

Parents' initial concerns about children and adolescents with developmental disorders

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ABSTRACT

Introduction. Developmental disorders (DD) are a group of chronic conditions that begin during brain development and typically manifest during childhood. Assessing parents' concerns about their child's development is a central part of developmental monitoring.

Objective. To analyze the relationship between the initial concerns expressed by families and the developmental diagnoses obtained at a specialized unit.

Population and methods. This was a cross-sectional, retrospective, observational, and analytical study. We reviewed transdisciplinary diagnostic evaluations conducted between April 1, 2017, and February 29, 2024, at a Developmental Pediatrics Unit. Patients aged 4 months to 19 years referred for suspected developmental disorders were included. Associations between parental concern profiles and diagnoses were analyzed using bivariate analysis and multivariate logistic regression.

Results. A total of 570 patients were analyzed. Family concerns showed statistically significant and diagnosis-specific associations. In autism spectrum disorders, concerns related to language and social skills were consistently associated with the diagnosis. In intellectual disability and learning disorders, academic concerns showed the most significant association, with distinct patterns compared to other areas. Additionally, associations were observed between male gender and attention-deficit/hyperactivity disorder, and between genetic syndromes and intellectual disability.

Conclusion. Parental concerns are a clinically relevant descriptive tool with specific patterns linked to developmental diagnoses. Systematic identification of these concerns can guide the initial evaluation and help prioritize referrals.

Keywords: neurodevelopmental disorders; early diagnosis; child development.

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INTRODUCTION

Developmental disorders (DD) are a group of chronic conditions that originate during brain development and manifest clinically in early childhood. They are characterized by difficulties in one or more areas of development (behavior, language, cognition, motor skills, and/or social interaction) with varying degrees of functional impact depending on personal, family, and contextual factors.¹

In the *Diagnostic and Statistical Manual of Mental Disorders*, fifth edition (DSM-5), these conditions are grouped under the heading “Neurodevelopmental Disorders” and include intellectual disability (ID), autism spectrum disorder (ASD), attention-deficit/hyperactivity disorder (ADHD), communication disorders, specific learning disorders, and motor disorders.² In the International Classification of Diseases, 11th Revision (ICD-11), they are included in the chapter on “Mental, behavioral, or neurodevelopmental disorders”.³

During early childhood, establishing a diagnosis presents challenges due to the dynamic nature of development; therefore, complementary conceptual frameworks such as the Diagnostic Classification of Mental Health and Developmental Disorders of Infancy and Early Childhood (DC:0-5) have been used.⁴

The global prevalence of developmental disorders is estimated to be between 8% and 16%, with variations depending on region, socioeconomic status, and diagnostic criteria.⁵⁻⁸ In Argentina, the estimated prevalence ranges from 9% to 20% of the child population, with variability depending on the type of disorder, the context, and the assessment method.⁹⁻¹¹

Pediatricians and primary care physicians play a key role in the early detection of developmental disorders. However, significant delays have been reported between parents’ initial concerns and access to a diagnosis, exacerbated by inequalities in access to specialized services.¹²⁻¹⁴

Parental concerns (PC) about development are defined as the concerns expressed by caregivers regarding a child’s progress in areas such as language, motor skills, behavior, social interaction, and academic performance. Prospective population-based studies have shown that they constitute an independent risk indicator for developmental disorders, with diagnostic value beyond developmental milestone delays. Incorporating the parental perspective into the

pediatric evaluation increases sensitivity in detecting early warning signs, which is particularly important during the first and second years of life.^{15,16} In line with this evidence, the Growth and Development Committee of the Sociedad Argentina de Pediatría states that the first step in the developmental history is to inquire about these concerns systematically.¹⁷

Development assessments can be conducted using different models. In interdisciplinary assessments, each professional evaluates independently, and the team synthesizes the results; in multidisciplinary assessments, evaluations are also independent, with little interaction between disciplines; in transdisciplinary assessments, one team member leads the process with input from the rest of the team and the family, integrating different perspectives into a coordinated process aimed at achieving a functional and comprehensive understanding of the child.^{18,19}

Initial parental concerns are often the first indicator of developmental abnormalities and can provide relevant clinical information about functioning profiles and underlying diagnoses. However, few studies systematically analyze the relationship between types of parental concerns and diagnoses obtained in transdisciplinary assessment settings.^{20,21}

The primary objective was to analyze the association between types of initial parental concerns and neurodevelopmental diagnoses obtained through a transdisciplinary evaluation. As a secondary objective, the study sought to identify specific patterns of parental concerns associated with each diagnosis.

