Ecobiopsychosocial profile and unmet healthcare needs of children with autism in Chile: a cross-sectional study

Ruben Castillo-Ortega

ruben.castillo@uss.cl

San Sebastián University

Carol Hewstone-Garcia

Centro de Estudios Latinoamericano de Educación Inclusiva - Celei

Gladys Belmar-Riquelme

San Sebastián University

Vannia Jara-Mella

San Sebastián University

María Jesús Sánchez-Cortés

San Sebastián University

Yessenia Chavez-Zepeda

University of Tarapacá

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Abstract

Background: Evidence on the ecobiopsychosocial conditions of autistic children in Latin America remains scarce, limiting the implementation of equitable policies and services. In Chile, this gap directly challenges the operationalization of Law No. 21,545 (“Autism Law”), which requires integrated responses across health, education and social systems. We aimed to characterize the ecobiopsychosocial profile and identify unmet needs among autistic children and adolescents in southern Chile.

Methods: We conducted a descriptive cross-sectional study of 160 autistic participants aged 2–17 years in Valdivia, Chile.

Results: Participants showed a high burden of clinical, nutritional and social vulnerability. Diagnosis was substantially delayed, with a mean gap of 34.3 months between first concerns (25.5 months) and diagnosis (59.8 months). Half of participants used at least one daily medication, and excess weight affected 60%, with central obesity present in 55.2%. Dietary patterns were predominantly Western and nutritionally unbalanced, alongside high rates of sensory integration difficulties (77.5%). Family burden was marked: mothers were primary caregivers in 89.4% of households, frequently leaving paid employment, while 21% of household income was allocated to therapies and 65.6% of caregivers reported no self-care. Despite 76.9% attending mainstream schools, 33.9% experienced bullying and 39.5% faced school-imposed reduced schedules, reflecting persistent barriers to inclusion.

Conclusions: Autistic children and their families in southern Chile experience substantial unmet needs across healthcare, nutrition, education and social support systems. Delayed diagnosis, high caregiver burden and structural barriers to inclusion reveal systemic gaps that may hinder the effective implementation of Chile’s Autism Law. These findings underscore the need for coordinated, intersectoral strategies to advance equitable pediatric autism care in middle-income settings.

Contribution to the field

Chile has scarce population-level and public-health evidence describing the ecobiopsychosocial needs of autistic children and adolescents and their families. This gap is especially relevant following the enactment of Law No. 21,545, which requires locally grounded data to guide implementation across health, education and social protection. In this study, we provide an ecobiopsychosocial snapshot of autistic children and adolescents in a Chilean city, integrating clinical and nutritional profiles with caregiver, service-use and schooling experiences. We document substantial diagnostic delay, high caregiver time and financial burden, and frequent school barriers—including bullying and reduced school day—highlighting priority areas for coordinated, intersectoral responses.

1. INTRODUCTION

Autism spectrum disorder (ASD) is a heterogeneous neurodevelopmental condition associated with a wide range of strengths, support needs and co-occurring health conditions across childhood and

adolescence [1]. Global prevalence estimates vary by methodology and context, but contemporary syntheses commonly place prevalence around 0.65% (65/10,000) [2], underscoring the importance of paediatric services that can respond to diverse developmental, medical and psychosocial needs.

In Chile, population-based evidence remains limited. The first estimate of autism prevalence in two urban provinces of Santiago reported 1.95% among young children [3], suggesting that autism may be common in the country while also highlighting the need for locally grounded data beyond the capital and across age groups. At the same time, Chile enacted Law No. 21,545 (“Autism Law”) [4], which aims to ensure equal opportunities and social inclusion for autistic children, adolescents and adults, prevent discrimination, and promote an integrated approach across social, health and education sectors. Effective implementation of this legal framework requires robust information on the lived realities, health profiles and service trajectories of autistic children and their families.

However, the scarcity of epidemiological and biopsychosocial characterisation studies in Chile constrains evidence-informed planning. Limited data can contribute to delayed or missed diagnosis, inequities in access to healthcare and educational supports, and sustained caregiver burden, ultimately affecting quality of life and participation [5]. From a public health perspective, an ecobiopsychosocial approach that considers biological, psychological, social and territorial factors can help identify actionable patterns and gaps across sectors.

Therefore, this study aimed to describe the ecobiopsychosocial profile of autistic children and adolescents in Valdivia, southern Chile, characterising clinical history and current health indicators, autism signs and diagnostic timing, diet-related features, caregiver burden and education experiences. By providing local evidence, the study seeks to inform intersectoral strategies and support the implementation of Law No. 21,545 in health, education and social inclusion.

2. STUDY DESIGN AND SETTING

We conducted a community-based cross-sectional study with prospectively collected data. Data collection took place in Valdivia, Chile, between December 2024 and September 2025.

Caregivers were interviewed using the AUTIVA instrument, a structured questionnaire specifically developed for this study to capture ecobiopsychosocial dimensions of autism, including clinical history, nutritional status, healthcare access, educational experiences, and caregiver burden. The instrument included both closed-ended and semi-structured items organised into predefined domains. AUTIVA was designed by an interdisciplinary team with expertise in pediatric health, nutrition, and neurodevelopment, drawing on existing literature and international frameworks in autism and child health, including DSM-5 and the WHO International Classification of Functioning. Prior to implementation, the instrument was pilot-tested in a sample of caregivers to assess clarity, feasibility, and cultural appropriateness, with minor revisions made to improve comprehension and flow. Although formal psychometric validation is ongoing, the instrument was developed to ensure content relevance and conceptual coherence across domains. The AUTIVA instrument was administered by trained health professionals. Interviewers

received standardised training prior to fieldwork, including role-playing, structured interviewing practice, and guidance on inclusive and neurodiversity-affirming language, to ensure consistency in data collection. Anthropometric measurements were performed by trained registered dietitians using standardised procedures and calibrated instruments (digital scale, stadiometer, and non-stretch measuring tape), following a written protocol to ensure measurement reliability across fieldwork. AUTIVA was designed for descriptive, exploratory public health profiling rather than diagnostic classification.

Participants and recruitment

Participants were primary caregivers of autistic children and adolescents (< 18 years) with a confirmed autism diagnosis verified via a screening interview conducted with the caregiver by trained health professionals. Recruitment was conducted through autism awareness/sensitisation talks delivered at the community organisation “Organización Amigo Autismo” in January–February 2025, during which families were invited to participate. Inclusion criteria were: (1) primary caregiver of a child/adolescent with a confirmed autism diagnosis verified via screening interview; (2) caregiver aged ≥ 18 years; and (3) ability to complete the interview. Caregivers were excluded if they were unable to respond to the questionnaire due to communication or comprehension difficulties. Because recruitment was conducted through a single community organisation, the sample may over-represent families who are already connected to support/advocacy networks and able to attend organised activities; therefore, findings may not fully generalise to autistic children and families who are not affiliated with (or cannot access) such organisations.

