282*	*N = 158*	*N = 39*
Pathological	355 (74.4%)[b]	196 (69.8%)[a]	126 (80.3%)[a]	33 (84.6%)
Non pathological	122 (25.6%)	85 (30.2%)	31 (19.7%)	6 (15.4%)
Externalizing problems[αα]				
Pathological	255 (53.2%)	142 (50.4%)	96 (60.8%)	17 (43.6%)
Non pathological	224 (46.8%)	140 (49.6%)	62 (39.2%)	22 (56.4%)
Affective problems				
Pathological	266 (55.7%)[a]	129 (45.7%)	109 (69.4%)[a]	28 (71.8%)
Non pathological	212 (44.3%)	153 (54.3%)	48 (30.6%)	11 (28.2%)
Anxiety problems				
Pathological	217 (45.3%)	74 (26.2%)	113 (71.5%)	30 (76.9%)
Non pathological	262 (54.7%)	208 (73.8%)	45 (28.5%)	9 (23.1%)
Attention deficit/hyperactivity problems				
Pathological	157 (32.8%)[a]	67 (23.8%)	76 (48.4%)[a]	14 (35.9%)
Non pathological	321 (67.2%)	215 (76.2%)	81 (51.6%)	25 (64.1%)
Oppositional defiant problems				
Pathological	112 (23.4%)	56 (19.9%)	45 (28.5%)	11 (28.2%)
Non pathological	367 (76.6%)	226 (80.1%)	113 (71.5%)	28 (71.8%)
Pervasive developmental problems (only < 6 years)	*N = 262*			
Pathological	210 (80.2%)	210 (80.2%)[&&&]	-	-
Non pathological	52 (19.8%)	52 (19.8%)		
Somatic problems (only ≥ 6 years)	*N = 197*			
Pathological	44 (22.6%)[b]	-	32 (20.5%)[b]	12 (30.8%)
Non pathological	151 (77.4%)		124 (79.5%)	27 (69.2%)

Table 5 (continued)

	All *N = 876*	Preschoolers [2–6 years[*N = 545*	Children [6–12 years[*N = 268*	Adolescents ≥ 12 years *N = 63*
Conduct problems (only ≥ 6 years)				
Pathological	52 (26.5%)[a]	-	41 (26.1%)[a]	11 (28.2%)
Non pathological	144 (73.5%)		116 (73.9%)	28 (71.8%)
Children's quality of life				
KIDSCREEN 27—parents	*N = 343*	*N = 183*	*N = 130*	*N = 30*
Physical well-being	43.3 (± 9.1)[a]	45.7 (± 8.7)	42.0 (± 8.2)[a]	35.0 (± 9.7)
Psychological well-being	45.9 (± 10.3)[c]	48.4 (± 9.5)[c]	44.7 (± 9.5)	36.5 (± 11.6)
Autonomy and parent relation	41.9 (± 11.1)[ε]	41.8 (± 12.5)[z]	42.2 (± 9.3)[s]	41.8 (± 10.5)
Social support and peers	27.6 (± 13.7)[u]	28.8 (± 14.5)[t]	27.1 (± 12.0)[d]	22.9 (± 15.7)[a]
School	42.0 (± 9.4)[o]	42.4 (± 9.3)[l]	42.2 (± 9.2)[d]	38.9 (± 10.9)

Data are given in mean (± SD) or n (%)

[a]1 missing data; [b]2 missing data; [c]3 missing data; [d]4 missing data; [e]5 missing data; [f]6 missing data; [g]7 missing data; [h]8 missing data; [i]9 missing data; [j]10 missing data; [k]12 missing data; [l]11 missing data; [m]13 missing data; [n]14 missing data; [o]15 missing data; [p]16 missing data; [q]17 missing data; [r]19 missing data; [s]20 missing data; [t]22 missing data; [u]27 missing data; [v]28 missing data; [w]34 missing data; [x]37 missing data; [y]38 missing data; [z]41 missing data; [¥]52 missing data; [$]57 missing data; [€]61 missing data; [£]64 missing data; [¤]75 missing data