POPULATION AND METHODS

Design

A cross-sectional, retrospective, observational, and analytical study was conducted at the Developmental Pediatrics Unit of the Hospital Británico de Buenos Aires.

Population

Patients between 4 months and 19 years of age were evaluated between April 1, 2017, and February 29, 2024, based on the routine clinical record. The study included initial evaluations of patients referred for suspected developmental disorders with a complete record of the initial interview, family questionnaires, and final diagnosis. Incomplete evaluations were excluded.

Data sources

Pre-interview questionnaire completed by the father, mother, or primary caregiver before the consultation. For most of the study period ($n = 500$), an open-ended question administered via email was used ("What concerns do you have about your child's development?"); subsequently ($n = 70$), a form with predefined categories (motor, language, social, behavioral, academic, or a combination) was implemented. In both cases, the responses were confirmed and elaborated during the initial interview and categorized according to the domains, with the presence or absence of concern recorded for each area. Data were also collected from the report and the electronic medical record.

Evaluation procedure

The team consisted of a developmental pediatrician, a fellowship trainee, an occupational therapist, an educational psychologist, and a speech-language pathologist. The evaluations were conducted using a transdisciplinary approach, typically over two sessions, with the participation of three or four professionals. The developmental pediatrician led the evaluation and participated in all stages. Standardized scales (*Supplementary material*) and DSM-5 diagnostic criteria were used. In cases of early-stage or heterogeneous clinical presentations, where symptoms did not meet the DSM-5 diagnostic thresholds, the DC:0-5 was used due to its greater sensitivity for early detection and its suitability for children aged 0 to 5 years.

The variables analyzed included age, sex, maternal educational level, initial parental concerns, and type of concern (motor, behavioral, language, social, academic, or a combination of two or more), age at onset of concerns, presence of school-related concerns, personal history (preterm birth <37 weeks, assisted reproductive technologies, intrauterine growth restriction, neurological, cardiac, or genetic disorders), first-degree family history of developmental disorders, and possession of a Argentine National Disability Certificate (CUD, by its Spanish acronym). The outcome variable was the final diagnosis according to DSM-5 or DC:0-5 criteria.

Statistical analysis

Database created in Microsoft Excel™ 2018 and analysis performed in R™ version 4.5.2. Quantitative variables were expressed as mean and standard deviation or median and interquartile

range, depending on the distribution. Categorical variables were presented as frequencies and percentages. Bivariate analyses were performed for each diagnosis using the following variables: type of initial parental concern (language, behavior, social, motor, and academic), age at diagnosis, age at the onset of parental concern, maternal educational level, sex, and personal and family history of DD. Subsequently, multivariate logistic regression models were constructed that included all categories of initial parental concerns and diagnoses coexisting with the diagnosis of interest as independent variables, to adjust for concomitant diagnoses and reduce the potential confounding effect of diagnostic overlap. A p -value <0.05 was considered statistically significant, and associations were expressed as odds ratios (OR) with 95% confidence intervals.

Ethical considerations

The study was approved by the Institutional Review Board of the Hospital Británico de Buenos Aires (approval date: July 26, 2024; PRIISA BA code: 13084). Because this was a retrospective study, informed consent was waived. Confidentiality and anonymity were ensured in accordance with current regulations.

RESULTS

Between April 2017 and February 2024, 714 patients were evaluated (*Figure 1*). Only the first evaluation was included in the analysis ($n = 570$). *Figure 2* details the diagnoses identified. The median age at diagnosis was 63 months (IQR 39-103). Seventy-two percent were male ($n = 414$), and 64.4% ($n = 360$) had a family history of DD (*Table 1*).