Measures

Data were collected using AUTIVA, a 60-item questionnaire designed to characterise ecobiopsychosocial features of paediatric autism. AUTIVA comprises six domains: (1) General Paediatric Profile, (2) Sex and Gender, (3) Autism Diagnosis and Concomitant Pathologies, (4) Family Income and the Impact of Autism on Socioeconomic Status, (5) Diet of the Autistic Person, and (6) Therapies and Schooling.

Autism diagnosis verification: Eligibility required a confirmed autism diagnosis, which was verified through a screening interview conducted with the primary caregiver by trained health professionals prior to administering AUTIVA. The screening interview was used to confirm the reported prior diagnosis and ensure participants met study inclusion criteria; the study did not aim to establish a new clinical diagnosis. Concomitant conditions, dietary patterns, therapies and schooling experiences were recorded as captured by AUTIVA items. Responses were entered into a coded database to protect participant confidentiality. Waist circumference (as a proxy of central obesity) was assessed from age 5 years onward, in line with Chilean Ministry of Health nutritional-assessment guidance for paediatric anthropometry [6].

Sample size

The study population comprised all eligible caregivers of autistic minors affiliated with “Organización Amigo Autismo” during the recruitment period (n = 160). We used a convenience sample, and included the totality of caregivers who met eligibility criteria and agreed to participate; no formal a priori sample size calculation was performed given the descriptive aim and census approach within the organisation.

Statistical analysis

Continuous variables were assessed for normality using the Shapiro–Wilk test and visual inspection of histograms. Data are reported as mean (SD) for approximately normal distributions and median (IQR) for non-normal distributions. Categorical variables are summarised as counts and percentages.

For bivariate analyses, statistical tests were selected according to variable type: Fisher’s exact test for small expected counts, Pearson’s χ^2 test for associations between categorical variables, and Cramér’s V to estimate association strength. Trends across ordered categories were evaluated using Cuzick’s test. Where global differences were identified, Bonferroni-adjusted post hoc comparisons were applied.

Associations involving continuous outcomes were explored using simple linear regression, with dummy-variable coding for categorical predictors where appropriate. Group comparisons were conducted using ANOVA when assumptions were met, or the Kruskal–Wallis test otherwise. Non-parametric associations were assessed using Spearman’s rho.

For multivariable analyses of categorical outcomes, logistic regression models were applied according to outcome structure: binary, ordinal (eg, Likert-type scales), or multinomial. Statistical significance was set at $p < 0.05$. Analyses were performed using Stata v.18 (StataCorp, College Station, TX, USA).

Missing data were handled using complete-case analysis. Denominators reflect the number of participants with non-missing data for each variable.

Ethics

The study was conducted in accordance with the Declaration of Helsinki and was approved by the Ethics Committee of Servicio de Salud de Los Ríos (ORD. N°308, 31 December 2024). All participating caregivers provided written informed consent prior to data collection. Data were de-identified using participant codes, and the study database was restricted to the principal investigator to safeguard confidentiality and sensitive information.

Patient and public involvement

The president of “Organización Amigo Autismo Valdivia” supported study implementation by facilitating coordination between the interviewer team and participating families, strengthening trust and enabling smooth fieldwork. Families and caregivers were not involved in the formulation of the research question, selection of outcome measures, or interpretation of findings. This study is reported in accordance with

the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) guideline, and the completed STROBE checklist is provided as Supplementary Material.

3. RESULTS

3.1 AUTIVA Domain 1: General Paediatric Profile

3.1.1.Sample characteristics and caregiving structure

The sample included 160 autistic children and adolescents aged 2–17 years (mean age 9 years; modal age 6 years). The distribution was skewed towards school-aged children and adolescents, who together represented nearly 80% of the sample.

Caregiving responsibilities were highly concentrated within households. Mothers were the primary caregiver in 89.4% of cases, while fathers accounted for only 5.0%.

3.1.2. Perinatal characteristics and family history

Most participants were born at term (71.3%); however, a substantial proportion (28.8%) were born preterm, including 27.5% late preterm and 1.3% extremely preterm.

A first-degree family history of autism was reported in 28.1% of participants. Parental consanguinity was rare (0.6%).

3.1.3. Health behaviours and preventive care

Low levels of structured physical activity were common, with 70.0% of participants not engaging in at least three hours per week of planned physical activity.

Vaccination coverage was high, with 94.4% of participants up to date according to the Chilean National Immunisation Programme. Among those not up to date, the main reported reasons were lack of time (44.4%) and hypersensitivity concerns (33.3%).

3.1.4. Medication use

Medication use was frequent, with participants reporting a mean of 1.2 medications per day (range 0–6). While 40.6% reported no medication use, half of the sample reported using at least one medication daily.

The most commonly used medication classes were atypical antipsychotics (33.0%), followed by non-benzodiazepine hypnotics (16.0%) and psychostimulants (10.1%).

3.1.5. Anthropometry and central obesity

A high burden of excess weight was observed. While 36.3% of participants had a healthy weight, 26.3% were classified as overweight, 18.8% as obese, and 15.0% as severely obese.

Most participants had normal stature (54.4%), although variations in height distribution were observed across the sample.

Central obesity was present in a substantial proportion of participants: 27.3% met criteria for central obesity and an additional 28.0% were at risk.

3.1.6. Toileting and gastrointestinal characteristics

Diaper use was reported in 23.8% of the sample, most commonly throughout the day. The mean age of daytime toilet training was 40.5 months and nighttime toilet training 41.6 months, with wide variability.

Stool patterns were predominantly within normal ranges, with 77.5% classified as normal according to the Bristol Stool Scale. However, 11.9% showed constipation-pattern stools and 10.6% diarrhoeal-pattern stools.

All detailed information for this domain can be found in Table 1.

Table 1. AUTIVA domain 1 (General Paediatric Profile) characteristics of autistic participants in Valdivia, Chile.

Characteristic	Overall
Sample size	**n=160**
Age, years	9.0 (SD 4.0); range 2–17
Modal age, years	6
Age group	
Preschool (2–5 years)	34/160 (21.3%)
School-aged (6–9 years)	58/160 (36.3%)
Adolescents (10–17 years)	68/160 (42.5%)
Primary caregiver	
Mother	143/160 (89.4%)
Father	8/160 (5.0%)
Other	9/160 (5.6%)
Parental consanguinity	
Yes	1/160 (0.6%)
No	159/160 (99.4%)
Gestational age at birth	
Term (≥38 weeks)	114/160 (71.3%)
Late preterm (32–36 weeks)	44/160 (27.5%)
Extremely preterm (<32 weeks)	2/160 (1.3%)
Planned physical activity	
<3 hours/week	112/160 (70.0%)
≥3 hours/week	48/160 (30.0%)
Vaccination status (Chile National Immunisation Programme)	
Up to date	151/160 (94.4%)
Not up to date	9/160 (5.6%)
Reason for not up to date (among those not up to date)	
Lack of time	4/9 (44.4%)
Hypersensitivity	3/9 (33.3%)
Other reasons	2/9 (22.2%)