[µ]Scholar and preschoolar results are pooled in column «All»

[β]CBCL: pathological status is defined as borderline clinical range ([60–64[) or clinical range (≥ 64); non pathological range is defined as normal range (< 60)

[αα]Internalizing problems is defined as: 1/if child < 6 years: emotionally reactive + anxious depressed + somatic complaints + withdrawn; 2/if child ≥ 6 years: anxious depressed + withdrawn depressed + somatics complaints

[α]Externalizing problems is defined as: 1/if child < 6 years: attention problems + aggressive behavior; 2/if child ≥ 6 years: Rule-breaking behavior + aggressive behavior

[ββ] Global score calculated with MABC and MABC-2: pathological status is defined as: 1/child with chronological age less than 5 years and global score (MABC or MABC-2) less or equal to 5th percentile; 2/child with chronological age greater or equal to 5 years and global score less or equal to 16th percentile for MABC and 15th percentile for MABC-2

**The scores indicate low (< 20), medium(20–40) and high (> 40) levels of aberrant behaviours (Rattaz et al., 2018)

Early Education and Intervention Services

The mean age at initial diagnosis was 58.8 months with considerable variability (± 33.5 months). The mean age at specialized interventions was 43.8 months (± 27.5 months), suggesting that children received services before receiving a formal diagnosis.

At the baseline visit, 81.9% of children were attending school. The attendance rate in special classrooms increased with age (4.3, 18.0 and 28.9% for preschoolers, children and adolescents, respectively). Most preschoolers and children received individualized support at school (68.2 and 62.4% respectively), while fewer adolescents did (46.3%). A total of 90% of autistic children received private therapies. Additional details about types of schools and services are in Table 6.

Parents' Psychosocial Characteristics

The perceived impact of ASD on parental quality of life was important (mean score = 56.1 ± 17.0 in mothers and 50.0 ± 16.3 in fathers) with similar coping strategies used by both parents, regardless of their child's age. Parental stress levels exceeded the 90 threshold (93.5 ± 23.3 for fathers, 97.7 ± 24.1 for mothers), indicating high stress levels in parenting a child with ASD. Similarly, a significant level of anxiety was reported in 39.4% of mothers and 23.4% of fathers, while a significant level of depression was described in 17.7% of mothers and 10.4% of fathers (Table 7).

Key Findings and Publications

The ELENA cohort is a unique longitudinal study dedicated to exploring outcome trajectories in autism within France. By gathering extensive biopsychosocial data, this study offers insights into the development, outcomes, and risk factors associated with autism throughout various childhood stages. The study examines the biological, psychological and social dimensions over time and how they impact the outcomes of children with autism. To date around 40 articles have been published using the ELENA cohort data investigating various aspects of ASD. [Visit: www.elena-cohorte.org/communication/publications-scientifiques for details].

Table 6 Education and intervention services at baseline (W0)