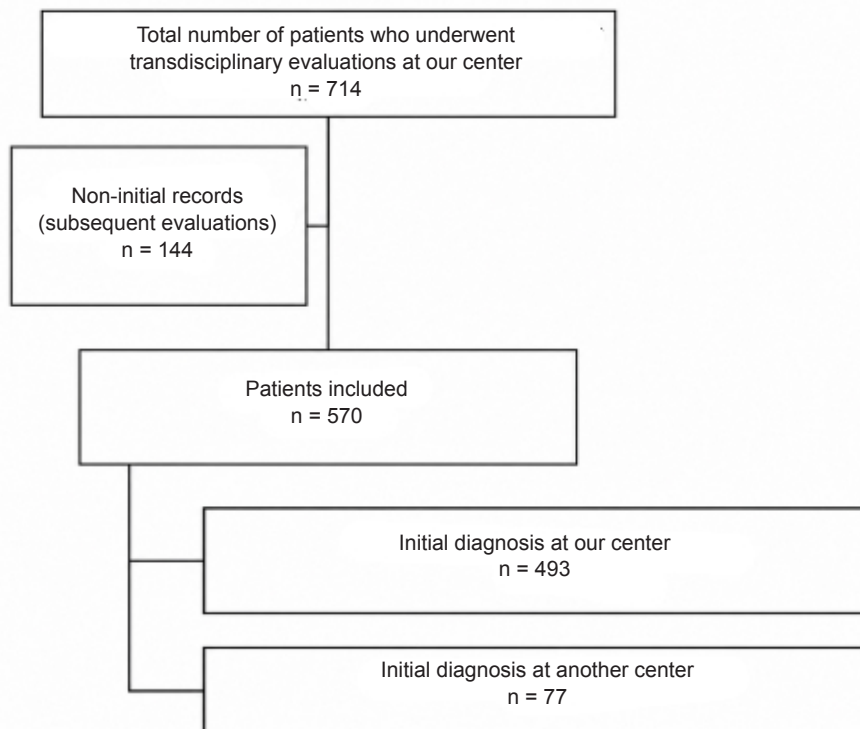
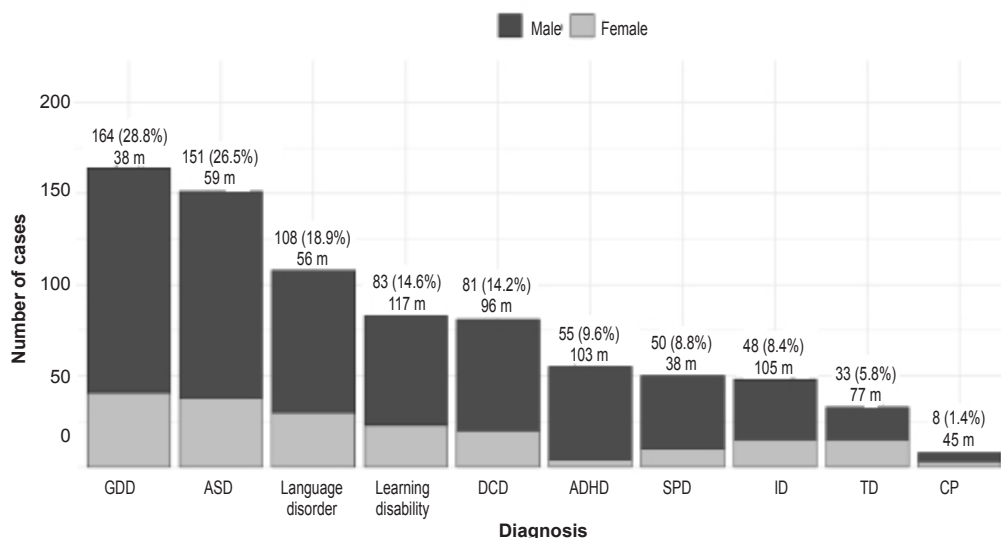
Family and school concerns

At least one concern was reported for 99.1% of families ($n = 565$) before the consultation. Schools reported concerns in 75.1% of cases ($n = 365$). The most common family concerns were language (47.2%; $n = 269$) and behavior (45.4%; $n = 259$).

In 41.4% of patients ($n = 236$), two or more initial parental concerns were recorded.

Associations between parental concerns and diagnoses

In the multivariate analysis, significant associations were observed between types of parental concerns and specific diagnoses (*Table 2*). In ASD, associations were found

FIGURE 1. Flowchart of the transdisciplinary evaluations included in the analysis**FIGURE 2. Distribution of diagnoses at the first evaluation**

m: months; GDD: global developmental delay; ASD: autism spectrum disorder; DCD: developmental coordination disorder; ADHD: attention-deficit/hyperactivity disorder; SPD: sensory processing disorder; ID: intellectual disability; TD: typical development; CP: cerebral palsy.

with concerns in the social domain (OR = 7.2; 95%CI: 4.2-12.5) and in the language domain (OR = 3.4; 95%CI: 1.96-5.9). In cases of global developmental delay (GDD), concerns were

associated with language (OR = 5.9; 95%CI: 3.6-9.7) and motor development (OR = 3.5; 95%CI: 1.9-6.6).