Daily medication use	
Number of medications/day	1.2 (SD 1.4); range 0–6
No daily medication	65/160 (40.6%)
≥1 daily medication	95/160 (59.4%)
Type of medication prescribed	
Atypical antipsychotics	62/188 (32.98%)
Non-Benzodiazepine Hypnotics	30/188 (15.96%)
Psychostimulants	19/188 (10.11%)
Corticosteroids	14/188 (7.45%)
Antidepressants	13/188 (6.91%)
Antihistamines	12/188 (6.38%)
Anticonvulsants	10/188 (5.32%)
Natural sedatives	6/188 (3.19%)
Osmotic laxatives	4/188 (2.13%)
Synthetic thyroid hormone	3/188 (1.60%)
Bronchodilator	3/188 (1.60%)
Proton-pump inhibitor	3/188 (1.60%)
Benzodiazepine anxiolytic	3/188 (1.60%)
Antimanic Agents	2/188 (1.06%)
Antihypertensive	1/188 (0.53%)
Diuretic pills	1/188 (0.53%)
Growth hormone	1/188 (0.53%)
First-degree family history of autism	
Yes	45/160 (28.1%)
No	115/160 (71.9%)
Nutritional status	
Healthy weight	58/160 (36.3%)
Overweight	42/160 (26.3%)
Obesity	30/160 (18.8%)

Severe obesity	24/160 (15.0%)
Risk of underweight	4/160 (2.5%)
Undernutrition	2/160 (1.3%)
Stature category	
Normal stature	87/160 (54.4%)
Normal–high stature	28/160 (17.5%)
Normal–low stature	25/160 (15.6%)
Short stature	8/160 (5.0%)
Tall stature	12/160 (7.5%)
Central obesity	
No central obesity	64/143 (44.8%)
At risk of central obesity	40/143 (28.0%)
Central obesity	39/143 (27.3%)
Toileting and stool pattern	
Current diaper use	38/160 (23.8%)
Pattern of diaper use (among diaper users)	
All day	23/38 (60.5%)
Night only	13/38 (34.2%)
Occasional	2/38 (5.3%)
Age at daytime toilet training, months	40.5 (SD 18.5); range 12–120
Age at nighttime toilet training, months	41.6 (SD 16.8); range 12–96
Stool pattern category (Bristol Stool Scale, categorised)	
Normal	124/160 (77.5%)
Constipation-pattern stools	19/160 (11.9%)
Diarrhoeal-pattern stools	17/160 (10.6%)

Abbreviations: SD, standard deviation.

Notes: Values are n/N (%) unless otherwise indicated. Waist circumference (marker of central obesity) was assessed from 5 years of age onward, in accordance with Chilean Ministry of Health guidelines (n=143) [6]. Percentages may not sum to 100 due to rounding.

3.2. AUTIVA Domain 2: Sex and Gender

3.2.1. Sex distribution

The sample was predominantly male, with 75.0% of participants identified as male and 23.1% as female.

3. **Gender diversity**

A small proportion of participants identified outside the binary gender categories, including 1.3% identifying as non-binary and 0.6% as transgender.

Gender incongruence, defined as not identifying with the sex assigned at birth, was reported in 1.9% of participants. In all cases, first verbalisation occurred at approximately 12 years of age.

All detailed information for this domain can be found in Table 2.

Table 2. AUTIVA domain 2 (Sex and Gender) characteristics of autistic participants in Valdivia, Chile.

Characteristic	Overall
Sample size	**n=160**
Gender identity	
Male	120/160 (75.0%)
Female	37/160 (23.1%)
Non-binary	2/160 (1.3%)
Transgender	1/160 (0.6%)
Gender incongruence (not identifying with gender assigned at birth)	
Yes	3/160 (1.9%)
No	157/160 (98.1%)
Age at first verbalisation of gender incongruence, years (among those reporting incongruence)	12 (3/3; 100%)

Notes: Values are n/N (%) unless otherwise indicated. Percentages may not sum to 100 due to rounding.

3. **AUTIVA Domain 3: Autism Diagnosis and Concomitant Pathologies**

3.3.1. Age at first signs and early developmental concerns

Early signs of autism were recognised at a mean age of 25.5 months (SD 26.1), with half of participants showing initial concerns between 6 and 18 months of age.

Most caregivers reported first signs emerging during early infancy (43.1%) or later infancy (30.6%), while fewer cases were identified during the preschool period (21.9%) and rarely during school age or adolescence.

The most frequently reported domains of early concern were language and communication (32.9%), followed by cognitive (18.4%), sensory (17.6%), and emotional domains (17.6%), with motor concerns less commonly reported (10.5%).

3.3.2. Diagnostic timing and delay

The mean age at diagnosis was 59.8 months (SD 42.9), compared with a mean age at first concerns of 25.5 months, with half of participants diagnosed between 10 and 48 months.

Most diagnoses were made during the preschool period (56.3%), followed by later infancy (16.9%), adolescence (13.1%), and school age (11.3%).

3.3.3. Autism support needs (DSM-5)

Reported DSM-5 support levels indicated that most participants required some degree of support, with 45.6% classified as level 1, 34.4% as level 2, and 10.0% as level 3. A proportion of caregivers reported not knowing the assigned support level.

3.3.4. Disability certification and access to support systems

Overall, 58.1% of participants were registered in the National Disability Registry (Registro Nacional de Discapacidad, RND), while 41.9% were not registered.

Among those registered, severity classification was predominantly severe (67.7%), followed by moderate (24.7%), mild (5.4%) and profound (2.2%). The mean disability score (55.8%) was consistent with a severe classification on average.

Among those not registered, 41.8% reported being in the process of registration. Reported barriers included lack of time (17.9%), the length and complexity of the process (9.0%), and concerns about potential limitations associated with registration (7.5%).

3.3.5. Co-occurring conditions

Participants presented a high prevalence of co-occurring conditions. The most frequently reported conditions included sensory integration difficulties (77.5%), behavioural disturbances (60.6%), motor dyspraxia (45.0%), and sleep disorders (41.9%). Intellectual disability was reported in 19.4% of participants, while epilepsy (2.5%) and hearing disability (5.0%) were less frequent.

In addition, 54.4% of participants reported other co-occurring conditions. Among these, neurodevelopmental conditions were the most common (52.9%), followed by respiratory (14.9%),

psychiatric (11.5%), dermatological (9.2%) and gastrointestinal conditions (3.5%). Other reported categories included genetic syndromes, cardiac, endocrine, ophthalmological, and traumatic/orthopaedic conditions.

All detailed information for this domain can be found in Table 3.

Table 3. AUTIVA domain 3 (Autism Diagnosis and Concomitant Pathologies) characteristics of autistic participants in Valdivia, Chile.