	All	Preschoolers [2–6 years[	Children [6–12 years[	Adolescents ≥ 12 years
	N = 876	*N = 545*	*N = 268*	*N = 63*
Age at first diagnosis (months)	*N = 549*	*N = 414*	*N = 116*	*N = 19*
	58.8 (± 33.5)	43.2 (± 13.0)	97.1 (± 22.0)	165.4 (± 13.6)
Age at first specialized intervention (months)	*N = 507*	*N = 296*	*N = 175*	*N = 36*
	43.8 (± 27.5)	32.5 (± 11.8)	56.1 (± 28.5)	76.8 (± 52.4)
Schooling				
School attendance	*N = 543*	*N = 314*	*N = 187*	*N = 42*
Yes	445 (81.9%)	233 (74.2%)	173 (92.5%)	39 (92.9%)
No	98 (18.1%)	81 (25.8%)	14 (7.5%)	3 (7.1%)
Among children attending school				
Kindergarten	*N = 222*	*N = 210*	*N = 12*	
Regular classroom	203 (91.5%)	192 (91.4%)	11 (91.7%)	–
Special classroom	9 (4.0%)	9 (4.3%)	0	–
Special classroom in residential placement	1 (0.5%)	1 (0.5%)	0	–
Unknown	9 (4.0%)	8 (3.8%)	1 (8.3%)	–
Elementary school	*N = 145*	*N = 12*	*N = 133*	
Regular classroom	116 (80.0%)	12 (100.0%)	104 (78.2%)	–
Special classroom	24 (16.6%)	0	24 (18.0%)	–
Special classroom in residential placement	1 (0.7%)	0	1 (0.8%)	–
Unknown	4 (2.7%)	0	4 (3.0%)	–
High school or college	*N = 61*		*N = 23*	*N = 38*
Regular classroom	41 (67.2%)	–	18 (78.3%)	23 (60.5%)
Special classroom	16 (26.2%)	–	5 (21.7%)	11 (28.9%)
Special classroom in residential placement	1 (1.7%)	–	0	1 (2.6%)
Unknown	3 (4.9%)	–	0	3 (7.9%)
Child receiving an individualized support (AVS) at school				
	N = 455	*N = 236*	*N = 178*	*N = 41*
Yes	291 (64.0%)	161 (68.2%)	111 (62.4%)	19 (46.3%)
No	164 (36.0%)	75 (31.8%)	67 (37.6%)	22 (53.7%)
Child receiving a special education or care service				
	N = 548	*N = 319*	*N = 187*	*N = 42*
Yes	277 (50.5%)	164 (51.4%)	94 (50.3%)	20 (47.6%)
No	271 (49.5%)	155 (48.6%)	93 (49.7%)	22 (52.4%)
Child receiving therapy with a private professional				
	N = 547	N = 319	N = 187	N = 41
Yes	494 (90.3%)	294 (92.2%)	169 (90.4%)	31 (75.6%)
No	53 (9.7%)	25 (7.8%)	18 (9.6%)	10 (24.4%)

Data are given in mean (± SD) or n (%)

Our findings have revealed the potential to identify subgroups at risk of poorer outcomes who require consistent developmental monitoring, targeted interventions, and support for both the children with ASD and their families. The ELENA cohort also plays a crucial role in raising awareness among the public and policymakers about the need for specific support for families in France.

The salient domains are highlighted below:

Developmental

Two studies on the ELENA cohort have focused on clarifying the developmental aspects of ASD during prenatal and perinatal periods and early childhood.

Impact of prenatal and perinatal factors on the severity of symptoms and deficits in intellectual and adaptive functioning): A study involving 169 subjects found that the risk of premature delivery was associated with an increased risk

Table 7 Parental psychosocial characteristics at baseline (W0)