For ADHD, initial concerns about behavior

TABLE 1. Sociodemographic and clinical characteristics of the study population (n = 570)

Variable	n (%)
Age in months (median, IQR 25-75)	63 (39-103)
Sex	
Female	156 (27.4)
Male	414 (72.6)
Family concerns	
Yes	565 (99.1)
No	5 (0.9)
School-related concerns	
Yes	365 (75.1)
No	121 (24.9)
Initial concerns	
Language	269 (47.2)
Behavior	259 (45.4)
Motor	80 (14)
Social	134 (23.5)
Academic	113 (19.8)
≥2 initial concerns	236 (41.4)
Medical history	
Neurological	49 (8.6)
Cardiovascular	14 (2.5)
Genetic	22 (3.9)
Prematurity	97 (17)
Assisted reproduction	27 (4.7)
IUGR	39 (6.9)
Family history of developmental disorders	360 (64.4)
Argentine National Disability Certificate	79 (13.9)

IQR: interquartile range; IUGR: intrauterine growth restriction.

were significantly associated (OR = 2.2; 95%CI: 1.1-4.5). For intellectual disability and learning disorders, concerns about academic performance

showed significant associations (OR = 10.7; 95%CI: 5.0-23.3 and OR = 15.4; 95%CI: 7.2-33.6, respectively). *Figure 3* shows the profiles of family concerns based on the diagnosis.

TABLE 2. Association between initial concerns and developmental diagnoses (multivariate logistic regression models)

Initial concern	ASD	GDD	ADHD	DCD	ID	Learning disorder	SPD	Language disorder
	OR (95%CI)	OR (95%CI)	OR (95%CI)	OR (95%CI)	OR (95%CI)	OR (95%CI)	OR (95%CI)	OR (95%CI)
Language	3.37 (1.96-5.92)	5.88 (3.63-9.74)	0.18 (0.07-0.41)	1.25 (0.67-2.34)	0.67 (0.33-1.35)	0.26 (0.10-0.62)	0.88 (0.43-1.79)	7.63 (4.10-14.64)
Behavior	1.18 (0.72-1.93)	0.97 (0.61-1.55)	2.16 (1.06-4.50)	1.10 (0.63-1.93)	0.97 (0.48-1.92)	0.56 (0.27-1.17)	2.11 (1.07-4.22)	1.19 (0.65-2.21)
Motor	1.15 (0.56-2.33)	3.47 (1.87-6.56)	0.33 (0.07-1.05)	1.09 (0.43-2.48)	0.62 (0.18-1.72)	0.24 (0.05-0.84)	1.48 (0.58-3.53)	1.15 (0.44-2.92)
Social	7.17 (4.22-12.49)	1.27 (0.74-2.19)	0.43 (0.15-1.04)	2.38 (1.21-4.68)	0.64 (0.24-1.54)	0.28 (0.08-0.79)	2.90 (1.39-5.97)	1.31 (0.58-2.92)
Academic	0.42 (0.18-0.92)	0.11 (0.04-0.25)	2.06 (0.84-4.95)	1.47 (0.66-3.17)	10.70 (4.96-23.35)	15.36 (7.23-33.63)		0.24 (0.09-0.59)

Multivariate logistic regression models adjusted for the presence of other coexisting developmental diagnoses. Only the associations related to the initial concerns are shown; the coefficients for the coexisting diagnoses are not presented in the table.

The estimate for academic concern in SPD showed quasi-complete separation and is not reported.

ASD: autism spectrum disorder; GDD: global developmental delay; ADHD: attention-deficit/hyperactivity disorder; DCD: developmental coordination disorder; ID: intellectual disability; SPD: sensory processing disorder.

Age at onset of concerns

The ages at which parental concerns began showed a heterogeneous distribution depending on the diagnosis (*Table 3*).