Characteristic	Overall
Sample size	**n=160**
Age at first recognised autism signs (months)	25.5 (SD 26.1); range 1–180
First signs, months (50% of sample)	6–18
Developmental stage at first signs	
Early infancy	69/160 (43.1%)
Later infancy	49/160 (30.6%)
Preschool	35/160 (21.9%)
School age	3/160 (1.9%)
Adolescence	4/160 (2.5%)
Primary domain of first concerns	
Language and communication	53/160 (33.1%)
Cognition	29/160 (18.1%)
Sensory	28/160 (17.5%)
Emotional	28/160 (17.5%)
Motor	17/160 (10.6%)
Global developmental impact	5/160 (3.1%)
Age at autism diagnosis (months)	59.8 (SD 42.9); range 10–204
Diagnosis, months (50% of sample)	10–48
Developmental stage at diagnosis	
Early infancy	4/160 (2.5%)
Later infancy	27/160 (16.9%)
Preschool	90/160 (56.3%)
School age	18/160 (11.3%)
Adolescence	21/160 (13.1%)
DSM-5 support level (caregiver reported)	
Level 1	73/160 (45.6%)
Level 2	55/160 (34.4%)

Level 3	16/160 (10.0%)
Unknown	16/160 (10.0%)
National Disability Registry (RND, Chile)	
Registered	93/160 (58.1%)
Not registered	67/160 (41.9%)
RND severity classification (among registered)	
Mild	5/93 (5.4%)
Moderate	23/93 (24.7%)
Severe	63/93 (67.7%)
Profound	2/93 (2.2%)
Disability classification score %, mean (SD); range (among registered)	55.8 (SD 18.7); 15.0–97.3
Reasons for not being registered (among not registered)	
In process of registration	28/67 (41.8%)
Lack of time	12/67 (17.9%)
Length of the process	6/67 (9.0%)
Concern registration could be limiting	5/67 (7.5%)
Other/unspecified	16/67 (23.9%)
Selected concomitant conditions	
Sensory integration disorder	124/160 (77.5%)
Behavioural disturbances	97/160 (60.6%)
Motor dyspraxia	72/160 (45.0%)
Sleep disorders	67/160 (41.9%)
Intellectual disability	31/160 (19.4%)
Hearing disability	8/160 (5.0%)
Epilepsy	4/160 (2.5%)
Other concomitant conditions (among those reporting any additional condition)	
Any additional concomitant condition reported	87/160 (54.4%)
Other neurodevelopmental conditions	46/87 (52.9%)

Respiratory conditions	13/87 (14.9%)
Psychiatric conditions	10/87 (11.5%)
Dermatological conditions	8/87 (9.2%)
Gastrointestinal conditions	3/87 (3.5%)
Genetic syndromes	2/87 (2.3%)
Cardiac conditions	2/87 (2.3%)
Endocrine conditions	1/87 (1.1%)
Ophthalmological conditions	1/87 (1.1%)
Traumatic/orthopaedic conditions	1/87 (1.1%)

Notes: Values are n/N (%) unless otherwise indicated. Percentages may not sum to 100 due to rounding.

3.4. AUTIVA Domain 4: Family Income and the Impact of Autism on Socioeconomic Status

3.4.1 Household composition and caregiver education

Households were typically composed of 3–5 members, with four-person households being the most common (38.1%).

Primary caregivers generally had moderate to high educational attainment, most frequently reporting university education (38.1%) or completed secondary education (37.5%), followed by technical education (20.0%).

3.4.2. Household income and financial burden of care

Household income distribution was heterogeneous, with 30.0% of households reporting monthly income ≥CLP 1,335,451, while 20.0% reported income below CLP 586,277.

Despite this variability, families reported a substantial financial burden associated with autism-related care. On average, 21.3% of monthly household income was allocated to therapies (SD 18.2; range 0%–98%). While most households (67.5%) reported spending up to 25% of their income on therapies, a considerable proportion reported higher levels of expenditure, including 27.5% allocating between 26% and 50%, and a smaller subset exceeding 50% of household income.

3.4.3. Employment conditions of caregivers

Employment patterns reflected significant caregiving demands. Nearly half of primary caregivers (45.0%) reported having no paid employment, while 32.5% worked full-time and 21.9% part-time.

Among caregivers with paid employment (n=87), 64.4% reported formal employment and 35.6% informal employment.

3.4.4 Caregiver self-care and barriers

Limited opportunities for self-care were common among caregivers. Overall, 65.6% reported no engagement in self-care activities.

Among those reporting any self-care, frequency was low (mean 1.44 times per week), with half engaging less than once per week.

Among caregivers reporting no self-care, the primary barrier was lack of time (87.6%), followed by lack of resources (4.8%), limited support networks (3.8%), lack of motivation (2.9%), and disabling illness (1.0%).

All detailed information for this domain can be found in Table 4.

Table 4. AUTIVA domain 4 (Family Income and the Impact of Autism on Socioeconomic Status) characteristics of autistic participants in Valdivia, Chile.

Characteristic	Overall
Sample size	**n=160**
Household size (number of members)	
2	13/160 (8.1%)
3	36/160 (22.5%)
4	61/160 (38.1%)
5	39/160 (24.4%)
6	10/160 (6.3%)
7	1/160 (0.6%)
Primary caregiver education level	
University education	61/160 (38.1%)
Completed secondary education	60/160 (37.5%)
Technical education	32/160 (20.0%)
Incomplete secondary/primary education	7/160 (4.4%)
Monthly household income (CLP)	
<586,277	32/160 (20.0%)
586,228–856,247	41/160 (25.6%)
857,248–1,335,450	39/160 (24.4%)
≥1,335,451	48/160 (30.0%)
Monthly income allocated to autism-related therapies	
Percent of household income, mean (SD); range	**21.27 (SD 18.18); 0–98**
0%–25%	108/160 (67.5%)
26%–50%	44/160 (27.5%)
51%–75%	5/160 (3.1%)
76%–100%	3/160 (1.9%)
Primary caregiver employment status	
No paid employment	72/160 (45.0%)
Full-time paid employment	52/160 (32.5%)

Part-time paid employment	35/160 (21.9%)
Retired	1/160 (0.6%)
Type of employment contract (among those with paid employment)	
Paid employment (denominator)	87/160 (54.4%)
Formal employment	56/87 (64.4%)
Informal employment	31/87 (35.6%)
Primary caregiver self-care	
No self-care activities	105/160 (65.6%)
Any self-care activities	55/160 (34.4%)
Self-care frequency, times/week, mean (SD) (among those reporting self-care)	1.44 (SD 0.89)
Self-care frequency (50% of those reporting self-care), times/week	0.03–1.0
Reasons for no self-care (among those reporting no self-care)	
Lack of time	92/105 (87.6%)
Lack of resources	5/105 (4.8%)
Lack of support network	4/105 (3.8%)
Lack of motivation	3/105 (2.9%)
Disabling illness	1/105 (1.0%)

3.5. Results — AUTIVA Domain 5: Diet of the Autistic Person

3.5.1. Food preparation and feeding dynamics

Food preparation was primarily concentrated within the household caregiving structure. Mothers were the main individuals responsible for meal preparation in 75.8% of households, followed by grandmothers (12.6%) and fathers (9.4%).

Most participants (73.8%) were reported to feed themselves independently. Among those requiring assistance, support was most commonly provided by the mother (22.7%).

Reported food allergy was present in 11.9% of participants.

3.5.2. Dietary patterns and nutritional intake

Dietary patterns were characterised by imbalances in food group consumption. While fruit intake was relatively frequent, with 55.6% consuming fruit 2–3 times per day, vegetable intake was less consistent, with 52.5% not consuming vegetables twice daily.