	All	Preschoolers [2–6 years[	Children [6–12 years[	Adolescents ≥ 12 years
	N = 876	*N* = 545	*N* = 268	*N* = 63
Parental health related quality of life: Par-DD-QoL¤¤				
Fathers				
Total QoL	*N* = 252	*N* = 162	*N* = 75	*N* = 15
Emotional score	50.0 (± 16.3)[e]	51.4 (± 16.8)[b]	48.1 (± 14.6)[c]	44.0 (± 17.0)
Daily disturbances score	52.6 (± 18.0)[b]	53.8 (± 18.7)[a]	51.3 (± 16.0)[a]	46.8 (± 20.3)
Mothers	46.8 (± 17.1)[c]	48.7 (± 17.6)[a]	43.9 (± 15.5)[b]	40.8 (± 16.5)
Total QoL	*N* = 376	*N* = 220	*N* = 125	*N* = 31
Emotional score	56.1 (± 17.0)[l]	56.5 (± 17.7)[g]	56.5 (± 15.9)[e]	52.1 (± 16.6)[a]
Daily disturbances score	59.9 (± 18.9)[f]	59.3 (± 19.1)[b]	61.4 (± 18.6)[c]	57.8 (± 19.0)[a]
	51.8 (± 17.9)[g]	53.2 (± 18.8)[e]	50.6 (± 16.2)[b]	46.5 (± 17.8)
Parental coping strategies: WCC-R				
Fathers	*N* = 259	*N* = 167	*N* = 77	*N* = 15
Problem focused coping	29.6 (± 5.5)[k]	30.1 (± 5.5)[g]	28.6 (± 5.7)[e]	28.5 (± 5.0)
Emotional focused coping	21.6 (± 5.5)[i]	21.9 (± 5.7)[g]	20.9 (± 5.0)[c]	21.6 (± 6.2)
Seeking social support	20.1 (± 5.5)[e]	20.4 (± 5.5)[c]	19.6 (± 5.4)[b]	19.0 (± 6.1)
Mothers	*N* = 346	*N* = 209	*N* = 113	*N* = 24
Problem focused coping	31.3 (± 5.0)[h]	31.4 (± 5.2)[d]	31.0 (± 4.4)[d]	31.7 (± 5.2)[a]
Emotional focused coping	22.7 (± 5.4)[m]	22.8 (± 5.5)[j]	22.7 (± 5.2)[f]	21.9 (± 6.1)[a]
Seeking social support	21.7 (± 5.5)[j]	21.9 (± 5.5)[e]	21.3 (± 5.3)[d]	22.1 (± 6.7)[b]
Parental Stress: PSI-SF				
Fathers	*N* = 244	*N* = 158	*N* = 72	*N* = 14
Total Score	93.5 (± 23.3)	95.7 (± 23.9)	89.6 (± 21.0)	88.1 (± 26.5)
Mothers	*N* = 337	*N* = 203	*N* = 109	*N* = 25
Total score	97.7 (± 24.1)	97.1 (± 24.4)	99.3 (± 23.2)	95.2 (± 26.2)
Parental anxiety and depression: HADS¤				
Fathers	*N* = 263	*N* = 169	*N* = 77	*N* = 17
Anxiety	7.9 (± 3.7)[g]	8.0 (± 3.7)[d]	7.7 (± 3.7)[c]	7.9 (± 4.6)
No anxiety	127 (49.6%)[g]	80 (48.5%)[d]	38 (51.4%)[c]	9 (52.9%)
Anxiety suspected	69 (27.0%)	46 (27.9%)	20 (27.0%)	3 (17.6%)
Anxiety	60 (23.4%)	39 (23.6%)	16 (21.6%)	5 (29.4%)
Depression	5.5 (± 3.8)[e]	6.0 (± 4.1)[c]	4.5 (± 2.9)[b]	4.8 (± 3.9)
No depression	186 (72.1%)[e]	110 (66.3%)[c]	64 (85.3%)[b]	12 (70.6%)
Depression suspected	45 (17.4%)	34 (20.4%)	7 (9.4%)	4 (23.5%)
Depression	27 (10.5%)	22 (13.3%)	4 (5.3%)	1 (5.9%)
Mothers	*N* = 349	*N* = 212	*N* = 111	*N* = 26
Anxiety	9.7 (± 3.8)[a]	9.7 (± 3.8)[a]	10.0 (± 3.9)	9.2 (± 3.7)
No anxiety	110 (31.6%)[a]	69 (32.7%)[a]	33 (29.8%)	8 (30.8%)
Anxiety suspected	101 (29.0%)	59 (28.0%)	32 (28.8%)	10 (38.4%)
Anxiety	137 (39.4%)	83 (39.3%)	46 (41.4%)	8 (30.8%)
Depression	6.6 (± 4.0)[d]	7.0 (± 4.1)[b]	6.2 (± 3.6)[a]	5.2 (± 4.1)[a]
No depression	212 (61.4%)[d]	123 (58.5%)[b]	71 (64.4%)[a]	18 (72.0%)[a]
Depression suspected	72 (20.9%)	43 (20.5%)	25 (22.7%)	4 (16.0%)
Depression	61 (17.7%)	44 (21.0%)	14 (12.7%)	3 (12.0%)