Clinical and diagnostic history

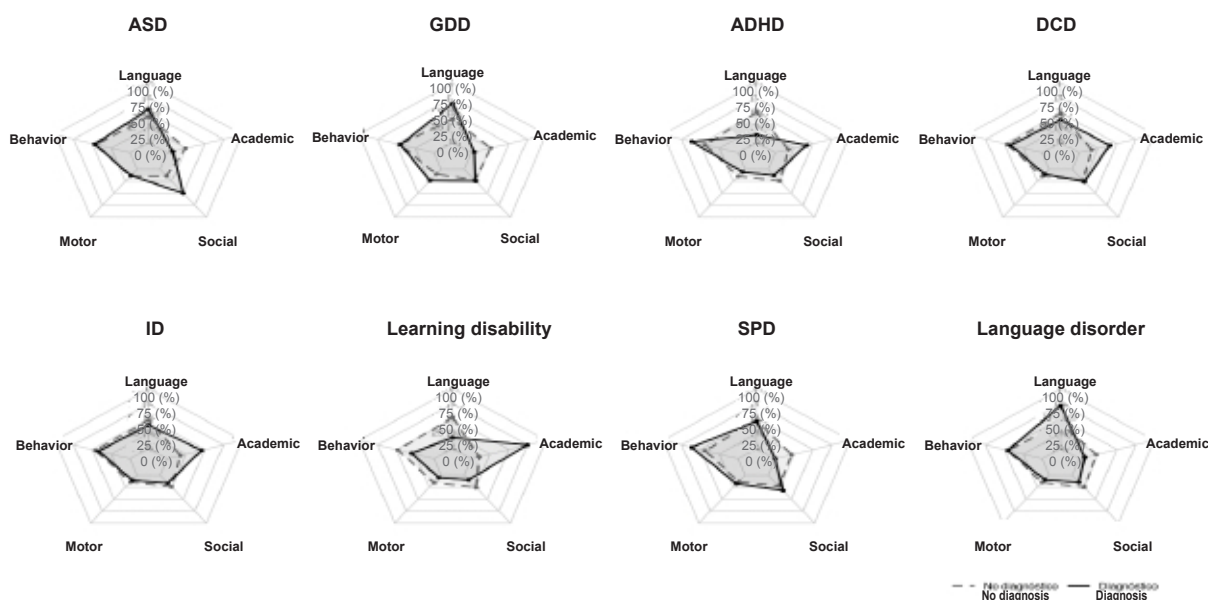
A positive association was observed between male sex and ADHD (OR = 5.8; 95%CI: 2.3-19.6),

and between genetic syndrome and intellectual disability (OR = 6.1; 95%CI: 2.3-15.7).

Unified disability certificate

Among patients with a CUD at the time of evaluation, more than half had previously been evaluated at another facility.

FIGURE 3. Average profile of initial parental concerns by developmental diagnosis



ASD: autism spectrum disorder; GDD: global developmental delay; ADHD: attention-deficit/hyperactivity disorder; DCD: developmental coordination disorder; ID: intellectual disability; SPD: sensory processing disorder.

TABLE 3. Age at onset of parental concerns by diagnosis

Diagnosis	Median age (years) at onset of PC (IQR)	p-value
GDD	1 (1-2)	<0.001
ASD	2 (1-3)	<0.001
ADHD	5 (3-6)	<0.001
DCD	3 (2-6)	0.004
ID	4 (2-6)	0.016
Learning disorders	6 (4-7)	<0.001
Language disorders	1 (1-2)	0.037
CP	2 (1-3)	0.824
TD	0 (0-0)	0.034
Typical development	2.5 (1-4.75)	0.459

PC: parental concerns; IQR: interquartile range; GDD: global developmental delay; ASD: autism spectrum disorder; ADHD: attention-deficit/hyperactivity disorder; DCD: developmental coordination disorder; ID: intellectual disability; CP: cerebral palsy. The p-value corresponds to the Wilcoxon test comparing the age at which parental concerns first arose among patients with and without each diagnosis.

DISCUSSION

This study describes the pediatric population referred to a specialized developmental unit and analyzes the relationship between initial family concerns and the resulting diagnoses. The main findings show a high frequency of parental and school-related concerns, with a predominance of language and behavioral issues, and differential associations between patterns of concerns and specific neurodevelopmental diagnoses.