Dairy consumption was commonly reported (74.4% consuming 2–3 times per day). In contrast, intake of key protein sources was less frequent: 60.0% consumed beef twice per week, while 52.1% did not consume legumes twice per week and 66.9% did not consume fish twice per week.

Frequent consumption of ultra-processed foods was common. Daily intake of sweet or salty snacks was reported in 61.3% of participants, while 24.4% reported daily consumption of sugar-sweetened beverages or juices, and 10.0% reported daily consumption of fried or high-cholesterol foods.

Water intake was moderate, with 57.5% reporting consumption of approximately four glasses per day.

3.5.3. Food preferences

Most participants (71.9%) did not report specific food colour preferences. Among those who did (28.1%), preference for vibrant colours (e.g., red, orange, and purple) was most common (60.0%).

All detailed information for this domain can be found in Table 5.

Table 5. AUTIVA domain 5 (Diet of the Autistic Person) characteristics of autistic participants in Valdivia, Chile.

Characteristic	Overall
Sample size	**n=160**
Person primarily preparing meals	
Mother	121/160 (75.6%)
Grandmother	20/160 (12.5%)
Father	15/160 (9.4%)
Other	4/160 (2.5%)
Who primarily feeds the autistic participant	
Self-feeding (independent)	118/160 (73.8%)
Mother	36/160 (22.5%)
Father	4/160 (2.5%)
Grandmother	2/160 (1.3%)
Food allergy	
No	141/160 (88.1%)
Yes	19/160 (11.9%)
Selected intake indicators (as reported in AUTIVA)	
Fruit intake 2–3 times/day	89/160 (55.6%)
Does **not** consume vegetables twice/day	84/160 (52.5%)
Dairy intake 2–3 times/day	119/160 (74.4%)
Beef consumption twice/week	96/160 (60.0%)
Does **not** consume legumes twice/week	83/160 (51.9%)
Does **not** consume fish twice/week	107/160 (66.9%)
Sweet or salty snacks consumed daily	98/160 (61.3%)
Fried/high-cholesterol foods consumed daily	16/160 (10.0%)
Sugar-sweetened beverages/juices consumed daily	39/160 (24.4%)
Water intake: 4 glasses/day	92/160 (57.5%)
Food colour preference	
No	115/160 (71.9%)
Yes	45/160 (28.1%)

Preferred colour category (among those reporting a colour preference)	
Vibrant colours (eg, red/orange/purple)	27/45 (60.0%)
Pale colours (eg, white/brown)	15/45 (33.3%)
Other/unspecified	3/45 (6.7%)

Notes: Values are n/N (%) unless otherwise indicated. Percentages may not sum to 100 due to rounding. “Does not consume …” indicates not meeting the specified frequency threshold as captured by AUTIVA.

3.6. AUTIVA Domain 6: Therapies and Schooling

3.6.1. Access to health services and therapy intensity

Most participants (91.9%) reported receiving autism-related health services, while 8.1% reported no access to such services.

Service provision was distributed across sectors, with care most commonly delivered through the public system (39.5%), followed by mixed public–private provision (31.3%) and private-only services (29.3%).

The mean therapy time was 1.62 hours/week. (SD 1.2). Most commonly, participants received 1–2 hours per week, with only a small proportion exceeding this level.

3.6.2. Timing of first contact with health services

First contact with autism-related health services occurred relatively late. The mean age at first appointment was 59.4 months (SD 44.6), with most initial contacts occurring during the preschool period (50.6%), and a substantial proportion accessed services later in childhood or adolescence.

3.6.3. Type of professionals involved in care

Care was predominantly multidisciplinary. The most frequently consulted professionals included occupational therapists (79.4%), paediatric neurologists (77.5%), special education professionals (64.4%), speech and language therapists (58.1%), and psychologists (50.6%).

Less frequently consulted professionals included psychiatry (15.6%), registered dietitians (15.6%), and chiropractic services (15.6%).

3.6.4. Family involvement and perceived effectiveness of therapy

Among participants receiving services, 55.1% reported that professionals actively integrated the family into therapy, and 68.7% of caregivers reported participating in therapy sessions.

Perceived effectiveness of therapy was generally positive, with 47.8% rating progress as very good and 39.0% as good (mean score 3.32/4).

3.6.5. Educational placement and participation

Most participants were enrolled in mainstream education (76.9%), followed by special education (17.5%) and other modalities. Overall, 98.8% of participants were enrolled in some form of education.

Among enrolled students, 60.4% attended public schools and 39.6% private schools. Participation in in-class activities was high (89.2%), although engagement in extracurricular (39.9%) and elective activities (28.5%) was less frequent.

3.6.6. School support and adaptations

Educational supports were heterogeneous. While 44.0% of participants received support through the School Integration Programme (PIE) with an Individual Curriculum Support Plan (PACI), 28.3% reported no PIE support and others reported limited knowledge of support structures.

Sensory adaptations were reported in 50.0% of students, most commonly environmental adaptations.

School-based referral to specialist care was limited, with only 35.2% of participants being referred to paediatric neurology by their school.

3.6.7. School environment, inclusion and barriers

Peer relationships were generally rated as good (mean 2.72/4), and classroom-team support was rated positively overall (mean 3.08/4).

However, perceived academic or developmental progress within the school system was more moderate (mean 2.37/4).

Bullying was reported in 34.0% of participants. Among these cases, most caregivers (61.1%) reported that no action was taken by the school.

School-level measures affecting educational participation were reported in 41.9% of participants. The most common was a school-imposed reduced school day, with fewer reports of conditional enrolment or enrolment cancellation.

All detailed information for this domain can be found in Table 6.

Table 6. AUTIVA domain 6 (Therapies and Schooling) characteristics of autistic participants in Valdivia, Chile

Characteristic	Overall
Sample size	**n=160**
Receiving autism-related health services	
Yes	147/160 (91.9%)
No	13/160 (8.1%)
Type of service provision (among those receiving services; n=147)	
Public only	58/147 (39.5%)
Mixed public–private	46/147 (31.3%)
Private only	43/147 (29.3%)
Weekly time in autism-related therapies (hours/week)	
Hours/week, mean (SD); range	1.62 (SD 1.20); 0–8
0–1 hour/week	25/160 (15.6%)
1 hour/week	60/160 (37.5%)
2 hours/week	48/160 (30.0%)
3 hours/week	15/160 (9.4%)
4 hours/week	8/160 (5.0%)
5 hours/week	3/160 (1.9%)
8 hours/week	1/160 (0.6%)
Age at first autism-related health appointment (months)	59.4 (SD 44.6); range 7–204
First appointment, months (50% of sample)	7–36
Developmental stage at first autism-related appointment	
Early infancy	8/160 (5.0%)
Later infancy	22/160 (13.8%)
Preschool	81/160 (50.6%)
School age	21/160 (13.1%)
Adolescence	28/160 (17.5%)
Professionals consulted (multiple responses permitted)	
Occupational therapist	127/160 (79.4%)