Data are given in mean (± SD) or n (%)

HADS hospital anxiety and depression scale, *Par-DD-QoL* parental-developmental disorder-quality of life, *PSI-SF* parental stress index short form, *QoL* qulity of life, *WCC-R* ways of coping checklist

[a]1 missing data; [b]2 missing data; [c]3 missing data; [d]4 missing data; [e]5 missing data; [f]6 missing data; [g]7 missing data; [h]9 missing data; [i]10 missing data; [j]11 missing data; [k]12 missing data; [l]13 missing data; [m]18 missing data

¤¤"No impact" corresponds to a QoL score less than 40, "Moderate impact" corresponds to a QoL score between 40 and 57 and "High impact" corresponds to a score higher than 57 (Rattaz et al., 2017)

¤The thresholds for the sub-scores anxiety and depression were: 0 to 7, absence of anxiety or depression; 8 to 10, anxiety or depression suspected; from 11 to 21, significant level of anxiety or depression

of severe ASD symptoms, while placental pathologies and birth complications were linked to a higher risk of communication deficits (Traver et al., 2021).

Frequency of the initiation of breastfeeding: In a subset of subjects (n = 243), a study found that breastfeeding rate among children with ASD were comparable to the general population and the rate of children still being breastfed at six months of age was higher. There was no contribution of initiation or duration of breastfeeding to the prevention of clinical severity of ASD (IQ, VABS-II, ADOS-2, SRS-2, ABC) (Peries et al., 2023).

Early diagnosis: Diagnosis of ASD before the age of three, was associated with co-occurring intellectual disability, higher severity of ASD symptom, and reduced communicative abilities (Rattaz et al., 2022).

Biological

Two studies within the ELENA cohort have examined the biological aspects of ASD, particularly through the investigation of sex-related differences and the impact of environmental exposures.

Sex: Girls and boys with ASD exhibited similar clinical profiles, except for ASD trait severity measured through a parental questionnaire (SRS-2), which suggested more severe social impairment among girls (Dellapiazza et al., 2022c).

Early residential proximity to agricultural crops (n = 193): An investigation analyzed the influence of proxy exposure to pesticides in a subset of 193 children with ASD The study revealed that as the crop acreage within 1000 m radius of homes increased by 20%, there was a significant decrease in communication scores of the VABS-II for children without intellectual disability during both pregnancy ($\beta = -2.21$, 95%CI: 4.16 to −0.27) and the first two years of life ($\beta = -1.90$, 95%CI: 3.68 to −0.11). No such association was found for children with intellectual disability (Ongono et al., 2022).

Psychological and Emotional

Six studies have been conducted focusing on psychological or emotional factors, including intellectual functioning, adaptive behaviors, atypical sensory processing, dimensional behavioral patterns, and anxiety.

Intellectual functioning: Examination of mental processes of the children and adolescent with ASD without intellectual disorders, revealed that they performed better on visual working-memory tasks compared to auditory tasks. Additionally, six WISC-V intellectual profiles based on verbal and reasoning skills were described (Audras-Torrent et al., 2021).

Adaptive behaviors (AB) in children and adolescents with ASD were found to be lower compared to typically developing children, irrespective of age group. These behaviors were associated with various clinical, interventional and familial factors (Miniarikova et al., 2023).

Atypical sensory processing was strongly associated with maladaptive behaviors, specifically irritability and hyperactivity, as well as lower adaptive scores (Dellapiazza et al., 2020). Longitudinally, researchers were able to identify three subgroups based on the course of sensory processing over three years (improvement, stable, and worsening), which were related to the adaptive skills and maladaptive behaviors exhibited by children (Dellapiazza et al., 2022a).