The high frequency of concerns regarding language and behavior is consistent with reports from various contexts. Yimgang *et al.* reported in a tertiary care clinic that approximately half of the concerns were related to language and one-fifth to behavior. However, these did not directly predict final diagnoses.²² A systematic review of concerns before evaluation for suspected ASD found that language, socialization, and behavior were the most frequent, serving as triggers for consultation.²³ Over 10 years, Kusumoto *et al.* showed that language was the primary concern, followed by behavioral and attentional difficulties.²⁴ This evidence supports the view that these concerns constitute relevant early signs for guiding the diagnostic process rather than for predicting specific diagnoses.

In ASD, social and language concerns showed the strongest associations and were reported at earlier ages than in other diagnoses. Prospective cohort studies have shown that parental concerns during the first year of life are more common in children who are later diagnosed with autism, and that concerns about language, social, and motor development constitute an independent risk factor.²⁵ Leach *et al.* studied a cohort of 853 parents of children aged 3 to 5 years; they found that a younger age at the onset of the first concern and the presence of specific concerns were associated with an earlier diagnosis, while a greater number of concerns was linked to a later diagnosis, suggesting that the nature of the concerns and clinical interpretation influence the diagnostic process.²⁶

In GDD, concerns regarding language and motor development were significantly associated, consistent with previous studies.^{24,26} In Latin America, similar patterns are reported, with a predominance of concerns regarding language, motor development, social interaction, and school adjustment.^{27,28} In more vulnerable settings, concerns related to the family environment, nutrition, and access to health care are also

expressed, highlighting the influence of the sociocultural context.^{29,30} Concerns were reported at an early age, likely due to greater clinical visibility and because this diagnosis can be made exclusively in children under five years of age.

In ADHD, concerns about behavior were significantly associated with the condition, consistent with the literature, which identifies behavioral problems as a common primary symptom, especially in preschool- and school-aged children.³¹

The strongest associations were found with concerns about academic performance in intellectual disability (ID) and learning disabilities (LD), highlighting the role of the school setting as a venue for detection. Given the cross-sectional design, these associations reflect a coexistence between the reason for consultation and the diagnosis rather than a direct temporal relationship.

Nearly two-thirds of the patients reported a first-degree family history of DD, highlighting the importance of family history in the initial evaluation, consistent with the findings reported by Xie *et al.* in a Swedish cohort of 567 436 children.³² The association between male gender and ADHD, and between genetic syndrome and ID, is consistent with widely described patterns.^{33,34} The negative association between neurological history and specific language disorder should be interpreted with caution. The fact that more than half of the patients with CUD had been previously evaluated at other centers suggests complex diagnostic trajectories. However, these could not be analyzed longitudinally in this study.

Limitations and methodological considerations

Although cerebral palsy is not a diagnosis included in the DSM-5, it was incorporated into the group of developmental disorders in line with conceptual models that view these conditions as part of a neurodevelopmental continuum, such as the one proposed by Capute and Accardo.

The cross-sectional, retrospective, single-center design makes it difficult to establish a clear temporal sequence between initial concerns and the assigned diagnoses and limits the generalizability of the results. The study population consists of children referred to a specialized unit at a community hospital, which reflects the profile of those who undergo diagnostic evaluation.

Reliance on clinical records and questionnaires may have introduced classification bias. The variable “initial parental concern” was recorded using an open-ended question for much of the period and later using multiple-choice questions, which could have led to differences in how the data were collected. The age at which concerns began was based on caregivers’ recollection, and variables such as the gender and age of the informants were not systematically recorded prospectively. Although the analysis focused on initial parental concerns, the high frequency of concerns reported by schools and their overlap with those reported by families suggest a significant degree of agreement among informants.

Despite these limitations, the systematic collection of family and school-related concerns made it possible to describe consultation profiles associated with neurodevelopmental diagnoses. They could help guide transdisciplinary assessment in settings with high demand for care.

CONCLUSION

In this cross-sectional study of transdisciplinary diagnostic evaluations, family concerns were highly prevalent and were differentially associated with neurodevelopmental diagnoses. The structured assessment of these concerns constitutes an important clinical tool within the diagnostic process and warrants their systematic incorporation into medical consultations. ■

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The supplementary material provided with this article is presented as submitted by the authors. It is available at: https://www.sap.org.ar/docs/publicaciones/archivosarg/2027/11042_AO_Ensenat_Anexo.pdf

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