Paediatric neurologist	124/160 (77.5%)
Special education teacher	103/160 (64.4%)
Speech and language therapist	93/160 (58.1%)
Psychologist	81/160 (50.6%)
Educational psychologist	62/160 (38.8%)
Psychiatrist	25/160 (15.6%)
Registered dietitian	25/160 (15.6%)
Chiropractor	25/160 (15.6%)
Family integration in therapy (among those receiving services; n=147)	
Professional integrates the family	81/147 (55.1%)
No integration reported	66/147 (44.9%)
Primary caregiver has participated in therapy sessions	101/147 (68.7%)
Perceived progress with therapies (0–4 Likert scale)	
Mean (SD)	3.32 (SD 0.78)
Very good	76/159 (47.8%)
Good	62/159 (39.0%)
Neither good nor bad	19/159 (12.0%)
Very poor	2/159 (1.3%)
Schooling modality	
Mainstream education	123/160 (76.9%)
Special education	28/160 (17.5%)
Free-study/independent examination	6/160 (3.8%)
Not enrolled	2/160 (1.3%)
Homeschooling	1/160 (0.6%)
School type (among enrolled students; n=158)	
Public school	95/158 (60.1%)
Private school	63/158 (39.9%)
Peer relationship rating (0–4 scale; among enrolled; n=158)	
Mean (SD)	2.72 (SD 0.77)

Very good	21/158 (13.3%)
Good	83/158 (52.5%)
Regular	45/158 (28.5%)
Poor	8/158 (5.1%)
Very poor	1/158 (0.6%)
Participation and adaptations (among enrolled; n=158)	
Participates in in-class activities	141/158 (89.2%)
Participates in extracurricular activities	63/158 (39.9%)
Participates in elective curricular activities (ACLE)	45/158 (28.5%)
Uses sensory adaptations	79/158 (50.0%)
Type of sensory adaptation (among those using adaptations; n=79)	
Environmental adaptation	48/79 (60.8%)
Sensory toy	22/79 (27.8%)
Comfort/attachment object	5/79 (6.3%)
Calming strategies	4/79 (5.1%)
School referral to paediatric neurology (item denominator n=159)	
Yes	56/159 (35.2%)
No	103/159 (64.8%)
School Integration Programme (PIE) support and format (item denominator n=159)	
Receives PIE support with an Individual Curriculum Support Plan (PACI)	70/159 (44.0%)
Receives PIE support without PACI	13/159 (8.2%)
Receives PIE support, format unknown	31/159 (19.5%)
No PIE support	45/159 (28.3%)
Classroom-team support rating (0–4 scale; item denominator n=159)	
Mean (SD)	3.08 (SD 0.95)
Very good	66/159 (41.5%)
Good	53/159 (33.3%)
Regular	30/159 (18.9%)

Poor	8/159 (5.0%)
Very poor	2/159 (1.3%)
Perceived progress in the school system (0–4 scale; item denominator n=159)	
Mean (SD)	2.37 (SD 1.03)
Very good	22/159 (13.8%)
Good	52/159 (32.7%)
Regular	57/159 (35.9%)
Poor	20/159 (12.6%)
Very poor	8/159 (5.0%)
Bullying experience (item denominator n=159)	
Yes	54/159 (34.0%)
No	92/159 (57.9%)
Not sure	13/159 (8.2%)
School response to bullying (among bullying reported; n=54)	
No action taken	33/54 (61.1%)
Caregiver meeting	10/54 (18.5%)
Aggressor suspended	5/54 (9.3%)
Other	6/54 (11.1%)
School measures affecting enrolment or school day	
Any measure reported	67/160 (41.9%)
No measures reported	93/160 (58.1%)
Type of measure reported (multiple responses permitted; total responses n=162)	
Reduced school day	64/162 (39.5%)
Conditional enrolment	3/162 (1.9%)
Enrolment cancellation	2/162 (1.2%)

Notes: Values are n/N (%) unless otherwise indicated. Percentages may not sum to 100 due to rounding. Multiple responses were permitted for “professionals consulted” and for “type of school measure”. For “type of school measure”, percentages are calculated over total responses (n=162) because two

caregivers reported more than one measure. Denominators vary across items due to not applicable responses; where denominators differ from n=160, they are shown explicitly.

4. DISCUSSION

This study provides a local, public-health–oriented ecobiopsychosocial characterisation of autistic children and adolescents in Valdivia, Chile.

AUTIVA Domain 1: General Paediatric Profile

In our cohort of 160 participants (2–17 years), adolescents represented the largest subgroup, followed by school-aged and preschool-aged children. This distribution is relevant for service planning, as it suggests that many families are navigating autism-related needs during later developmental stages, when educational demands, comorbidities, and caregiver strain may intensify.

Caregiving was strongly gendered, with mothers acting as the primary caregiver in 89.4% of households. This pattern is consistent with international evidence highlighting mothers as the main caregivers and documenting associated time constraints and mental health burden [7–9].

Parental consanguinity was uncommon (0.6%), suggesting it is unlikely to be a major driver of autism burden in this setting. This aligns with studies reporting no clear association with autism risk or severity, although findings remain mixed across contexts [10–12].

Prematurity was frequent (28.8%), substantially higher than the ~9% reported in the general Chilean population [13,14], suggesting over-representation among autistic children in this sample. While not interpretable as a population risk estimate, this finding aligns with evidence linking preterm birth to increased neurodevelopmental vulnerability and autism risk, and supports its relevance for clinical follow-up and health-system planning [15–18].

Physical inactivity was common, with 70.0% of participants not meeting recommended activity levels. Evidence from other settings similarly highlights limited physical activity and its association with quality of life and broader health outcomes, supporting the need to strengthen structured opportunities for movement in autistic populations [19–21].

Vaccination coverage was high (94.4%). Among those not up to date, the main reported reasons were lack of time and hypersensitivity. These findings are consistent with evidence rejecting a causal link between vaccination and autism, and instead suggest that incomplete schedules are more likely related to caregiver burden and service access constraints, with implications for tailored clinical support in specific subgroups [22,23].

Participants used a mean of 1.2 medications per day, most commonly atypical antipsychotics, hypnotics, and psychostimulants. This likely reflects management of associated symptoms rather than core autism features. Given known adverse effects, particularly metabolic risks, these findings underscore the

importance of careful monitoring and safe prescribing practices, consistent with international guidance [24–28].

A first-degree family history of autism was reported in 28.1% of participants, higher than in some international samples, possibly reflecting familial clustering or recruitment characteristics. Evidence suggests that family history may be associated with increased clinical complexity and highlights the importance of family-informed surveillance and early referral for siblings [29–31].

Excess weight was highly prevalent, affecting 60.1% of participants, exceeding levels reported in the general Chilean paediatric population [32]. This aligns with international evidence showing increased risk of overweight and obesity in autistic children and reinforces the need for targeted prevention and care strategies [33–37].

Height distribution was heterogeneous, with both higher and lower growth profiles observed. Compared with general population estimates, the proportion with growth delay appears elevated, supporting the need for comprehensive growth monitoring beyond obesity alone [32,38–40].