Comorbidity and Dimensional Behavioral Patterns: In a subset of subjects with both ASD and comorbid ADHD, internalizing behaviors were more frequently associated with the severity of ASD symptoms, while externalizing behaviors were linked to the severity of ADHD symptoms. Interestingly, the level of social impairment was comparable between children with ASD alone and those with both ASD and ADHD (Dellapiazza et al., 2021). As for *anxiety*, the study found that 45% of the children initially exhibited clinically significant levels of anxiety, and this prevalence increased to 50% three years later. Notably, high level of repetitive and restrictive behaviors, as well as higher IQ, were identified as early predictors of increased anxiety. Conversely, greater ASD severity and fewer sensory processing difficulties were associated with lower anxiety levels (Dellapiazza et al., 2022b).

Social Domain

Seven studies within the ELENA cohort have examined the social aspects of ASD, particularly by investigating parental mental health and quality of life, family environment, and social and educational inclusion. Additionally, three other studies within the social domain address the impact of COVID-19 lockdowns on parents and children.

Parental Quality of Life (QoL): The study found that mothers tended to perceive a greater impact than fathers. The perception of QoL in mothers was linked to their children's internalizing disorders, whereas in fathers, it was associated with their children's externalizing disorders (Vernhet et al., 2022). Over the course of three years following the ASD diagnosis, both parents experienced a decrease in anxiety. However, stress levels significantly decreased only in mothers, who initially had higher stress levels at the time of diagnosis (Rattaz et al., 2023).

Coping strategies: A dyadic effect of coping was observed, with mothers' emotion focused coping strategies playing a crucial role in fathers' perception of QoL (Brillet et al., 2022). There was also a decrease in emotion-focused

coping strategy, particularly avoidance or escape, over the three-year period following the ASD diagnosis, in relation to the acceptance process (Rattaz et al., 2023). Additionally, during the lockdown, *mothers' anxiety and depression levels* were significantly associated with their child's challenging behaviors, teleworking from home, and their perceived knowledge about Covid-19 (Miniarikova et al., 2022).

Age of ASD diagnosis: The children and adolescents in low socio-economic status families tended to receive an earlier diagnosis (Rattaz et al., 2022). The age of diagnosis was not related to the presence of an older sibling with ASD. The mean age at initial diagnosis showed considerable variation but was on average later than the mean age at commencement of specialized interventions.

Social and educational inclusion: The findings showed the equity in availability of early services based on need irrespective of later attribution of diagnosis. Approximately, eighty-eight percent of children and adolescents were *attending school*, however, challenging behaviors and sensory processing difficulties were associated with partial inclusion, while full-time inclusion was linked to the presence of co-occurring anxiety symptoms (Rattaz et al., 2020).

Covid lockdown: An analysis of the impact of containment measures during the Covid-19 lockdown revealed that more than one third of children exceeded recommended levels of screen time, with half of parents reporting increased screen time for their children due to the measures (Berard et al., 2022). Parents observed a deterioration in challenging behaviors and sleep in their children and adolescents, especially in those with higher symptom severity scores and those living in a single-parent families (Berard et al., 2021). However, there was evidence of improved communicative abilities in children who continued to receive specialized interventions during the confinement period (Berard et al., 2021).

Discussion and Future Challenges

This article describes previously unpublished baseline characteristics of participants in the ELENA Autism Cohort Study. It aims to recognize the interplay among developmental, biological, psychological, environmental and sociodemographic factors in determining outcomes in ASD. Unlike many existing studies, ELENA addresses less frequently studied environmental and psychosocial dimensions, providing a broader perspective on ASD trajectories.

Unique Aspects of the ELENA Study

The ELENA study represents a significant dataset involving 876 children, with an average age of six years (SD ± 3.3), newly diagnosed with ASD between 2012 and 2019 across several regions in France. With a 79.5% participation rate after three years of follow-up, the study demonstrates strong engagement and robust longitudinal data. Notably, the sample, shows an overrepresentation of low and high SES families, while middle-income families are underrepresented compared to general population (Venturi, 2016). Additionally, attrition is most significant among low SES families, a trend commonly observed in longitudinal studies (Gustavson et al., 2012; Richard et al., 2018). Although loss to follow-up is more frequent in lower SES families, children lost to follow-up across all SES have lower socialization scores on the Vineland scale, which is in line with the findings of Richard et al. (2018). Additionally, in high SES families, these children also show lower IQ and daily living skills scores, unlike those from middle and lower SES. These differences may be due to factors such as stigma (with high SES families seeking more discreet care) and access to services (as they rely less on public services).