Central obesity was also common, affecting over a quarter of participants, with additional individuals at risk. This finding reinforces concerns regarding cardiometabolic health and the need to integrate anthropometric monitoring into routine care [41–43].

Toileting and gastrointestinal issues were frequent. Diaper use persisted in nearly one-quarter of participants, and 22.5% showed non-normal stool patterns. These findings are consistent with evidence describing higher rates of gastrointestinal and continence-related difficulties in autistic children, supporting the need for systematic screening and management within routine care [44–50].

AUTIVA Domain 2: Sex and Gender

In the Sex and Gender domain, the predominance of males (75.0% male; 23.1% female) is consistent with DSM-5 descriptions indicating that autism is diagnosed more frequently in males (approximately 4:1), including findings from Chilean studies [3,51,52].

However, interpretation of these patterns should consider the measurement context, as AUTIVA was completed by caregivers rather than by autistic individuals themselves, which may underestimate gender diversity and gender incongruence—particularly in younger participants or in contexts with limited opportunities for disclosure.

This is relevant given evidence that autistic females may camouflage traits more frequently than males, potentially reducing observable signs and contributing to delayed or missed recognition [53,54]. Accordingly, the small proportion of caregiver-reported non-binary or transgender identities (1.9%) should be interpreted cautiously, as it may reflect reporting and disclosure dynamics rather than true prevalence.

AUTIVA Domain 3: Autism Diagnosis and Concomitant Pathologies

In this study, early signs of autism were recognised at a mean age of 25.5 months, with half of participants showing initial concerns between 6 and 18 months. Despite this early recognition, diagnosis occurred substantially later, at a mean age of 59.8 months, indicating an average delay of approximately 34 months. This pattern is consistent with national and international evidence documenting persistent gaps between first concerns and formal diagnosis, influenced by symptom presentation, caregiver interpretation, and access to diagnostic pathways [55–57].

Notably, a large proportion of caregivers reported early signs during infancy, reinforcing evidence that caregiver concerns can emerge within the first year of life and represent a valuable entry point for early identification and referral [56,58]. Language and communication difficulties were the most frequently reported initial concern, consistent with previous studies, and highlighting the critical role of paediatric and early-childhood services in recognising developmental deviations and initiating timely evaluation [57–60].

Although half of participants were diagnosed before 48 months, the wide distribution of diagnostic age indicates that a substantial subgroup is identified much later in development. This is consistent with international estimates but remains higher than those reported in more recent child-focused cohorts, suggesting ongoing delays in access to assessment pathways [61]. From a pediatric public health perspective, reducing this delay remains a priority, given the well-established benefits of early intervention during periods of heightened neurodevelopmental plasticity [62–64].

Caregivers reported DSM-5 support needs as level 1 in 45.6%, level 2 in 34.4%, and level 3 in 10.0%, while around one in ten did not know the assigned level. Although these categories are not directly equivalent to “mild/moderate/severe” groupings, the distribution is broadly consistent with Chilean figures summarised in a parliamentary technical briefing based on US National Health Statistics Reports, where most children were classified as mild, followed by moderate and severe [65]. Compared with these figures, our cohort shows a slightly higher proportion of participants in the highest-support category and a lower proportion in the lowest, which may reflect differences in case-mix, sampling, and the use of caregiver-reported rather than standardised clinical assessments.

In Chile, disability certification is administered through the National Disability Registry (RND), which enables access to benefits and supports. In this sample, 58.1% of participants were registered, while 41.9% were not. Among those registered, severity classification was predominantly severe, followed by moderate, mild, and profound, with a mean disability score consistent with a severe classification overall. This is relevant because “severity” is often defined based on core autism domains, which may not fully capture broader disability-related needs and functional impacts considered in certification systems [66].

Access to formal disability certification was incomplete, with 58.1% of participants registered in the National Disability Registry and a substantial proportion not registered or still in the process. Reported barriers—including time constraints, administrative burden, and concerns about potential limitations

associated with certification—are consistent with broader evidence on structural and psychosocial barriers to service access, including stigma and complexity of administrative pathways [67–69].

Co-occurring conditions were highly prevalent, reflecting a complex clinical profile. The most frequently reported included sensory integration difficulties, behavioural disturbances, motor dyspraxia, and sleep disorders, alongside intellectual disability. This pattern aligns with existing evidence highlighting the high burden of multimorbidity in autistic populations and its implications for functioning, participation, and care needs [70–73].

Behavioural disturbances were common, consistent with literature describing irritability, dysregulation and self-injurious behaviours in autistic children, particularly in the presence of intellectual disability and communication challenges [74]. Sleep problems were also frequent, in line with previous studies, and are clinically relevant given their impact on daytime behaviour and caregiver burden [75]. Motor difficulties were reported in nearly half of participants, supporting evidence that motor features are common and may affect participation in play, schooling and physical activity [76]. In contrast, epilepsy was less frequently reported than in other autistic populations, which may reflect differences in ascertainment, access to specialist services, or sample composition [77,78]. Among participants reporting additional conditions, other neurodevelopmental disorders—particularly ADHD—were most common, a co-occurrence consistently associated with increased complexity in assessment, intervention and educational support needs [79–80].

AUTIVA Domain 4: Family Income and the Impact of Autism on Socioeconomic Status

In this Chilean cohort, primary caregivers were predominantly mothers (≈90%), most with at least secondary, technical, or university education. However, nearly half reported no paid employment, suggesting that caregiving demands may displace mothers from the labour market despite their educational attainment. This pattern aligns with international evidence showing reduced maternal labour force participation among families of autistic children and employment gaps influenced by autism severity and policy context [81,82]. Caregiving responsibilities may also constrain broader occupational participation, including work, community and leisure activities, with implications for caregiver quality of life [83]. Among those employed, a substantial proportion reported informal work, reinforcing the impact of caregiving on employment stability.

Families allocated a mean of 21.3% of household income to autism-related therapies, indicating a substantial out-of-pocket financial burden. This is consistent with broader evidence of increased financial strain and adverse employment effects among caregivers, particularly mothers, as well as rising socioeconomic costs associated with autism, including healthcare utilisation and long-term informal care [84–88].

Most primary caregivers (65.6%) reported no self-care activities, and among those who did, frequency was low. Lack of time was the main reported barrier, followed by limited resources and support networks. This pattern is consistent with evidence showing that caregivers often reorganise daily life

around their child's needs, restricting their own participation in valued activities and affecting wellbeing [89,90]. Evidence also suggests that access to leisure and social support can improve caregiver quality of life, while lack of self-care—as observed in this cohort—may exacerbate emotional distress, fatigue, and social isolation, with implications for sustained caregiving capacity [91–93].

AUTIVA Domain 5: Diet of the autistic person

In the Diet domain, we observed a pattern consistent with a Westernised diet, characterised by low intake of vegetables, legumes and fish, alongside frequent consumption of ultra-processed snacks and sugar-sweetened beverages. This aligns with evidence showing greater food selectivity in autistic children, with preference for energy-dense foods and lower vegetable intake compared with typically developing peers [94,95].