The mean age of participants in ELENA is higher than in previous ASD cohort studies (Stenberg et al., 2021; Szatmari et al., 2015), and the prevalence (45.7%) of co-occurring intellectual disabilities is higher than in multisource active surveillance systems but aligns with clinically referred settings (Maenner et al., 2023; Postorino et al., 2016). The study also confirms higher symptom severity among girls compared to boys, consistent with global reports (Lord et al., 2022).

Broader Scope of Potential Predictors

The ELENA study explored a comprehensive set of potential predictors of ASD trajectories. Findings suggest strong links between behavioral issues and clinical dimensions, such as sensory processing (Dellapiazza et al., 2020, 2022a), ASD severity (Dellapiazza et al., in press), repetitive behaviors (Dellapiazza et al., 2022b), and intellectual functioning (Audras-Torrent et al., 2021). These insights highlight the importance of thorough and regular assessments and targeted interventions for these dimensions. Additionally, the baseline psychosocial characteristics of parents, including high stress levels and significant anxiety and depression (Rattaz et al., 2023; Vernhet et al., 2022), underscore the need for tailored support to address these challenges.

Impact on Public Policy and Early Intervention

Our results also offer important lessons for public policy. In France, as in other countries, children can receive special educational services under the category of "developmental delay" without a specific diagnosis, enabling them to receive support at the first signs of difficulty and to be referred to specialized services for a formal diagnosis of ASD. Although precise data on the proportion of children

receiving services for reasons other than ASD are not always available, it is important to recognize this possibility in international comparisons to better understand the impact of healthcare and education systems on the care of autistic children (Rattaz et al., 2022). These settings provide a structured environment that fosters the development of children's social, cognitive, emotional, and physical skills. Although not specifically tailored to ASD, they serve as a foundational safety net for early social inclusion. Consistent with French registry data (Delobel-Ayoub et al., 2015) and in contrast to North American studies (Durkin et al., 2017), our findings suggest that families with low socio-economic status tend to receive earlier diagnoses, indicating the protective role of universal healthcare access. Our results, which highlight a high proportion of autistic children receiving private therapies must be understood within the context of the French educational and healthcare systems. Specific therapies, such as speech therapy or physical therapy, are primarily available through private providers, yet they are reimbursed by health insurance. Additionally, public services specialized in autism are often overburdened, with long waiting times, which drives families to seek private options. Furthermore, the persistent stigma surrounding ASD can lead parents to choose more discreet private interventions to avoid social judgment.

Parental Support and Coping

Findings on quality of life and parental coping (Brillet et al., 2022; Rattaz et al., 2023) emphasize the need for more systematic supportive interventions. Recent research highlights the feasibility of implementing such programs (Naheed et al., 2022), stressing the importance for clinicians to tailor parental education programs to the individual differences in how fathers and mothers cope with their child's ASD diagnosis.

Novel Contributions and Methodological Strengths

The ELENA study offers a groundbreaking contribution to ASD research by focusing on the natural course of ASD, prospectively examining long-term clinical outcomes from initial diagnosis without the confounding effects of various therapeutic interventions. This approach is essential for understanding the influence of early factors on outcomes over time, and identifying critical periods for effective interventions. While other studies, such as the Norwegian ABC study (Stoltenberg et al., 2010) and the northern Canadian Pathways studies (Szatmari et al., 2015), have explored ASD trajectories, few have included substantial samples of young children, standardized multidimensional data collection at multiple time points, and long-term follow-up (Baghdadli et al., 2012; Charman et al., 2017). The ELENA study enriches data collection by including diverse exposures measures, both biomedical, environmental and social, during gestation and early childhood to study their impact on outcome trajectories. Additionally, ELENA employs a uniform strategy for recruiting and assessing participants across 13 regional sites, coordinated by six regional centers. This approach, focusing on first-time diagnoses, minimizes the variability often observed in multicenter studies and enhances the reliability of the results across different geographic areas.