Dietary patterns in autism have also been linked to sensory processing and autistic traits, suggesting that sensory sensitivities may contribute to restricted food repertoires and potential micronutrient deficiencies [96,97], leading to unbalanced diets [98]. Emerging evidence indicates that targeted nutritional interventions may yield functional benefits, supporting the need for context-specific strategies that integrate sensory-informed feeding approaches and family-centred guidance [99].

Food allergy was reported in 11.9% of participants, a proportion higher than estimates for the general Chilean paediatric population (~5.5%) [100], and consistent with evidence suggesting an association between autism and food allergy or sensitisation [101,102]. Given the increasing recognition of food allergy as a public health concern in Chile [103,104], these findings highlight the importance of incorporating allergic comorbidity into nutritional assessment and care in autistic populations.

AUTIVA Domain 6: Therapies and Schooling

In this cohort, 91.9% of participants accessed autism-related health services, highlighting the central role of multidisciplinary care. However, service intensity was present with a mean of 1.62 hours/week, markedly below the ~25 hours/week reported in early intensive intervention studies [105,106]. This corresponds to approximately 6.5% of recommended intensity, suggesting a substantial "intervention gap". Evidence indicates that greater intervention exposure is associated with improved developmental outcomes, reinforcing concerns that limited intensity may constrain gains [107]. While other low-resource settings have achieved higher service levels [108], suggesting modifiable barriers, intervention access and intensity in this cohort appear shaped by sociodemographic constraints and service availability [110]. Although over half of participants accessed services during the preschool period, consistent with early-intervention recommendations [110,111], low therapy dose and high caregiving demands—primarily borne by mothers—may limit effectiveness.

Most participants attended mainstream education (76.9%), primarily in public schools. While peer relationships and classroom support were generally rated as positive, participation in extracurricular activities was low, half of students required sensory adaptations, and only 35.2% were referred by

schools for specialist evaluation. Although 44.0% received structured support through the School Integration Programme, perceived progress within the school system was moderate, suggesting gaps between support provision and outcomes.

Bullying was reported in 34.0% of cases, and 41.9% experienced measures affecting participation, most commonly a reduced school day. Although mainstream placement is central to inclusive education, these findings suggest that placement may exceed system readiness to support meaningful participation, as reflected in partial engagement, unmet support needs, and limited referral capacity [112,113].

These patterns align with evidence indicating that teachers often lack autism-specific training and that school staff show only moderate preparedness for inclusive education, which may contribute to reduced participation and weaker inclusion outcomes [114–117]. Consistent with this, autistic students frequently report limited understanding from teachers, bullying, and challenges related to rigid and unpredictable environments, all of which undermine school belonging [118].

Taken together, these findings point to a clear implementation gap: improving inclusion requires not only access to mainstream education, but also strengthened teacher training, consistent sensory-inclusive practices, effective anti-bullying strategies, and integrated referral pathways within the education system.

5. CONCLUSIONS

This study provides one of the first public health–oriented ecobiopsychosocial characterisations of autistic children and adolescents in southern Chile. Beyond a descriptive profile, the findings reveal a consistent pattern of systemic gaps across the continuum of pediatric care, spanning early identification, clinical and nutritional management, access to services, educational inclusion, and caregiver wellbeing.

The evidence points to a clear implementation gap: outcomes appear to depend less on the nominal availability of services than on their timeliness, intensity, continuity, and coordination across health, education, and social protection systems. In this context, autism emerges not as a condition insufficiently recognised, but as one insufficiently addressed through integrated, sustained, and equitable care pathways.

From a pediatric public health perspective, these findings support the need to reposition autism as an intersectoral chronic-condition priority, requiring defined standards of care, measurable service pathways, and system-level accountability. Key priorities include strengthening early identification and referral in primary care and early childhood settings; ensuring equitable access to multidisciplinary interventions with minimum effective intensity; integrating nutrition, physical activity, and cardiometabolic monitoring into routine care; standardising the management of functional conditions

such as constipation and continence; and embedding caregiver support—through time, respite, training, and social networks—as a core component of service delivery.

In parallel, the persistence of bullying and school-imposed restrictions highlights structural limitations in educational inclusion, underscoring the need for enforceable inclusive practices, trained personnel, and formalised coordination between schools and health and social services.

Taken together, these findings suggest that the main challenge is no longer the recognition of autism, but the capacity of systems to respond coherently and equitably to its multidimensional needs. By providing territorially grounded evidence, this study can inform local planning and strengthen the implementation of Chile's Law No. 21,545. Future research should expand this approach across regions, incorporate standardised clinical measures alongside caregiver-reported data, and evaluate how social conditions and service models shape developmental trajectories over time.

STRENGTHS AND LIMITATIONS

This study has several strengths. First, it provides locally grounded evidence from southern Chile by offering an ecobiopsychosocial characterisation of autistic children and adolescents in Valdivia, a setting where paediatric autism data remain limited. By structuring findings across multiple AUTIVA domains, the study captures a multidimensional profile that extends beyond clinical diagnosis to include perinatal factors, lifestyle, comorbidities, nutrition, service use, and educational experiences. The inclusion of a wide age range (2–17 years) also allows the identification of needs across developmental stages, which is relevant for service planning. In addition, data were collected using a structured approach, and diagnosis was verified through a screening interview, strengthening case definition compared with studies relying solely on unverified caregiver report. Finally, several indicators generated in this study—such as therapy intensity, access to services, and educational supports—are directly translatable into system-level monitoring and planning.

However, these findings must be interpreted in light of important limitations. The sample is local and non-probabilistic, limiting representativeness and generalisability to the broader Chilean autistic population. Recruitment through caregiver networks and service-linked pathways may have introduced selection bias, potentially over-representing families with higher engagement with services or, alternatively, those with greater support needs.

The cross-sectional design precludes causal inference and limits the ability to assess developmental trajectories or temporal relationships between exposures and outcomes. In addition, most variables were based on caregiver report, which introduces potential recall bias, reporting bias, and variability in interpretation—particularly for domains such as age at first concerns, support level classification, and comorbid conditions. Although diagnosis was screened, the study did not include standardised clinical instruments for severity or functional assessment, which may affect comparability with clinically characterised cohorts.

The absence of an internal comparison group restricts the interpretation of observed differences, which rely on external national and international benchmarks. Furthermore, the study does not incorporate multivariable modelling, limiting the ability to disentangle the relative contribution of factors such as socioeconomic conditions, service access, and support needs. Finally, the AUTIVA instrument, although structured and pilot-tested, is not yet fully psychometrically validated, which may affect measurement precision and comparability across settings.

Declarations

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HUMAN ETHICS AND CONSENT TO PARTICIPATE

The study was conducted in accordance with the Declaration of Helsinki, and approved by the Ethics Committee “Servicio de Salud de Los Ríos, Chile” (ORD. N°308 on December 31st, 2024). Informed consent was obtained from all subjects involved in the study. Clinical trial number: not applicable.

DATA AVAILABILITY STATEMENT

The data supporting the findings of this study are available upon reasonable request from the corresponding author.

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CONFLICTS OF INTEREST

The author declares no conflicts of interest.

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SUPPLEMENTARY MATERIALS

Supplementary Material is available in the online version of this article.

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