Limitation and Generalizability

It is important to acknowledge several factors that may limit the interpretation and generalizability of the findings. First, ELENA doesn't fully represent the French population of children and adolescents with ASD, as it includes participants from secondary and tertiary specialized centers. The overrepresentation of low and high SES families in our sample may be attributed to recruitment biases, such as low SES families joining to access free services and the diverse regional socio-economic profiles. Middle SES families might face difficulties accessing specialized services, as they lack both the financial aid available to low SES families and the resources of high SES families. The higher prevalence (45.7%) of intellectual disability in the cohort reflects challenges in recruiting a broader array of subjects without intellectual disabilities. However, the mean IQ was around 73, and adaptive functioning measures for communication and socialization were in the low range (mean = 69.9), indicating that the study population is not highly impaired. Second, the wide age range of participants may pose methodological challenges in analyzing developmental trajectories. Retrospective data collection on the peri and postnatal periods might be constrained by memory bias, particularly among parents of older children and adolescents. Nonetheless, the inclusive age range ensures responsiveness to the entire population's needs. Third, funding constraints have limited biological data collection, impacting insights into the genetic and biological foundations of ASD. These gaps have prompted adjustments in our research focus, methodological approaches and the initiation of collaborative efforts through the establishment of the new prenatal cohort in France, the MARIANNE Cohort.

Conclusion

In conclusion, the ELENA study has been a pioneering effort that captures multiple domains in investigating ASD. The study reflects a comprehensive approach to understanding the multifaceted nature of ASD, which aligns with global efforts like the UN General Assembly's resolution in 2007

to create World Autism Awareness Day, emphasizing challenges faced worldwide. The ELENA study has since served as a global model for an evidence-based holistic framework for action on ASD that highlight five foundations: (i) early awareness and diagnosis; (ii) evidence-based services; (iii) family supports; (iv) access to public education and social inclusion; and (v) participation in high quality research that encompasses parent and community perspectives (Munir et al., 2016). Although each foundation stands to provide important contributions in understanding ASD, they are also part of complex interplay influencing future outcomes. Although it is necessary for studies to adapt to resource-intensive limitations entailed in data collection, given the ever-increasing importance of ASD, the developmental biopsychosocial framework, in the long run, is more likely to be successful in bringing convergence between health, social care, and lived experience perspectives in addressing the future lives and well-being of children.

Collaboration

The ELENA cohort will continue to collect data on outcome trajectories and multiple exposure domains. For more information, refer to the website [www.elena-cohorte.org]. Researchers interested in collaboration are invited to address their request to the corresponding author [rech-clinique-autisme@chu-montpellier.fr] accompanied by a dedicated project form for evaluation by the ELENA executive and scientific committees.

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Author Contributions Amaria Baghdadli as the PI of ELENA study contributed to the study conception and design. Julie Loubersac and Laetitia Ferrando were in charge of data quality control. Marianne Peries and Cécile Michelon performed the statistical analyses under supervision of Marie-Christine Picot and Amaria Baghdadli. The first draft of the manuscript was written by Amaria Baghdadli, Aurore David, Cécile Michelon, Cécile Rattaz and Marianne Peries. Kerim Munir contributed to a critical revision of the initial manuscript, and all authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

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Data Availability The datasets used and analyzed during the current study are available from the corresponding author upon reasonable request.

Declarations

Conflict of interest The authors have no financial interests to disclose.

Ethical Approval The ELENA cohort study was performed in line with the principles of the Declaration of Helsinki. This study was approved by the South Mediterranean Ethics Committee on the Research of Human Subjects of Marseille (ID RCB: 2014-A01423-44) and the National Commission for Computing and Liberties (CNIL; number DR-2015-393).

Consent to Participate Informed consent of the parent's participants was obtained after the nature of the procedures had been fully explained.

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